Growing Up With Cancer:
A qualitative study of the impact of cancer on the experience of growing up

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Dip App Sc. (Nursing), BA

A thesis submitted in fulfilment of the requirements
For the award of the degree of
Doctor of Philosophy

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The University of Sydney
2012
Supervisor’s Certification

I, Doctor Christopher Jordens, certify that the PhD thesis entitled “Growing up with cancer: a qualitative study of the impact of cancer on the experience of growing up” by Peter Lewis is in a form suitable for examination.

____________________________
Christopher Jordens

Date: ______________________
Author’s Declaration

I, Peter Rees Lewis, declare that this thesis, submitted for the award of the degree of Doctor of Philosophy, in the Faculty of Medicine, University of Sydney, is wholly my own work unless otherwise referenced or acknowledged. This document has not been submitted for qualifications at any other academic institution. The University of Sydney Human Research Ethics Committee approved all research practices associated with this thesis.

_______________________
Peter Rees Lewis

Date: ____________________
Acknowledgements and Dedication

Many people have supported me and shown faith in my abilities throughout my doctoral candidature making it possible for me to complete this thesis. They deserve my warmest thanks. Primarily I’d like to thank the research team on the Growing Up With Cancer project for giving me the opportunity to work on such a stimulating research project and for developing my interest and ability in conducting research with young people. Some have been more central than others to this process and I would like to acknowledge the important contributions made by some specific individuals.

Dr Christopher Jordens has worked tirelessly to push me to new heights of academic skill and this thesis is the result of those efforts. He has taught me much about how to think and write in an academic way and much about the academic life. His lessons have been invaluable during my time at VELiM. Thanks to Associate Professor Ian Kerridge for fostering my interest in research and nurturing my early ideas.

Dr Julie Mooney-Somers deserves special thanks for her critical companionship, her generosity, and her timely and insightful feedback on my ideas as they have developed. We shared presentations of my findings at two international conferences and she has always been there for me at the most critical moments of my candidature. So much of my thinking about my findings and my approach to qualitative research has been shaped by my conversations with her.

Mr Kris Smith cared for the participants in this study during their creative activities. His skill and sensitivity ensured that participants shared a great deal of themselves in their post-creative interviews.

Other staff members and students of VELiM have acted as role models and inspirations for me during my candidature. They have provided a collegial and stimulating environment in which to work and I have enjoyed my experience immensely because of that. I’d especially like to thank F. Scott Fitzpatrick, from Cubical 5, and Christopher Mayes for their companionship and for being a safe outlet for my expressions of uncertainty and frustration.

I dedicate this thesis to my wife Jozica and my sons, Angus and Aiden, who sacrificed so much for the completion of this thesis without any complaint. I love them all and hope I can repay what I owe them for their unfailing love and support.
Peer Reviewed Presentations


**Lewis, P.** Mooney-Somers, J. and Kerridge, I. “I just want to help people”: Complicating young cancer survivor’s accounts of being a better person. Making Sense: Health Illness, and Disease. Oxford University, U.K. 6-8 September 2011.*


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*Full papers published in conference program as they appear in Appendix 6 and 7 at the end of this thesis.*
Seminar Presentations

**Lewis, P.** “Growing up with Cancer: an overview” University of Sydney Faculty of Medicine Young Investigator Seminar Series, 25 September 2009.

**Lewis, P.** and Mooney-Somers, J. Growing up with cancer: Project overview. Bi-Annual CanTeen All Staff Meeting, Torquay, Victoria, 8 – 10 June 2010.

**Lewis, P.** and Mooney-Somers, J. Growing up with Cancer: A collaborative research project between the University of Sydney, Newcastle University, and CanTeen. Adolescent Medicine Unit, the Children’s Hospital at Westmead, 17 August 2010.

**Lewis, P.** and Mooney-Somers, J. Growing up With Cancer: Preliminary Findings. Youth Health Forum. The Children’s Hospital at Westmead 4 November 2010.

**Lewis, P.** “I Just Want to Help People”: Complicating young cancer survivors’ accounts of ‘being a better person’ Adolescent Medicine Unit, The Children’s Hospital at Westmead 19 July 2011.

**Lewis, P.** Growing Up With Cancer: Transitions from adolescence to young adulthood. South East Sydney Illawarra Area Health Service Cancer Education Day. Prince of Wales Hospital, Sydney, 12 August 2011.

**Lewis, P.** and Mooney-Somers, J. Creative Methods and the Growing Up With Cancer Project. Lecture delivered to Master of Nursing students, Sydney Nursing School, The University of Sydney. 22 September 2011.

Publications Indirectly Related to This Thesis


Preface

The Growing Up With Cancer Project

The Growing Up With Cancer project (GUWC) was funded by a competitive grant awarded by the Australian Research Council (ARC) in 2008. GUWC was a Linkage Grant project (LP0883632) funded for three years. The Centre for Values, Ethics and the Law in Medicine at the University of Sydney and Newcastle University were linked with an industry partner, CanTeen, Australia’s premier support and advocacy group for adolescents and young adults living with cancer. Linkage Grant projects encourage and develop long-term strategic research alliances between higher education organisations and collaborating organisations which can lead to significant national economic, environmental, social, and cultural outcomes. The aim of GUWC was to use mixed methods to determine the nature and extent of the impact of cancer on the transition from adolescence to adulthood.

Personnel

The research team comprised researchers and clinicians from different disciplinary backgrounds each contributing unique expertise to the conduct of the project.

Chief Investigator 1: Associate Professor Ian Kerridge, Director, the Centre for Values, Ethics, and the Law in Medicine, University of Sydney, New South Wales, Australia. Staff Haematologist Royal North Shore Hospital, Sydney.

Chief Investigator 2: Dr Christopher F.C. Jordens, Senior Lecturer in Bioethics, the Centre for Values, Ethics, and the Law in Medicine, University of Sydney, New South Wales, Australia.

Chief Investigator 3: Mr Kris Smith, Associate Lecturer in Fine Art, Newcastle University, New South Wales, Australia.

Partner Investigator 1: Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen. Head Office, Sydney, Australia.

Partner Investigator 2: Professor David Bennett, Senior Staff Specialist in Adolescent Medicine. Head, New South Wales Centre for the Advancement of Adolescent Health. The Children’s Hospital at Westmead, New South Wales, Australia.

Project Co-Ordinator: Dr Julie Mooney-Somers, Senior Lecturer in Qualitative Health Research, the Centre for Values, Ethics, and the Law in Medicine, University of Sydney, New South Wales, Australia.

Participant Groups

Participant groups included adolescents and young adults with cancer (young cancer survivors) aged 14-29 years, parents of young people who had been treated for cancer, health
care professionals specialising in the care of young people with cancer, and high school students with no close personal contact with cancer. Data collection methods are outlined in table 1.

Table 1 Participant Groups and Data Collection Methods for Growing Up With Cancer

<table>
<thead>
<tr>
<th>Participant Groups</th>
<th>Data Collection Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young cancer survivors aged 14 – 29 years</td>
<td>Online psychometric measure</td>
</tr>
<tr>
<td></td>
<td>One on one interview (1)</td>
</tr>
<tr>
<td></td>
<td>Creation of a Self Portrait</td>
</tr>
<tr>
<td></td>
<td>One on one interview (2)</td>
</tr>
<tr>
<td></td>
<td>Repeat online psychometric measure</td>
</tr>
<tr>
<td>Parents</td>
<td>Focus group</td>
</tr>
<tr>
<td>Specialist health care professionals</td>
<td>One on one interview</td>
</tr>
<tr>
<td>School students aged 14 – 18 years</td>
<td>Focus group</td>
</tr>
</tbody>
</table>

Data collected from each participant group was analysed separately.

**Project Components for Young Cancer Survivors aged 14 – 29 years**

Young cancer survivors are the focus of this thesis and were invited to participate in a survey that collected basic demographic information and combined 3 validated psychometric instruments:

- SF-36
- Hospital Anxiety and Depression Scale (HADS)
- Identity Style Inventory 6-G (ISI-6G)

Plus one or more of the following:

- One initial semi-structured and in-depth interview
- Workshop attendance and creation of a self-portrait(s)
- One follow-up semi-structured and in-depth interview
- Follow up online survey
- Public exhibition of self-portraits
- Documentary film

Participants could choose to withdraw from the study at any stage. My thesis is based entirely on one data set, namely, 49 interviews conducted with 27 young people.

**My Contribution to the Project**

My contribution to the project began after the first funding application was rejected by the ARC. Chief Investigators Kerridge and Jordens included me and my ideas in their reworking of this project that gained funding when it was resubmitted to the ARC in 2008. The idea to focus on self-identity and to use visual methods came from my small research project “Hospital Bedside Displays” [2, 3], and I assisted Chief Investigators Kerridge and Jordens with the preparation and submission of this project for ethical approval.
My Roles on the Project
I fulfilled two roles on GUWC. First, I was appointed as a PhD candidate. ARC Linkage projects include a scholarship to fund the training of a PhD student. The scholarship is known as an Australian Post Graduate Award, Industry. As the PhD student attached to the project, I co-ordinated the recruitment of young people as participants in the study, collected and analysed interview data, presented my findings at local, national, and international clinical and research forums, and wrote this thesis.¹

Secondly, during 2011 and 2012 I worked as a research assistant on the project recruiting participants and collecting and analysing data from the three remaining participant groups. I recruited parent participants, arranged and co-ordinated two focus group discussions, co-facilitated focus groups, and participated in a thematic analysis of focus group data. I have also participated in a discourse analysis of interview data collected by Dr Mooney-Somers from health care professionals who specialise in the care of adolescents and young adults with cancer.

I located an independent school, secured the support of one of its teachers, and arranged and co-facilitated, with Dr Mooney-Somers, creative workshops with students at the school. We conducted three workshops with students enrolled in drama classes from years 8, 9, and 11. We commenced the workshops by asking small groups of students to write a brief television news report about a young person their age diagnosed with cancer. We then asked students to perform their news story for the rest of the class. Dr Mooney-Somers recorded the performances on digital video. Finally, I facilitated a focus group discussion with students from each class focussed on the content of the performances they had just witnessed and their perceptions of the effects of a cancer diagnosis on a young persons’ life.

My participation in this project has provided me with a broad range of learning experiences each of which has advanced my development as a researcher.

¹ Details of participant recruitment, data collection, and data analysis are detailed in Part II of this thesis. A list of my dissemination activities appears after my thesis overview.
Abstract

Introduction

Because more young people are surviving cancer than ever before, more young people than ever before are living with the physical, psychological, emotional and social consequences of cancer illness and treatment. They do so during a transitional time of life and much is already known about their experiences of the physical and psychological effects of cancer illness and treatment. Less is known about the social consequences as they are experienced in relationship with other people. This thesis therefore focuses on the social consequences of cancer illness and treatment in young people who have completed their treatment and have returned to their usual social worlds.

This thesis has two aims. First, to expand on our current understandings of the experience of young Australians with cancer by focussing on the period of remission and recovery. Second, to determine how young Australians conduct social interactions in light of their cancer experience. The thesis will address these aims by answering the research question: “what is the impact of cancer illness and treatment on the experience of growing up?”

Methodology and Methods

A quota sampling strategy ensured we recruited a balanced sample of women and men and of young people from different diagnostic categories. Participants ranged in age from 16 to 29 years old at the time of their first interview. They ranged from 10 to 22 years old at the time of their diagnosis. I conducted a thematic analysis of 49 interviews collected from 27 participants guided by the theoretical perspective of Symbolic Interactionism.

Findings

At the time of their cancer illness and treatment, participants became dependent on their families for care. During their period of remission and recovery, older participants sought to regain the independence they had lost or given up during their period of illness and treatment while maintaining the intimacy they had developed with their parents.

When treatment allowed, participants re-entered their usual social worlds where they experienced heightened levels of attention from their peers. Participants welcomed some forms of attention while resisting others as they undertook a process of accommodating their cancer experience into their post-cancer sense of self.
As their social worlds expanded, participants met new acquaintances and formed new relationships. Participants underwent a difficult process of deciding how to disclose their cancer history to their new acquaintances and of negotiating the place of “cancer” in their new relationships.

Discussion
The impact of cancer on the process of growing up is evident in relationships with parents, peers, and new acquaintances. However, the impact is different for young people in early adolescence, mid-adolescence, late adolescence, and young adulthood. The difference reflects the normal changes in focus on different relationships during these phases of life. In childhood and early adolescence, the focus is on relationships with parents. In middle adolescence the focus shifts to relationships with peers. In late adolescence and young adulthood, the focus shifts to the young person’s independence and relationships of a romantic and/or sexual nature.

Conclusion
Findings from this study have practical implications for young people who have had cancer, their parents, peers, and new romantic and/or sexual partners. The challenge for these groups is to accommodate the ongoing effects of cancer illness and treatment into their relationships while young people continue the process of growing up.
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Part I: Introduction and Background

Chapter 1: Introduction
This is a story about growing up. In modern Australia, young people traverse the path to adulthood in much the same way as their contemporaries in other Western democracies. They balance life decisions such as choice of career and life partner with the immediate demands of completing education and pursuing a social life. While a standard script of sequential movement from childhood to adulthood prevails in popular Western culture, many young people experience disruptions to their process of growing up influenced by factors within and beyond their control. They may do less well in their final school exams than they had hoped and subsequently miss out on entry into the university course they had planned to start. They may lose the job that they relied upon for their independence and as a first step towards achieving their career goals or they may experience the break-down of a romantic relationship that they had foreseen continuing into the future. Any of these events has the potential to alter a young person’s planned life course leading her to question her sense of self and purpose in life.

In rare cases, the standard, sequential path to adulthood is complicated by a diagnosis of cancer. A diagnosis of cancer dramatically alters a young person’s sense of self, creating a sense of uncertainty about who she is and about what the future holds. Cancer illness and treatment alters a young person’s bodily appearance and function in dramatic ways that are sometimes ongoing for months or years after she has completed treatment. Young people treated for cancer cease to look like they once did and cease to look the way they want to. They can experience years of pain and fatigue as a result of their cancer experience. The effects of cancer illness and treatment can undermine a young person’s self-confidence creating anxiety about attracting a romantic partner. Those who have experienced living independently from their parents may suddenly return to their family of origin during their illness and treatment and have difficulty regaining their independence after their treatment is complete. In summary cancer has the potential to impose a considerable physical and social burden on young people.

However, this is only part of the story. Many young people also experience positive outcomes from their cancer experience including a change in their outlook on life, gaining a new appreciation for the value of close interpersonal relationships, and feeling deeper levels of
empathy for others’ suffering and greater wisdom and insight into life’s challenges. Sometimes their cancer experience gives young people ideas for future life directions – for careers in health care, or for raising a family of their own. Whether young people experience the ongoing effects of their cancer as positive or negative (or both), or as providing gain or loss, they engage in an ongoing process of accommodating their cancer experience into their developing sense of self and life as a cancer survivor.

In this thesis I will argue that the experience of growing up with a diagnosis of cancer for young people is one of both gain and loss with outcomes that young people perceive as both positive and negative. I argue, therefore, that the experience of cancer survivorship for young people is paradoxical. Furthermore, the impact of cancer illness and treatment is evident in young people’s relationships with their parents, peers, and new acquaintances. Diagnosis and treatment is typically a period of crisis; the main focus is simply to stay alive. It is chaotic but it is also usually transient. The crisis is followed by an ongoing period of remission and recovery during which the young person experiences the paradox of being both sick and well. They also experience the paradox of developing more slowly in some areas of life while developing more quickly in others compared to how they expected to develop, how they observe their peers developing, and compared to the normal transitions of adolescence and young adulthood represented in popular culture.

This thesis is divided into four parts. Part I includes introductory and background chapters. In chapter 2 I describe three grand narratives of transition from childhood to adulthood. I describe the biological narrative of puberty, the narrative of developmental psychology, and the social narrative of role transition. In chapter 3 I describe the epidemiology of and common treatment regimens for cancer in young people between 10 and 24 years of age. In chapter 4 I review the research literature that describes what is currently known about the effects of cancer on young people’s process of growing up. Researchers of the experience of cancer survivorship in young people commonly conceptualise adolescence and young adulthood as periods of transition. Authors combine aspects of all three grand narratives of transition that I describe in chapter 2 when they report on studies of young cancer survivors. I argue, however, that biological and psychological narratives of transition dominate this literature and less is known about young peoples’ social experiences of growing up with a diagnosis of cancer. In Part II, chapter 5, I describe the methodology of this research study and methods of data collection and analysis. I chose to analyse interview data using the
theoretical perspective of Symbolic Interactionism in order to focus on participants’ interactions and experiences of relationships with other people. In Part III I present my findings. Chapter 6 describes the impact of cancer on relationships between participants and their parents. Chapter 7 describes the impact of cancer on participants’ relationships with their peers. Chapter 8 describes the impact of cancer on participants’ relationships with new acquaintances and romantic partners. In Part IV I discuss what these findings mean for young cancer survivors, those with whom they closely associate, and the health care professionals who care for them. Finally, I conclude that the impact of cancer is disruptive to young people’s experience of growing up in both expected and unexpected ways. Their lives are likely to include, with the support of their parents and peers, an ongoing process of accommodating the effects of their cancer illness and treatment into their relationships and sense of self.

Chapter 2: Young People in Transition

2.1 Synopsis
Youth is predominantly described in Western culture as a period of transition. Holmbeck has provided a model of transition through adolescence and young adulthood intended to guide the study of young people by health researchers. The model depicts the primary transitions of adolescence - biological, psychological, and social – as interacting with each other to provide a framework for understanding adolescent development and adjustment [4]. Holmbeck lists the primary outcomes of adolescence as achievement, autonomy, identity, intimacy, psychosocial adjustment, and sexuality [4] (p. 411). These transitions are typically described as linear and predictable and as taking place within three distinct sub-phases: early adolescence (ages 11 – 14 years), middle adolescence (ages 15 – 17 years), and late adolescence (ages 18 – 20 years) [5] (p. 812). To these, Arnett has added a phase of emerging adulthood between the ages of 18 and 25 which overlaps with late adolescence. This is described in section 2.3.2.

A review of studies of young people with cancer requires an understanding of the dominant theoretical perspectives on young people that have guided research into this population. Therefore, in this chapter I will describe three grand narratives of transition evident in this literature. First, I describe the biological transitions found in the grand narrative of puberty. This transition occurs outside the control of individuals. During puberty, young people
transition to sexual maturity. This involves changes to the endocrine, neurological, and reproductive systems of the body. These changes result in alterations to bodily appearance and function. Second, I describe psychological transitions found in the grand narrative of developmental psychology. During adolescence and young adulthood, according to theories of developmental psychology, young people seek to establish a sense of self-identity by answering the question “who am I?” They play an active role in this process and the answers they choose have implications for their social lives. Third, I describe young peoples’ social transitions found in the grand narratives of changes in social roles. Historically, social transitions have been marked by rites of passage and narrated in stories of departure and return. In modern Western culture, social transitions include finishing school and starting work (or tertiary education), marrying, and becoming a parent. Late modern critiques of standard, linear scripts of social transition highlight the innumerable variations experienced by individuals during their transitional phases. This creates a tension for young people who, on the one hand, may choose the course their lives will take while, on the other hand, experiencing the constraints imposed on that choice by social structures that adhere to old, linear models of transition.

2.2 Biological Transitions

2.2.1 Changes brought about by Puberty

Puberty is not so much an abrupt change in the way a young person is constituted biologically as it is a predictable outcome in an ever changing system. Puberty begins when the inhibitory mechanism of the central nervous system in the region of the hypothalamus loses its sensitivity to the levels of circulating sex hormones in a child’s body [5] (p. 812). At this point, gonadotropin releasing hormone (GnRH) gradually increases to a level high enough to stimulate gonadotropin and steroid hormone secretion, resulting (eventually) in sexual maturation [6] (p. 68).

This process precedes any noticeable physical changes by about one year and results in increased secretion of oestrogen from a girl’s ovaries and androgen in a boy’s testes by factors of six and 20 respectively [6] (p. 69). Boys and girls each have circulating volumes of androgen and oestrogen. The balance shifts during puberty to the extent that boy’s androgen

\[2\] Although I treat these grand narratives separately, they each interact with the others in an ongoing way. For example, developmental psychological and social narratives of transition rely upon the grand narrative of puberty to delineate a particular population within the life cycle – one that experiences rapid and dramatic physical change.
levels become 20%-60% higher than those of girls, and girls’ levels of oestrogen become 20%-30% higher than those of boys [7]. Androgen causes bodily changes including growth of pubic hair, body odour, acne, and growth in body size and shape in both boys and girls [8].

Oestrogen causes the growth and development of the vagina, uterus, and fallopian tubes as well as the skin of the labia majora. Oestrogen causes girls’ breasts to enlarge and the areola and nipples to darken in colour [5] (pp. 812-813). Testosterone causes the growth and development of the penis, scrotum, prostate, and seminal vesicles of the testicles [5] (p. 814). Marshall and Tanner developed the classic 5-stage model of pubertal changes in girls and boys (Table 2) [9, 10].

Table 2 Pubertal Changes in Girls and Boys

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Girls</th>
<th>Boys</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No pubic hair; essentially the same as during childhood; no distinction between hair on pubis and over the abdomen</td>
<td>No pubic hair; essentially the same as during childhood; no distinction between hair on pubis and over the abdomen</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Sparse growth of long, straight, downy, and slightly pigmented hair extending along labia; between stages 2 and 3 begins to appear on pubis</td>
<td>Initial enlargement of scrotum and testes; reddening and textural changes of scrotal skin; sparse growth of long, straight, downy and slightly pigmented hair at base of penis</td>
</tr>
<tr>
<td></td>
<td>Breast bud stage – small area of elevation around papilla; enlargement of areolar diameter</td>
<td></td>
</tr>
<tr>
<td>Stage 3</td>
<td>Hair darker, coarser, and curly and spread sparsely over entire pubis in the typical female triangle Further enlargement of breast and areolar with no separation of their contours</td>
<td>Initial enlargement of penis, mainly in length; testes and scrotum further enlarged; hair darker, coarser, and curly and spread sparsely over entire pubis</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Pubic hair denser, curled, and adult in distribution but less abundant and restricted to pubic area Projection of areolar and papilla to form a secondary mound</td>
<td>Increased size of penis with growth in diameter and development of glans; glans larger and broader; scrotum darker; pubic hair more abundant and curling but restricted to pubic area</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Hair adult in quantity, type, and pattern with spread to inner aspect of thighs Mature configuration; projection of papilla only caused by recession of areolar into general contour</td>
<td>Testes, scrotum, and penis adult in size and shape; hair adult in quality and type and spread to inner surface of thighs</td>
</tr>
</tbody>
</table>
These five stages are the primary source of measurement and tracking of pubertal changes by researchers and clinicians to this day [11].

Bodily changes are often dramatic. Boys and girls both grow in height during a “growth spurt” that normally begins one year after pubertal hormonal activity has been initiated. The growth spurt lasts on average until between 12 and 16 years of age, peaking at 14 years of age. During this time, girls’ height increases on average by 19.6cm and boys by 21.1cm. Weight gain is also prevalent including increases in both muscle and fat. Increased muscle mass leads to increased strength and bodily control. Body proportions also change. Before the onset of puberty, shoulder width slightly exceeds hip width in both boys and girls. The ratio diminishes in girls and increases in boys during puberty [6] (p. 73).

2.2.2 Neurological Changes
Recent research using MRI technology has mapped the growth and development of the brain in young people, enhancing our understanding of the structural changes in a young person’s brain. These studies have shown, for instance, that frontal grey matter volumes peak at 11 years in girls and 12.1 years in boys while temporal grey matter volumes peak at 16.7 years in girls and 16.2 years in boys. The dorsal lateral prefrontal cortex, an area of the brain important for controlling impulses, reaches adult dimensions in the early 20s [12, 13].

Some neurologists argue that experience influences the development of young people’s brains by influencing the process of “synaptic pruning” that reshape young people’s brains during puberty, adolescence, and young adulthood [14]. They argue that young people’s brains do not simply grow larger but that they change shape in such a way that neurological pathways important in childhood are culled and those important in adulthood are strengthened [14]. For this reason, Dahl advocates for multidisciplinary research into and social contextual understandings of the neurological development of adolescents and young adults [14] (p. 1). Adolescents and young adults are constructed as impulsive risk takers who endanger themselves and others with their socially inappropriate action. Their changing neurological structures may partly account for their behaviour, but their behaviour must be understood within their social context.
Some researchers acknowledge that risk taking may be as much socially as neurologically
determined. For example, Reyna and Farley argue that risk aversion is adaptive and that the
decisional processes that support aversion are more advanced than those that support risk
taking [15]. They also argue that, although in theory young people are capable of making rational decisions, in practice rational decision making is dependent on the social context in which they are situated. *In the heat of passion, in the presence of peers, on the spur of the moment, in unfamiliar situations ... adolescents are likely to reason more poorly than adults do* [15] (p. 1).

2.2.3 Endocrine Changes and Individual Behaviour
The effects of hormonal changes on emotions and behaviour are contested. Rowe *et al* found no link between testosterone levels and aggressive behaviour amongst boys. However, elevated testosterone levels have been associated with deviant behaviour amongst boys who associate with “deviant” peers or in the demonstration of leadership abilities and behaviours amongst those with “non-deviant” peers [16]. Buchanan *et al* identified that increasing or decreasing concentrations of hormones within a normal range affect moods and behaviours. For example, in both adult men and women, higher oestrogen levels are associated with a more positive mood and lower levels are associated with depression and negative affect [17]. However, higher levels of testosterone in adolescent boys has been associated with lower tolerance of frustration and increased aggression [6] (p. 75). Buchanan *et al* found only limited links between fluctuating or irregular hormone levels and mood swings [17].

Other research suggests that links between levels of neuropeptides (influenced by levels of oestrogen and testosterone) and experiences of arousal and sexual pleasure are less equivocal than the influence of hormones on mood. Oxytocin is associated with pleasure during sexual arousal for both men and women, and vasopressin is released only during male sexual arousal [6] (p. 75). Hiller suggests that feelings of love and romance may be induced by increased levels of oxytocin while sexual arousal may be influenced by increased vasopressin. These studies suggest possible biological evidence for behavioural and attitudinal differences in sexuality between males and females [18]. For boys, circulating levels of testosterone are a significant predictor of sexual arousal, coital activity, masturbation, thinking about sex and future intentions with respect to sexual activity. For girls, the adrenal androgens – including testosterone – predict non-coital sexual activity (such as fantasy and masturbation) and arousal [6] (p. 76).
2.2.4 Summary
Young peoples’ bodies grow and develop at the onset of puberty as a result of their brains’ increased receptivity to the circulating volume of sex hormones. Young people therefore undergo a transition from being sexually immature to sexually mature. Changes are prominent to the reproductive, neurological, and endocrine systems of the body and these changes have implications for the way young people perceive themselves and are perceived by others. I will use the biological transitions of puberty to outline how biological, psychological, and social changes combine to form an overall sense of the process of growing up in section 2.5.

2.3 Transitions in Developmental Psychology
The discipline of psychology largely situates the formation and maintenance of personal identity within the individual. Identity is thus seen as something that arises from essential characteristics of the human being and is attributable to certain inherent traits. Different branches of psychology view identity formation and maintenance in different ways. This section describes the periods of adolescence and young adulthood from the perspective of developmental psychology.

2.3.1 Erikson’s Theory of Human Development
Developmental psychological theories of adolescence and young adulthood dominate research of the experiences of young people with cancer. Erikson locates identity formation within his theory of human development across the life span from birth to old age. He posits eight stages in the life cycle [19]. Each stage is framed as a conflict, the resolution of which enables a person to progress to the next stage. For Erikson, identity formation takes place at stage V which corresponds to the chronological period of adolescence (12-20 years old). According to Erikson, the conflict to be resolved is one of identity versus identity confusion. Resolution to the conflict in stage V is brought about by answering the question “who am I?”[19]. Stage VI corresponds with the chronological period of young adulthood (20-24 years old). The conflict to be resolved in this stage is one of intimacy versus isolation. Resolution of the conflict in stage VI is brought about when a young person successfully forms loving relationships with other people (i.e. new relationships of a romantic and/or sexual nature) [19]. Maintenance of identity is conducted in all subsequent stages of the life cycle.

3 Cognitive psychological development is relevant to young people’s capacity to understand information, and what is appropriate in terms of content and the means of communicating information to young people. It therefore has implications for the concept of informed consent. Whilst this is an important area of research, it is not directly relevant to this thesis.
In early adolescence, the sense of identity developed during childhood becomes unstable, begins to dissipate, and the development of a new “individuated” sense of identity is needed to take its place – one in which a young person can accurately identify the things about him or her that are unique compared to other people. According to Erikson, adolescence is a period divided between the need to establish a sense of one’s current and future self and a lack of commitment and stability. He characterized adolescence as *the period in the human life cycle during which the individual must establish a sense of personal identity and avoid the dangers of role diffusion and identity confusion* [20] (p. 60). The dangers of role diffusion and identity confusion are that a young person will experience ongoing psychological distress.

The answer to the question “Who am I?” may be found by addressing three further questions: Where have I come from? Who am I now? What do I want to become? [20]. The search for an identity involves establishing a meaningful self-concept in which past, present, and future are brought together to form a unified whole [20]. The task of an adolescent is to answer these questions for him- or herself rather than to have them answered on their behalf by someone else. For example, according to Erikson, if parents take responsibility for their child’s identity formation, identity confusion is likely to result. According to Erikson, self-identity is not given to an individual by society. Nor is it an inevitable outcome of biological processes operating within the right context. Self-identity is acquired through sustained individual effort. The consequences for the individual who fails to work on the development of their identity include role diffusion (that is, uncertainty about their true identity), which may result in a sense of social alienation, isolation and confusion [20] (p. 60).

Erikson wrote at a particular historical time during which people typically started careers and formed couples in their early twenties. Hence, Erikson’s chronological categorisations of young people are not necessarily reflected in Western cultures in the twenty-first century. Erikson anticipated this when he commented on the prolonged adolescence he began to observe in people living in Western industrialised societies and of the *psychosocial moratorium* granted to young people in such societies *during which the young adult through free role experimentation may find a niche in some section of his society* [19] (p. 156). Levinson echoed this concept in his own concept of the *novice phase*, from 17 – 33 years old. He conceived this as a time in which people move into the adult world and build a stable life structure. During this phase, young people experience considerable change and instability.
while sorting through various possibilities of love and work in the course of establishing a sense of self [21].

Whilst Erikson’s theory remains highly influential in the study of young people, it has been widely criticised. One criticism concerns its dichotomous nature: individuals either achieve or do not achieve a coherent identity. An expansion by Marcia introduces two dimensions to the original dichotomy conceptualised by Erikson, that is, exploration and commitment. These dimensions generate four distinct identity statuses rather than two: Identity Diffusion, Identity Foreclosure, Identity Moratorium, and Identity Achievement [22]. Of these four identity statuses, Identity Moratorium most effectively captures the notion that young people are in an unstable state between those of child and adult. Moratorium is the status of a young person who is actively engaged in exploring different identities without having made a commitment to any of them [22].

The similar concepts of psychosocial moratorium, novice phase, and identity moratorium are important to these early theories of development in young people. They provide the social conditions within which young people can answer their questions of self-identity through their own sustained individual effort. In other words, the mid-twentieth century societies in which these authors wrote theoretically created a social space which allowed young people to explore different options for establishing their self-identity. This does not, however, mean that those social spaces determined the answers to the question “who am I?” I will describe the social constraints on the number and type of answers to the question “who am I?” in more detail in section 2.4.2.2. Currently, in Australia, those social spaces might be said to exist in the concept of the gap year, the year between finishing high school and commencing a university degree or embarking upon a career, and in the university itself, where young people are free to explore who they are.

2.3.2 Arnett’s Theory of Emerging Adulthood
Arnett has recently added a further developmental stage to Erikson’s eight stages of the life cycle. His theory works as a revision of Erikson’s human development across the life span by including the period of psychosocial moratorium as an integral step in the framework. This revision may have been necessary considering the generational changes that had taken place between the time of Erikson’s work and the time of Arnett’s. For example, since Erikson’s time, generations X and Y have been identified by cultural researchers as distinct demographic groups. Arnett argues that emerging adulthood (ages 18-25 years) is a distinct
period in the life cycle demographically, subjectively, and in terms of identity explorations [23] (p. 469). According to Arnett, young people are entering roles that have traditionally served as markers of adulthood later than they did in the past. Ages at first marriage have risen for young women and men since 1970 and average age at first child birth has risen for women. The early twenties were historically a period of entering and settling into long term social roles. They are now a period of frequent change and exploration [23] (p. 469). This perspective overlaps significantly with social science perspectives of transition.

According to Arnett, emerging adults have left the dependency of childhood and adolescence behind. They are independent, but are not yet subject to normative adult role expectations. They are therefore free to explore a variety of possible life directions in love, work, and world views. Emerging adulthood is a period when many different directions remain possible, little about the future has been decided for certain, and when the scope of independent life possibilities is greater for most people than it will be at any other period in their lives [23] (p. 469).

Arnett argues for emerging adulthood as a distinctive life phase in three ways. First, emerging adulthood is distinct demographically because this phase has no demographic norms. This contrasts with the periods of adolescence (12 – 17 years old) and adulthood (30 years and older). For example, Arnett argues for demographic normativity in adolescence on the grounds that 95% of 12 – 17 year olds live with their parents and 98% of them are unmarried [23] (p. 471). The demographic status of emerging adults is unpredictable because they are unconstrained by role expectations. Arnett quotes Parsons (1942) as nominating adolescence the roleless role and argues that the term better fits emerging adulthood [23] (p. 471).

Most emerging adults leave the family home for diverse destinations including the semi-autonomy of college living, independent living and employment, or cohabitation with a romantic partner. Arnett argues that these arrangements are unstable, with emerging adults experiencing higher frequencies of residential relocation than any other age group. Arnett argues that these changes reflect the exploratory nature of emerging adulthood because residential changes typically coincide with the end of one period of exploration and the beginning of another [23] (p. 471). Arnett also argues that emerging adults stay at school longer and attend college more than people of previous generations. Again their destinations are diverse. In the United States, about one third of 25 – 29 year olds finish a four year degree, college students combine study with work and mix periods of attendance with periods

26
of non-attendance. One third of those who complete their degrees enrol in “grad school” the following year [23].

Second, emerging adulthood is distinct subjectively. Arnett argues that when emerging adults are asked if they have reached adulthood they say “in some respects yes, in some respects no”. According to Arnett, they do not feel as though they are either adolescents or young adults, they are something in between. He argues that this is because our society has not provided a name for the stage they are in. Arnett argues that emerging adults value “accepting responsibility for oneself” and “making independent decisions” as the most important markers of adulthood followed by achieving financial independence. They prioritise these above role changes such as marriage and the establishment of a career. The exception to this is a change in status to that of parent. Young people who become parents consistently report a subjective feeling of having become an adult. So, the goal of emerging adulthood is self-sufficiency [23] (p. 473).

Third, emerging adulthood is distinct for identity explorations. Arnett contests Erikson’s location of the period of identity exploration within the period of adolescence by arguing that it actually takes place in emerging adulthood in three specific areas; love, work, and world views. Arnett argues that love in adolescence tends to be tenuous and transient and focused on experimentation whereas love in emerging adulthood tends to involve deeper levels of intimacy [23]. Work in adolescence tends to be tenuous and transient and focused on experimentation. Arnett argues that adolescents see work as a way to get money to sustain their leisure activities rather than as occupational preparation. Work in emerging adulthood tends to be more “serious” and focused on preparation for adult work roles. The goals of both love and work for emerging adults are exploration for exploration’s sake rather than preparation for commitment to long term and restrictive adult roles [23]. Arnett concedes that his concept of emerging adulthood is culturally bound when he argues that emerging adulthood ... is not a universal period but a period that exists only in cultures that postpone the entry into adult roles and responsibilities until well past the late teens. ... most likely ... countries that are highly industrialised or post industrial [23] (p. 478).

Arnett’s thesis is clear. He sees a gap in the developmental progression from childhood to adulthood that is not covered by the concepts of adolescence or young adulthood. He locates another developmental phase between adolescence and young adulthood in order to fill this
gap. He also makes some claims about why this is necessary and how his theoretical developmental phase differs from those that Erikson developed in the mid twentieth century.

Arnett’s argument achieves a number of things. First, it makes the developmental period of adolescence more fixed and stable than it is generally regarded to be, although he does argue that young people do not emerge from adolescence fully formed and stable. He “stabilises” adolescence by referring to the homogeneity of their demographic – that they are nearly all in school, living at home and unmarried. Arnett then relies on this argument to sustain his argument that emerging adulthood is dynamic, changing, and unfixed. Second, Arnett claims that young people are also demographically homogeneous and uses that to bolster his argument in favour of emerging adulthood as a distinct developmental phase. Third, by inserting a developmental phase (or new developmental category) between adolescence and young adulthood, Arnett adds two new thresholds of transition to the process of “growing up”. One is the transition from the relatively static, homogeneous period of adolescence into the dynamic, unpredictable, and heterogeneous period of emerging adulthood. The other is from emerging adulthood to the static, homogeneous period of young adulthood that commences at age 30.4

Arnett adds nothing new to the idea that young people are in between stable stages of development. What he does is relocate the instability and confusion that Erikson associates with the period of adolescence to the chronological period of 18 – 25 years old. He substantiates this relocation by referring to the prolonged periods of dependence on parents and deferral of the assumption of adult roles usually associated with late modern sociological perspectives of growing up. However, he does not indicate that the process of achieving a self-identity is anything other than a process of sustained individual effort. Therefore, Arnett’s theory is a useful bridge between the discipline of psychology and current social perspectives of young people’s transition to adulthood.

2.3.3 Summary
For developmental psychologists, the task of adolescence is to answer the question “who am I?” as comprehensively as possible. Psychologists focus on the individual. However Arnett’s articulation of his theory of emerging adulthood provides a useful overlap between the perspectives of psychology and those of the social sciences. Social scientists have also

4 I will describe the metaphor of “thresholds” as a point of transition for young people in more detail in section 2.4.1
studied the nature of adolescence and young adulthood and developed explanatory frameworks that both complement psychological theories and provide an alternative to them.

2.4 Social Science Perspectives of Transition
Social sciences perspectives differ from those of psychology in their focus on the development of identity. The perspective of psychology is that personal identity is generated from within individuals and is manifested in their social settings and interactions with others. Social sciences perspectives hold that the social structures individuals inhabit and the interactions they have with others shape their sense of a personal identity.

2.4.1 Historical Perspectives of Social Transitions
French anthropologist Arnold Van Gennep produced the seminal work on rites of passage in the early twentieth century. It is therefore infused with the cultural mores of the time. Van Gennep’s Europe was a patriarchal and colonialist society which tended to marginalise the voices of women and objectify people of colonised places. Van Gennep’s work must be read with this in mind. However, his insights into rites of passage and the social events that mark them are relevant to this thesis in that they deal directly with people engaged in life transition. As I have described, one of the definitive characteristics of youth is its transience.

According to Van Gennep, rites of passage are subdivided into rites of separation, transition, and incorporation [24] (p. 11). Rites of separation occur when young people leave their usual social world and enter an unfamiliar and unstable world. This unstable world is a social space between two stable spaces where rites of initiation are carried out. Young people experience rites of incorporation when they return to their usual social worlds as people who have been transformed to maturity. Rites of passage are therefore spatially, temporally and culturally constructed rituals and symbols that mark a person’s passage from one status to another. Central to this is the spatial metaphor of the threshold over which individuals pass during their transitional state. The rite of passage is not the mechanism by which the person’s status changes, it is simply the outward marker of such a change. Van Gennep dedicates a chapter to “puberty rites” that he argues mark the transition of young people from the asexual world to the sexual world [24]5. Van Gennep’s socially and temporally bound descriptions of rites of passage are mirrored in modern Western culture in the construction of adolescence and young adulthood. These categories are regarded as discreet periods of the life span and different rites of passage mark a young person’s progress through these periods from childhood to

5 This is a socio-cultural manifestation of the grand narrative of biological grand narrative.
adulthood. However, as I will describe in section 2.4.2, a young person’s arrival in the category of “adult” is less well defined in late modernity than was represented as being in early twentieth century Europe.

Van Gennep’s rites of passage are reflected in the stories people tell about themselves. In The Hero with a Thousand Faces, Campbell provides a description of what he calls the monomyth – a story common to a wide variety of cultures throughout time and space [25]. Campbell demonstrates that the basic template for these stories-in-common is the heroic narrative. The heroic narrative has a three part structure. In the beginning the hero departs the safety and security of the home having heeded a call to adventure. During the middle phase the hero undergoes rites of initiation during which he faces a series of trials. The ending comes about when the hero returns with the lessons he or she has learnt from withstanding the trials – what Campbell calls a “boon” [25]. Campbell wrote this work in the mid-twentieth century United States. This society was divided differently by class, race, and gender than are Western societies today. However, we can cautiously apply Campbell’s monomyth to late modern Western society if we accept that young women are now as likely to heed a call to adventure and act heroically as young men were assumed to in the early and mid-twentieth century.

In Campbell’s monomyth, we can see a reflection of Van Gennep’s process of rites of passage. For Campbell, the hero crosses a threshold into a liminal space in which his secure world is destabilised. Campbell was interested in the similarities between the myths he collected rather than in the differences. This places him at odds with any post-modern perspective that concentrates on difference rather than similarity. We should be cautious about applying Campbell’s template to all stories, however, because whenever we compare a specific instance of a story with a model or template, there is always a gap between the details of the individual story and its template. The application of any of these three grand narratives – biological, psychological, or sociological – will likely reveal a gap between the experiences of individuals and the normative experience described by the grand narrative.

2.4.2 Destabilising the Life Course: Late-Modern Youth Transitions

Historically, social grand narratives of transition from childhood to adulthood have reflected those of biology and psychology in their predictability and linearity [26]. Transitions important in the social sciences have included those between different social settings such as
the transition from school to work or parent’s home to own home, and between different social roles, such as those from student to employee or from single person to marriage partner. Three prominent social theorists - Bauman, Beck, and Giddens - have questioned the applicability of the predictable and linear model of transition through the life course. Late modern perspectives of transition contrast with those produced in the early and mid-twentieth century that I have described in section 2.4.1 and have heavily influenced social sciences research with young people.

2.4.2.1 Three Theorists
Bauman’s concept of Liquid Modernity

... projects us into a world in which everything is elusive, where the anguish, pain and insecurity caused by ‘living in society’ require a patient and ongoing examination of reality and how individuals are ‘placed’ within it. [27] (p. 3)

Elliott highlights the contrasts Bauman makes between the modernist project of self and the postmodern experience of selfhood. He points out that the modern self is one “obsessed with stability, reliability, consistency, and predictability” [28] (p. 154). To Bauman he attributes the notion that the modern search for self-mastery is “self-defeating, illusory, and fictitious” [28] (p. 154). In other words, the goal of self-mastery supposedly sought by individuals in modern society was never an achievable goal in the first place. Instead, post-modern global socio-political conditions have highlighted the fragmentary and unstable nature of individual quests to create a stable and durable sense of self.

The impact of this on individuals seems to be a feeling of ambivalence about identity. Bauman describes identity as “hopelessly ambiguous” and as a “double edged sword” [27] (p. 76). The double edged sword may be used equally as a means of inclusion into any given social group or of exclusion from any group depending upon the dominant norms, values, or conventions of that group. Individuals therefore “try on” different identities consecutively, without being particularly mindful of the possibility that these identities may be incompatible or contradictory.

Bauman also critiques the notion that identity development is similar to the process of constructing a jigsaw puzzle. A jigsaw puzzle bought from a shop in a box is assumed to contain all the pieces necessary to complete the picture. Furthermore, the picture is represented in advance of commencement of the project on the lid of the box. In this way, completing a jigsaw puzzle is goal-oriented, that is, it starts with a clear impression of what
the conclusion will be. The end is already known. When developing an identity, however, we have no way of knowing what the finished product will be, or how many pieces of what type we have access to. Identity development is therefore means-oriented. You start with what you have (the nature of which is incompletely known) and order and reorder the pieces until you find a way to fit them together. The jigsaw puzzle follows the logic of instrumental rationality (selecting the correct means to a given end). According to Bauman, however, the job of the identity-constructor is that of a bricoleur - one who conjures up all sorts of things out of the material at hand [27] (p. 47-50).

Beck and Beck-Gernsheim coin the term “individualisation” to describe the consequence of social change in late modernity in which individuals are increasingly required to construct their own lives. They refer to this process as “elective”, “reflexive”, or “do-it-yourself biography” [29] (p. 25). Beck and Beck-Gernsheim base their concept of individualisation in two meanings. First, individualisation means the “disintegration of previously existing social forms” [29] (p. 24). Secondly, it means the “collapse of state-sanctioned normal biographies, frames of reference, [and] role models” [29] (p. 24). In other words, whereas one’s identity was traditionally determined from birth by custom, in late modernity it is something that needs to be chosen and constructed by the individual.

A critical debate has emerged amongst authors who interpret these late modern perspectives, such as Beck’s notion of “choice biographies”, over the roles of agency and social structure in young peoples’ constructions of their self-identity [30]. On the one hand, some authors argue that Beck over-emphasises individual agency in his theory at the expense of social structural constraints on individual action. On the other hand some authors claim that Beck has little interest in the nexus between personal choice and social-structural constraint and claim that he argues that at this historical moment, the break-down of established structural constraints also acts to weaken the function of new, deliberate choices. What this debate points to is a choice/constraint continuum that has implications for young peoples’ transitions in the empirical world.

The third theorist, Giddens, introduced the concept of the Reflective Project of Self in which people engage in an active process of making and remaking their biographies over time [31]. Giddens argues that, because of rapid and dramatic social changes in late modernity, it is no

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6 Bauman borrows this term from Levi-Strauss
longer possible for young people to develop their self-identity simply by emulating their parents or reproducing the model of adult life that surrounds them [31]. Instead, we all engage in a process of inventing ourselves by making decisions about who we are and who we want to be. Giddens further argues that one of the most important tasks we undertake in this process is to tell narratives of the self. These narratives articulate explanations of the past and intentions for the future. The Reflexive Project of Self is therefore the process whereby self-identity is constituted by the reflexive ordering of self-narratives [31] (p. 244).

The similar point made by each of these three theorists is that the social structures that historically shaped the life course of individuals are breaking down because of changing global economic conditions. This means that the onus is on individuals to shape their own life course with limited social-structural constraint. These theories are reflected in the lives of young people in generation Y to a greater or lesser extent [32].

2.4.2.2 Research into Youth Transitions
Recent empirical research has sought to combine the disruptions to the standard script of youth transition while, at times, resisting the consequence of individualisation described by Bauman, Beck, and Giddens. The standard script of transition, as Giddens argues, has been de-sequenced and de-standardised during late modernity [26, 33]. However, it has also been argued that young people may feel a tension about the de-standardisation of their life transitions. This tension arises out of structural constraints upon young people’s choices because social policies and institutions dedicated to facilitating transitions to adulthood, specifically the transition from school to work, adhere to old, linear models of youth transition [34]. Social institutions that aim to support transitions of young people are therefore in conflict with the realities of transition experienced by young people in late modernity. Individualisation is therefore experienced within a late modern Western social system structured by models of youth transition that apply less broadly than they once did.

The theoretical perspectives outlined in section 2.3.2.1 have implications for young people’s experience of transition. The path to adulthood is no longer regarded as linear and predictable. Rather, young peoples’ “journeys” may be accelerated, delayed, or reversed by life events including unexpected job loss, relationship break down, or a health crisis [35]. The

Generation Y usually refers to people born between 1982 and the mid to late 1990’s. All participants in this study fall into this category.
traditional linear path to independence may now be seen as cyclical, that is, from dependence to independence and back to dependence. This has been described as yo-yoing [36]. Yo-yoing suggests that the traditional linear transition to independence has been replaced by a prolonged state of semi-dependence [37].

As Holdsworth and Morgan point out, such transitions do not result from an individual set of decisions and experiences but *a process involving inter-relationships and interdependencies on numerous ‘others’* [38] (p. 3). In this context I take ‘others’ to mean other individuals as well as social institutions with which young people engage. For late modern social scientists therefore the act of leaving the family home is shaped by economic and social factors, in addition to resulting from an inward desire to express a psychological self-identity. These actions also evoke reciprocal responses from others. A young person’s move from the family home not only effects them but also those left behind [38, 39].

**2.4.3 Summary**

Historically, grand narratives of transition have described adolescence and young adulthood as the period between childhood and adulthood. Furthermore, this transitional period has been regarded as linear and predictable. Traditional perspectives of the transition from childhood to adulthood are normative and portray the transitions and their outcomes as inevitable. Grand narratives of biology and psychology continue to inform our understanding of the process of growing up. Despite this, theorists in the social sciences have argued that traditional social structures are breaking down in late modernity rendering traditional role transitions redundant. One consequence of this is that transitions have been de-sequence and de-standardised making individuals responsible for navigating their own pathways towards adulthood – through bricolage, choice biography, or the Reflexive Project of Self. However, they do so within the structural constraints imposed by social institutions that adhere to an old, linear model of transition.

**2.5 Overlap of Three Grand Narratives of Growing Up**

I have treated these three grand narratives of transition separately in order to describe them clearly. However, they overlap significantly in young people’s lives. Consequently, growing up is an amalgamation of the changes described in all of these grand narratives of transition. Changes in one of these grand narratives can result in changes in the other grand narratives.
One area of life where this is vividly illustrated is in the socio-cultural meanings of puberty. This provides a good example of the processes involved in combining biological, psychological, and social grand narratives. The timing of puberty has an impact on how individuals perceive themselves and are perceived by their peers. Moore and Rosenthal cite older studies, for example Mussen and Jones (1957) and Peskin (1967) that ascribe advantages to early maturing boys. However, more recent studies suggest that early maturing boys are more likely to exhibit “behaviour problems” such as “mild delinquency”, misbehaviour at school, drug and alcohol use, depression and even tendencies towards psychopathology [6] (p. 83). Early maturity may also be a disadvantage for girls. More physically mature girls have poorer body images and are more likely to experience eating disorders than later maturing girls [6] (p. 83). Simmons et al showed that early maturing girls tended to be more depressed than later maturing girls and experienced more disciplinary problems at school. By age 16, early maturing girls were “dating” more and considered themselves more popular with boys [40]. However, the young women did not consider this popularity to be positive, linking it to lowered self-esteem. Research conclusions are that early maturity is stressful for both girls and boys in a way that late maturity is not. Having said that, the most stressful situations to be in are those of the earliest maturing girls and the latest maturing boys [6]: 84.

One of the socio-cultural meanings of puberty in Western societies is that it makes the latent sexuality of childhood overt and explicit. Sexuality is seen as part of our essential selves [41] (p. 5) and as a central aspect of being human throughout life and encompasses sex, gender, identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction [42] (p.167). A person’s perception of their sexuality is likely to be influenced by cultural, ethnic and religious beliefs and practices [43] (p. 3). Aspects of sexuality also have implications for the performance of social roles. Marriage and parenthood, for example, are markers of adulthood arising specifically from a young person’s sexuality.

As adolescents grow older, peers influence many of their attitudes and behaviours including those related to sex. For example, according to Moore and Rosenthal, 69% of sexually active 17 – 20 year old university undergraduates felt they could discuss their concerns about sex with their friends [44]. This figure decreased to 33% for discussion with mothers and 15% for discussion with fathers. Although discussions were common, practical assistance from peers in accessing contraception or encouraging safe sex practices was rare: 22% reported that their
friends helped arrange access to contraception, and 17% reported that friends promoted safe sex by buying condoms. Practical assistance from parents, however, was rarer still: only 5% of fathers had assisted by arranging contraception [44]. The most influential factor on sexual behaviour for both men and women was the individual’s perceptions of the sexual behaviour of their peers. If peers were believed to be engaging in sexual activity, then individuals were more likely to be engaging in sexual activity or, at least, to report an increased desire for sexual activity. Peers also worked to limit sexual activity. If peers are perceived to be not sexually active and if the group norm is against sexual behaviour, then individuals within the group were less likely to be sexually active [6] (p. 105-109).

The influence of having a romantic partner on participation in sexual activity has also been studied. For example, Marin et al and Miller et al both found that having a partner at least 2-3 years older was strongly associated with having had sex [45, 46]. Female college students were significantly more likely than males to have discussed the prospect of sex with their partner before it occurred, considered themselves ‘in love’, felt pressured by their partner to have sex and wished they had waited [47]. Moore et al (1993) found that communication with a partner about contraception was a major predictor of safe sex behaviour [6] (p. 109).

To summarise, growing up is best understood as an amalgamation of the biological, psychological, and social transitions young people experience. Ill-health can destabilise transitions from childhood to adulthood and health care institutions define and conceptualise young people in particular ways. Overlapping perspectives of the process of transition are evident in recent research conducted with young people who have had cancer. However, before I review that literature in detail I will provide a brief overview of the epidemiology of cancer in young people, common treatment regimens, and common side effects of disease and treatment.
Chapter 3: Young People with Cancer

3.1 Synopsis
“Cancer” refers to a group of diseases affecting every bodily system and people of all ages [48]. In this chapter I will describe the incidence of cancer and the common outcomes of treatment for young people diagnosed in Australia between the ages of 10 and 24 years. I will also describe the common modes of treatment for different cancer diagnoses. Each of these treatment modalities, whether administered singly or in combination, has ongoing and sometimes late effects on young peoples’ developing bodies that have implications for their interactions with other people. In chapter 4 I will describe young people’s experience of cancer survivorship as it has been reported in recent studies.

3.2 Diagnosis and Incidence of Cancer
In this section I will describe common cancer diagnoses in adolescence and young adulthood and their incidence. Treatment modalities referred to in this section will be described in more detail in section 3.5.

3.2.1 Diagnostic Groups
Leukemia: Leukaemia is a broad term referring to malignant diseases of the bone marrow and lymphatic systems of the body. The most common types of leukaemia in young people are Acute Lymphoblastic Leukemia (ALL) and Acute Myeloid Leukemia (AML). Leukemias are caused by extensive and rapid growth of immature white blood cells in the blood-forming tissues of the body. These dysfunctional white blood cells then infiltrate and replace any bodily tissue, most extensively in highly vascular organs such as liver and spleen. Leukemias depress the function of the bone marrow. This means that young people most often present for treatment with a combination of fatigue, pallor, fever, anorexia, haemorrhage, and bone and joint pain. Leukemias are treated with chemotherapy [49] (p. 1583-1584).

Lymphomas: The two most commonly diagnosed lymphomas in young people are Hodgkin Disease and non-Hodgkin Lymphoma. Hodgkin Disease originates in the lymph nodes and typically metastasizes (migrates) to extra-lymphatic organs such as liver, spleen, bone marrow, lungs, and mediastinum (the mass of organs that separate the two lungs including the heart, trachea, and oesophagus). The enlargement of the lymph nodes is painless but they can be felt as firm, non-tender, moveable lumps most often located above the collar bone and in

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8 All statistics in this section come from the report of health and wellbeing compiled by the Australian Institute of Health and Welfare.
the neck area. Other signs include a persistent, non-productive cough (caused by lumps in the mediastinum pressing against the trachea), abdominal pain, fever, anorexia, nausea, weight loss, and night sweats. Primary treatment modalities for Hodgkin Disease are a combination of radiotherapy and chemotherapy [49] (p. 1587-1588).

Non-Hodgkin Lymphoma is different to Hodgkin Disease because it is usually diffuse rather than nodular (widespread rather than localised), and it spreads earlier and more rapidly than Hodgkin Disease. Many of the signs of Hodgkin Disease are present in non-Hodgkin Lymphoma (apart from the easily palpable, large lumps present in Hodgkin Lymphoma). Non-Hodgkin Lymphoma is treated with a combination of radio and chemotherapy [49] (p. 1588-1590).

Nervous System Tumours: Two common types of nervous system solid tumours are brain tumours and Neuroblastoma. Symptoms of brain tumour vary according to the size and location of the tumour. However, the most common indicators of a brain tumour are headache (especially on waking) and vomiting which is unrelated to feeding. Other symptoms include neuromuscular changes (e.g. poor fine motor control, weakness, paralysis), behavioural changes (e.g. irritability, lethargy, fatigue), and disturbances of vital signs (e.g. decreased pulse and respiration, increased blood pressure). Brain tumours are treated with a combination of surgery, radiotherapy and chemotherapy [49] (p. 1590-1592).

Neuroblastoma arises from the adrenal medulla and the sympathetic nervous system. The primary site is usually within the abdomen. Most often, young people with a neuroblastoma present for treatment with a more or less palpable mass in their abdomen (depending on the size of the tumour) that presses against adjacent organs. The least severe Neuroblastomas are surgically removed as much as possible and radiation is applied post operatively. The most severe Neuroblastomas are treated with radiotherapy to shrink the tumour followed by surgical removal where possible. Chemotherapy may also be used [49] (p. 1596).

Bone Tumours: Bone tumours cause pain at the location of the tumour. The pain can be relieved by flexing the muscle over the site of the tumour and may be attributed to trauma or vague complaints such as “growing pains”. Bone tumours draw attention when they cause a young person to limp or to have difficulty with or cease physical activity. One type of bone tumour, Osteosarcoma, occurs in the wide part of the shaft of the long bones, usually of the
legs. More than half of all osteosarcomas occur in the femur. Other primary sites include the humerus, tibia, pelvis, and jaw. Treatment for Osteosarcoma usually involves a combination of surgery (limb salvage or amputation) and chemotherapy. Another type of bone tumour, Ewing Sarcoma, originates in the shaft of long bones. Most common primary sites are femur, tibia, fibula, humerus, ulna, vertebra, scapula, ribs, pelvic bone, and skull. Ewing Sarcoma is usually treated with a combination of radiation and chemotherapy. Surgical amputation of the affected bone is considered if the bone is deformed or made useless by radiotherapy [49] (p. 1598-1599).

3.2.2 Incidence of Cancer in Young Australians
In 2007, the year for which the most recent statistics are available, 979 young people were diagnosed with cancer for the first time. This represents 26 new cases of cancer per 100,000 young people. This figure has remained stable since 1996 when 29 new cases of cancer per 100,000 young people aged 12-24 years were diagnosed. Incidence in men and women was similar in 2007 (27 new cases per 100,000 for men; 25 new cases per 100,000 for women), however, incidence increased with age: 13 cases per 100,000 in 12-14 year olds, 22 cases per 100,000 in 15-19 year olds, and 36 cases per 100,000 in 20-24 year olds. The most commonly diagnosed cancers in young people in 2007 were cancer of the testes and melanoma of the skin in young men (5 and 4 new cases per 100,000 respectively), and melanoma of the skin and Hodgkin lymphoma in women (6 and 4 new cases per 100,000 respectively) [50] (p. 43).

3.3 Mortality
In 2007, 1,418 young Australians died from all causes. This represents 37 deaths per 100,000 young people. Death was more common for young men (51 per 100,000) compared to young women (23 per 100,000) while the incidence of death in young people increased with age (14 per 100,000 in 12-14 year olds, 36 per 100,000 in 15-19 year olds, 52 per 100,000 in 20-24 year olds) (p. 20). Leading causes of death in 12-24 year old Australians in 2007 were injuries and poisoning (25 per 100,000), cancer (4 per 100,000), and diseases of the nervous system (2 per 100,000). Cancer was, therefore, the second most common cause of death in 12-24 year old Australians in 2007. Leukemias (ALL and AML) accounted for 32% of deaths from cancer and brain cancers accounted for 11% of deaths [50] (p. 21).

3.4 Survival
Measurements of survival in young people with cancer show that fewer young people die from cancer now than they have in previous years. The AIHW publish relative survival rates for young people diagnosed with cancer. A relative survival rate is the likelihood, expressed
as a percentage, that a young person diagnosed with cancer will still be alive five years after their diagnosis compared to the likelihood that their peers of the same age and sex who were not diagnosed with cancer will be alive at the same time. The relative survival rate for all young Australians aged 12-24 years diagnosed with cancer between 1998 and 2004 was 85%⁹. This figure increased from 77% for those diagnosed between 1982 and 1986. This increase in relative survival of young people diagnosed with cancer means that the prevalence of cancer survivors aged 12-24 years in the general population has increased [50] (p. 44). These figures clearly indicate that most young Australians diagnosed with cancer survive their illness and treatment. This has implications for their ongoing health and well-being.

3.5 Treatments for Cancer and Their Side Effects
Four common modalities are used to treat cancer. All modes of treatment have adverse physical, psychological, and social effects in the short and long terms [51, 52]. I will describe these in detail in chapter 4 when I describe the experience of cancer illness and treatment. Treatment regimens may be administered singly for some diagnostic groups, but more often are delivered in combination. The four treatment modes are chemotherapy, radiotherapy (radiation therapy), surgery, and bone marrow transplant.

3.5.1 Chemotherapy
Definition: Chemotherapy or ‘chemo’ is the most common form of treatment for cancer. Chemo refers to cytotoxic drugs, that is, drugs that kill cancer cells or slow their multiplication.

Delivery: Chemo may be delivered intravenously, intramuscularly, or orally. Because these methods of delivery are systemic, (i.e. they are not targeted directly at the tumour or illness), their effects on bodily systems are widespread. Chemo regimes alternate periods of treatment with periods of recovery in order to minimise side effects. Chemo may be delivered in hospital, but is more commonly delivered in the outpatient setting or at home. The decision to recommend chemo to young people can be influenced by the patient’s living arrangements and general capacity to maintain the chemo regime especially when they are unwell. There are no particular safety issues that preclude delivery of oral chemo outside the hospital, but caution must be exercised by those handling bodily waste and fluids that can contain

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⁹ This means that in a randomly selected sample of 100 young people between the ages of 12 and 24 years diagnosed in this period, you could expect 85% of them to be alive five years later.
Adherence Complications: Young people often have more difficulty complying with oral maintenance chemo than they do with either other therapies or than younger children or older adults because this mode of therapy is self-administered. Young people may lack supervision from parents commonly experienced by children, and lack the support of a partner common in older adults. Other impediments to adherence to therapy for young people with cancer include financial limitations and the intrusion of the therapy upon school or work routines [53, 54]. Financial limitations in Australia may arise when oncologists prescribe medications the cost of which are not subsidised by the Pharmaceutical Benefits Scheme (a financial support scheme aimed at reducing the costs of prescription medications for patients).

3.5.2 Radiotherapy (or Radiation Therapy)

Definition: Radiotherapy uses high energy X-rays, gamma rays or electrons to kill cancer cells in a specific part of the body. Unlike chemotherapy, radiotherapy is a localised or targeted treatment for cancer. Ionising radiation is used to damage cancer cells as a way of stopping their growth.

Delivery: Radiotherapy is delivered in two different ways. Radiation can be externally applied to the patient from a machine. Alternatively, a small quantity of radioactive material

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10 Options for fertility preservation will be discussed in the section 4.2.3.2
can be inserted directly into the tumour or into the patient alongside the tumour. Sometimes both methods are used in combination. External radiotherapy is usually delivered in an outpatient setting. No residual radiation persists within the body and a patient is, therefore, of no danger to others with whom they come into contact. Internal radiotherapy is usually delivered in a hospital inpatient setting. The patient either remains in hospital for the duration of the treatment, after which the radioactive material is removed from his or her body, or is discharged from hospital while the radioactive material remains inside the body once the emission of radioactive particles has reached a safe level [49] (p. 1569).

Physical Side Effects: Side effects of radiotherapy are usually less severe and widespread than for chemotherapy because radiotherapy is localised, not systemic. Side effects include skin irritation in the treated area, lethargy and loss of appetite. Radiotherapy can also result in a decrease in the number of white blood cells. Adverse effects are usually easily managed [49] (p. 1570).

3.5.3 Surgery

Definition: Surgery is used to treat the group of diseases comprising discreet solid tumours that can be identified and removed from the body (e.g. brain tumours, osteosarcoma, Ewing Sarcoma). Like radiotherapy, surgery is a localised treatment targeted directly at the area(s) of the body affected by cancer.

Delivery: Surgical treatment for cancer may involve the opening of bodily cavities to remove solid tumours adhering to internal organs. Regardless of the severity of the treatment, surgery is carried out in a hospital inpatient setting requiring hospital admission because of the need for a sterile environment, general anaesthetic, and post-operative care [49] (p. 1562).

Physical Side Effects: Surgery has a range of side effects including nausea and vomiting, pain, respiratory depression, and death. The severity of side effects are often, but not always, associated with the duration of the procedure (and coincidentally, the duration of the general anaesthetic), and the operative site. Surgery involving multiple bodily systems and/or that lasts for a long time (hours) is most likely to result in adverse effects [55] (p. 1094-1096).
3.5.4 Bone Marrow Transplant
Definition: Bone Marrow Transplant (BMT) is the destruction of diseased bone marrow using toxic doses of chemotherapy and its replacement with non-diseased bone marrow [49] (p. 1569).

Delivery: Diseased bone marrow is destroyed with chemo or radiotherapy. A compatible bone marrow donor is sourced, healthy bone marrow harvested and transplanted to the patient via intravenous infusion. A transplant using the patient’s own bone marrow (where the patient is the donor) is known as autologous bone marrow transplantation. A transplant using an identical twin as a donor is known as a syngeneic transplantation, and a transplant using an unrelated donor is known as an allogeneic transplant.

Physical Side Effects: The destruction of a person’s bone marrow renders their immune system non-existent. The risk of this is substantial and potentially fatal, because the body cannot fight infection. This is why BMT is always delivered in an isolated area of an inpatient hospital ward [49] (p. 1569 – 1570), with no contact with the outside world (excluding health care professionals and close family). If the patient’s body “rejects” the transfused bone marrow, it will have no functional immune system and will be unable to fight infection. Another side effect common in allogeneic stem cell transplant patients is Graft versus Host Disease. This occurs where immune cells in the transplanted tissue (the graft) recognise the recipient (host) as a foreign body. The immune cells then attack the body. This results in damage to the liver, skin, and gastro-intestinal tract, and can sometimes be fatal [49] (1573 – 1575).

3.5.5 Summary
Different types of cancer may be treated in one or more of the modalities outlined above. Different treatment modalities have varying degrees of success and all have potentially adverse, even fatal, consequences. Despite this, relative survival rates for young people treated for cancer is approximately 80% across all diagnostic groups. Many local protocols exist guiding the treatment administered for different types of cancer, for patients in different age groups and for different stages of disease. A detailed description of these protocols is outside the scope of this thesis. However, the ongoing and late effects of cancer treatment have particular implications for adolescents and young adults that I will detail in chapter 4.
Because late effects persist or develop after five years from the time of diagnosis, the care of young people diagnosed in adolescence is transferred from the paediatric health care setting to adult settings. This can have implications for the timely diagnosis and treatment of young people with cancer. This in turn has implications for their embodied experience of cancer illness and treatment and their interactions with others.

3.6 Health Care Services
3.6.1 Synopsis
Sarah Geehan was a 26 year old cancer survivor when she published her reflections on her personal experience of receiving treatment at age 17 [56]. Geehan praises the quality of care she received in a specialist adolescent treatment unit compared to the care she received in non-specialised units [56]. Aspects of the treatment site she values include the presence of specialist nurses who deliver care in an age appropriate way; reciprocal support and inspiration shared by patients; the inclusion of parents in the care of the young person; provision of interesting, age appropriate activities to relieve boredom; provision of personalised tuition to enable continuing education and access to psychological support [56]. Outcomes of treatment depend on location and philosophy of care and access to clinical trials [57, 58]. This section briefly outlines the different models of care delivery and illustrates how the concept of transition, central to our understandings of young people, are operationalised in the health care settings that shape their cancer experience.

3.6.2 Care of Young People with Cancer
Treatment protocols designed specifically for children result in longer event-free survival for young people diagnosed with Acute Lymphoblastic Leukemia (ALL) [59-62], Ewing’s Sarcoma [63], and Rhabdomyosarcoma [64]. Other diagnostic groups may experience longer event free survival when treated with protocols specifically designed for adults. Young people over 18 years old experience difficulties when they are referred to adult services whose staff have limited knowledge of - or interest in - administering paediatric treatment protocols. Thomas et al propose that, in Australia, more effective treatment of young people may be achieved with more appropriate concentration of resources and expertise [65]. An additional benefit to concentrating resources may be the increased recruitment of young people to clinical trials which are an indicator for positive treatment outcomes in this age group [57].
3.6.3 Transitional Care for Young People
A recent study of 9,434 young adult survivors of paediatric cancer in the United States and Canada found that only 19% of participants had attended follow-up in a cancer care service within the previous two years [66]. This has potential adverse consequences because it limits the opportunity for health care professionals to detect signs of medical complications or relapse at an early stage. Some authors therefore advocate for care of young people to be relocated from tertiary health care services, such as long-term follow-up clinics, to primary health care such as general practice [67-69].

“Transition” usually relates to the change in the location of care delivery from paediatric to adult health care settings. Transition programs for young people are based upon the acquisition of skills in the facilitation of self-care. This in turn relies upon the achievement of certain global developmental milestones. The potential implications of this are that care becomes individualised and individual patients are expected by health care professionals to take responsibility for their own care. There are two facets to transition commonly considered by health care teams. “Transition” is the passage from one form, state, style to another [70] (p. 1703). “Transfer” is the conveyance of a person or thing from one place to another [70] (p. 1703) which occurs at the time of separation from paediatric care. The commonly used definition of transition in NSW Health is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health care systems [71]. Planning includes the recognition by health carers of the developmental stages attained by each individual.

According to this framework, there are four major elements of successful transition [72]. These elements are:

1) Future Orientation: this involves preparing patients, parents, and health care team members to expect transition in late adolescence.

2) Start Early: Initial groundwork should be commenced at the time of diagnosis and preparation should continue throughout the course of paediatric treatment.

3) Independence: Out of respect for adolescents emerging autonomy, independent consideration of their health care should be encouraged. This is another process requiring ongoing monitoring of the adolescent’s cognitive and emotional development.
4) Transition Plan: Such a plan might include early identification of a receiving adult health care service, acquisition of skills necessary for the autonomous conduct of health care tasks and negotiation between health care services about what information might be provided.

Reiss and Gibson’s four elements rely upon the initial engagement of parents with health care professionals as they move towards transition [72]. As the adolescent develops different skills and adopts a larger role in their own health care, they need to be supported and guided through the process. According to the policy guidelines of NSW Health, paediatric and adolescent health care teams have four responsibilities towards patients with chronic illnesses [70]. These are:

1) To provide a clinical database to the adult health care team which includes a clinical history of the person’s disease, a list of current and potential problems and specific recommendations for the nature and timing of monitoring.
2) To promote self-efficacy of survivors by educating them on their treatment history and its implications for current and future health care. This should also include long term monitoring even when the person is asymptomatic.
3) To engage in the education of the adult health care team by providing regular updates on childhood cancer, its treatment and late effects.
4) To maintain effective communication strategies between teams.

According to NSW Health policy guidelines, transition should be driven by the paediatric health care team because of the established relationship they have with the patient and family. However, the adult health care team is responsible for recognising and understanding the specific follow-up required for individual patients and for expressing a commitment to maintain that follow-up regime [70]. The most successful transition programs are those conducted between paediatric and adult departments within the same institution. In essence, these programs represent a process of transition but not of transfer [70]. More commonly in Australia, transition is conducted between two separate institutions. This requires effective communication between health care teams which is sometimes a challenge.

The model of transition prevalent in NSW Health provides a good example of the point I made in section 2.4.2.2. Despite widespread recognition that young people’s transitions to
adulthood have been de-sequenced and de-standardised, transition policy continues to model a linear transition through the health care system. “Yo-yoing” is not taken into consideration. When a patient is transferred between institutions, he or she remains in the new institution and cannot return to the old institution for care. The implications for young people who have had cancer is that the social transitions they experience unrelated to their health or treatment will also be linear and predictable.

3.6.4 Summary
Although new cancer diagnoses in young people account for only 1% of all new cancer diagnoses, and thus are comparatively rare, systems for delivering care to young people are being reconsidered and revised by health care providers. Concentration of resources and expertise in a centralised geographical location is one way of increasing the likelihood that young people will access the treatment and follow-up available to them. A model of care that decentralises service delivery to primary health care professionals might be a good alternative when they are supported by specialist health care professionals. This is especially advantageous if we accept that young cancer survivors are likely to need life-long follow-up. It has also been argued that patients prefer the centralisation of specialist care favoured in New South Wales to non-specialist care of young people in either paediatric or adult health care settings [56]. This is likely to be so during phases of acute illness. This may not apply to their preferences for long term follow-up, however.

These institutional definitions of transition and their application to young people with cancer rest upon much broader definitions of adolescence and young adulthood as distinctive transitional phases of life through which people pass on their way from childhood to adulthood.
Chapter 4: Experiences of Cancer in Adolescence and Young Adulthood

4.1 Synopsis

The experience of surviving cancer in adolescence and young adulthood is the subject of increasing research interest. To learn what is currently known about the experience of surviving a cancer diagnosed in adolescence or young adulthood, I conducted a systematic search of the extant literature. First, I searched the electronic data base “Web of Knowledge” which includes the databases Medline, Cinahl, and PsychInfo. My search combined the key words “adolescent” or “young adult” with “cancer” and “illness experience”. I limited the search to books or journal articles published in English between 1990 and 2008. I repeated the search in subsequent years to capture the most recently published literature. I included literature reporting findings from empirical studies of young people diagnosed in adolescence or young adulthood. I also included reports of research that included participants who were either younger than 12 years old or over 25 years old when data from these people and those collected from adolescents and young adults was analysed separately. I excluded research reports in which data from participants of all ages were analysed together, so that it was not possible to distinguish the experience of adolescents and young adults from that of children or older adults. I also excluded reports of research into the experience of young people in palliative care or who were dying from cancer. I then scanned the reference lists of all books and articles located by my search in order to identify other relevant literature. This yielded additional relevant books and articles published prior to 1990. My combined electronic and hand search strategies yielded several hundred publications.

The experience of cancer survivorship in young people has been described as both positive and negative [73-76] and as a paradox [77, 78]. This chapter describes what is currently known about the impact of cancer on bodily, psychological, and social transitions of young people.

First, bodily appearance and function change in all young people as they grow to sexual maturity. Cancer illness and treatment disrupt these normal changes by altering bodily appearance and function in unexpected and undesirable ways. These have psychological and social consequences for the experience of growing up. Second, cancer illness and treatment disrupt the process of growing up by causing young people to question their values in life, what their purpose is, and who they really are. Erikson’s theory normalises the process of questioning self-identity during adolescence. Young cancer survivors are forced to ask these questions in unexpected ways. In other words, cancer illness and treatment precipitate an
existential crisis in young people. According to recent research with young cancer survivors, the answers to these questions have implications for a young person’s attempts to resolve her existential crisis and for her development of a new way of being in the world.

4.2 Effects on Bodily Appearance and Function
The normal biological transitions of puberty alter young people’s bodily appearance and function in rapid and dramatic ways. However, when young people are treated for cancer this normal transition is disrupted. Their bodies are marked both visibly (e.g. by scarring) and invisibly (e.g. by making them infertile) by their disease and treatment for months or years after their treatment finishes. As a result, cancer illness and treatment alters their bodily appearance and function in ways that they do not expect and that they usually do not desire. These changes have implications for their well-being. In this section I will describe the impact of cancer on young people’s bodily appearance and function. I will then describe the psychological and social consequences of alterations to young people’s bodily appearance and function. I will summarise by briefly discussing the importance of these impacts to our understanding of young people with cancer and by suggesting that our current knowledge of the experience of growing up with cancer is incomplete.

4.2.1 Impact of Cancer on Bodily Appearance
When young people enter puberty they often experience a decreased level of control over their bodily appearance and function. This prompts them to compare themselves with their peers in order to evaluate what is “normal”. Alterations to bodily appearance and function resulting from cancer and its treatment exacerbate feelings of diminished control [79]. Cancer illness and treatment alters bodily appearance in different ways and to different extents. For example, cancer itself can induce weight loss, skin pallor, and short stature. Chemotherapy can induce hair loss. Treatment with corticosteroids can result in weight gain. Surgery can result in the presence of visible devices to assist in treatment (such as portable catheters), surgical scarring, and limb amputation [80]. None of these alterations are consistent with the usual changes in bodily appearance brought about by puberty. Therefore, they can be distressing for young people with cancer.

Altered bodily appearance can have an adverse effect a young person’s body image [79, 81] (p. 36). A body image is a person’s perceptions, thoughts and feelings about his or her body [82] (p. 1). Some argue that disturbances to a young person’s body image that result from cancer illness and treatment can have adverse consequences for their self-esteem both during
the period in which the effects are visible and obvious to others and during the period of recovery when the visible effects begin to fade [83-86]. Self-esteem refers to the degree to which one values or likes oneself [84]. Weight loss is sometimes experienced as a positive consequence of having cancer, but weight gain (e.g. due to treatment with corticosteroids) is unexpected and troubling: clothes no longer fit, body shape is altered, and self-confidence is eroded [85]. However, it is unclear that altered body image results in diminished self-esteem for young people more generally. For example, Grogan argues that diminished self-esteem actually leads to a poor body image and that interventions from health professionals aimed at enhancing feelings of personal control over a given situation and self-worth are likely to succeed in enhancing body image [82] (p.183).

Developing body image has also been linked to adolescent’s developing sexuality (i.e. sense of a sexual self-identity) [84]. For young women who have had cancer, hair loss is acutely disruptive because of the adverse impact it has on their self-identity, how they present to the world, and on their sexual self-confidence [87]. Hilton et al highlight the different experiences of hair loss in men and women as being symbolic of gender differences more generally by drawing on Synnott’s “theory of hair” [88] (p. 581). Synnott’s theory suggests that the subtle differences in the distribution of hair on men’s and women’s bodies provides a way for men and women to symbolically maximise their differences [89].

The effects of altered bodily appearance are not confined to a young person’s self-identity. They also have implications for their interactions in the social world. Some young people with cancer may feel as though they look normal when they are treated in a cancer unit specialising in the care of young people [90, 91]. However, this raises questions about the possibility that young people with cancer might experience social isolation from their peers as they become increasingly socialised into the role of cancer patient. Therefore, young people with cancer are also encouraged and supported by their parents and treating health professionals to maintain contact with their peers in the wider community [92].

The changes in bodily appearance that result from cancer illness and treatment impact upon young people’s social worlds in their interactions with friends and peers and in their

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11 This theory taps into modern Western normative dichotomies of masculine and feminine sexuality and associated ideals of feminine beauty. I have not analysed interviews with a particular focus on gender differences in their experience of surviving cancer. Therefore, this is a peripheral point in my thesis.
developing romantic and sexual relationships. They threaten a young person’s ability to attract a sexual partner or to establish and maintain intimate relationships of a romantic nature [79]. Diminished self-confidence and lowered self-esteem may lead to feelings of isolation for a young person who fears being rejected by their peers because of their appearance. They may also withdraw socially.

The role of peers has significant implications for young cancer survivors’ ability to navigate their re-entry into their usual social worlds [83] (p. 625). Some young cancer survivors experience protection from reliable and trustworthy friends in social situations in which they are vulnerable to experiencing adverse responses to their appearance from others [83, 93]. For example, in social settings such as night clubs, strangers sometimes pass unsolicited derogatory comments on young people’s appearance and young people may stop attending these social spaces as a result [85]. Larouche and Chin Peukert introduced the concept of the “peer shield” as protection against this type of adverse event [93]. A peer shield describes the process whereby young people deflect adverse attention from a friend who has been treated for cancer when their appearance attracts unwanted attention in their broader social worlds. However, the support of faithful friends is likely to only be partially successful in protecting young cancer survivors from the adverse effects of these encounters [85]. By considering appearance only in terms of body image, one limits it to a subjective issue (i.e. how people feel about the way they look), rather than seeing the social implications [83, 94, 95]. However, physical effects of treatment, such as hair loss, weight gain or loss, and disfigured appearance, can reduce young peoples’ desire to be with their peers resulting in social isolation [96].

4.2.2 Body Function
Common adverse effects of cancer on bodily function include fatigue, pain, and sexual dysfunction. These are reported as adverse outcomes for individual’s sense of well-being. The consequences of these effects are not always visible to others. The discomfort and disability related to cancer may be transient or ongoing, mild or severe depending on a young person’s diagnosis and treatment regimen [75]. In this section I will describe the ways in which impaired bodily function can impact upon a young person’s experience of growing up.

4.2.2.1 Disruptions to Bodily Function
During a phase of life when young people develop a mastery over the changes in their bodily functions that occur during puberty, cancer illness and treatment can cause a number of
bodily dysfunctions including fatigue [97-105], pain [97, 106-111], and compromise to physical mobility that disrupt their physical transition [112, 113]. These adverse effects of cancer are distinct from the expected bodily changes of puberty.

Although sleep patterns normally change during puberty, fatigue is one ongoing adverse effect of cancer that marks young people as different to their peers. Symptoms of fatigue include feeling sleepy or mentally and physically tired, feeling exhausted, wrung out, worn out, or apathetic [101, 104]. Symptoms of fatigue have also been associated with feelings of pain, nausea, and sleep-wake disturbance [98] in young people treated for cancer. Davies conceptualises fatigue as a dynamic relationship between symptoms and relief. Cancer can deplete a young persons’ energy but she can take steps to conserve or replenish her energy using some of the techniques of relief [103]. Fatigue can be caused by treatment, boredom [97, 102], noise, negative emotion, and disrupted sleep [102]. It can then result in feelings of anger and self-pity [101], frustration and distress [105].

Fatigue can also be alleviated by distraction and entertainment [97, 102], and participation in physical therapy [102]. Fatigue diminishes as remission and recovery progress [98, 105] and young people get used to the bodily changes cancer has brought about [100]. However, they get used to bodily function that is developmentally abnormal and which therefore sets them apart from their peers. Fatigue has also been found to inhibit young peoples’ daily function [99] including their interactions with their family and friends [97]. In young people treated for cancer this can result in decreased satisfaction with daily social interactions[98], and difficulty participating in the normal daily activities enjoyed by their peers [98, 99].

The experience of fatigue can therefore be a lonely one for young people who have survived cancer. It is a side effect of illness and treatment that sets young people apart from their peers by limiting their capacity for social engagement. This can be frustrating which, given that fatigue can be exacerbated by negative emotion, may be difficult for a young person to deal with. Fatigue is a side effect that is not necessarily visible to other people and young people who experience it may have trouble explaining to their family and peers the extent to which it disrupts their lives.

Young people experience pain as a result of both cancer (e.g. due to the presence of solid tumours) [97] and as the result of treatment (e.g. pain caused by needles) [97, 111]. Pain has
been described as occurring most commonly in the stomach, joints, legs, and back [106]. Young people fear the occurrence of treatment-related pain [107] but they can negotiate the management of this with their health care providers [114]. Pain can cause decreased health-related quality of life in young people with cancer compared to their siblings [110] and compared to their age matched peers [115]. An optimistic outlook on life has been shown to limit the adverse effects of pain on health related quality of life [109]. Studies of young people treated for cancer have shown that pain can be relieved using analgesia, by rest, by distraction, and by the presence of social support [97, 106]. Pain also contributes to limitations in physical function [110].

Causes of pain that are illness and treatment related, one might expect young people to experience pain only during their period of illness and treatment. These are experiences that disrupt young people’s social worlds regardless of any side effects of treatment they experience. Young people can experience chronic pain after their treatment finishes [116]. Chronic pain is not always visible to others. However, the effects of chronic pain can limit a young person’s social activities.

Woodgate studied 15 young people diagnosed with cancer between 12 and 18 years old in Canada [113]. Her findings relate to young people’s experience of their bodies during treatment. Woodgate has classified experiences of physical dysfunction into different categories according to their impact on young people’s self-identity. First, her participants experienced life as a klutz when their cancer illness and treatment made their bodies unruly and unreliable. This occurred when they experienced a failure to control their bodily functions. A failure of control has implications for young people’s interactions in the social worlds. They may inadvertently attract unwanted attention to themselves or become embarrassed by their bodily dysfunction. Second, they experienced life as a prisoner when they became dependent on other people for their care. This can be explained as a challenge to the normal process of transition to adulthood which includes a transition to independence. A prisoner has limited freedom of movement which resonates with a young person with cancer who sometimes cannot care for him or herself.

Third, they experienced life as an invalid when they experienced a “really sick body” – one that convinced them of the reality of their illness. This state may prompt young people to adopt a sick role which has implications for their relationships with others.
Fourth, they experienced life as an *alien* when their bodies became distorted or foreign to them. This may result from the changes to bodily appearance brought about by cancer illness and treatment. However, it also resonates with the experience of lacking control over one’s bodily function. Fifth, they experienced life as a *zombie* when they are overwhelmed by fatigue that arises from cancer illness and treatment. Finally, young cancer survivors experience life as a *kid* when they complete treatment, the side effects of treatment dissipate, and they experience a sense of living in a renewed body [113] (p. 10-12).

The first five of Woodgate’s descriptors focus on abnormality and difference. Cancer illness and treatment result in young people’s failure to conform to normal transitions of growing up. This can result in feelings of difference – difference compared to one’s own expectations and difference compared to the experiences of peers. The social consequences of being different for young people vary but, as I said above, young people look to each other to assess whether their progress through life is normal. However, in the final category of *kid* Woodgate suggests that, although young cancer survivors do not return to normal, the differences young people experience can resolve as the period of illness and treatment passes.

### 4.2.2.2 Bodily Function and Relationships with Family and Peers

When young people experience compromises to their bodily function due to cancer illness and treatment, they often rely upon the support of their family and friends. Social support from family members, especially mothers, has long been recognised as important to young peoples’ care during their cancer illness and treatment [117-124]. In their survey of young people between 18 and 35 years, Zebrack *et al*, for example, report that support from family and friends were the most highly ranked supportive care needs [125]. Younger respondents attributed greater importance to support from family than friends, however, and this suggests that the need for support is different during different phases of life [125]. As young people grow up the focus of their social worlds change from their family of origin to their friends and peers. Support from family members manifests as a commitment by parents to “be there” for their child during hospitalisation for treatment [126]. According to Woodgate, who studied young Canadians receiving cancer treatment aged between 12 and 18 years, as well as their parents and friends, provide support by “being there” in five ways during hospitalisation. Parents are “there” to provide comfort, to hold hands, to prevent loneliness, to foster a positive attitude, and to treat their child as normal [126]. Support from parents
continues into the period of remission and recovery during which time parents remain involved in their child’s medical care and decision making about life [127].

The social support young people receive from their parents can help them develop a sense of independence [85]. Independence from parents is assumed to be a normal outcome of growing up in studies of young people with cancer. This normal process is said to be compromised when young people are thrown back into a dependent relationship with their parents during treatment because of compromises to their bodily function [119, 121]. Some studies suggest that a move such as this can promote family cohesiveness and are important factors in a young person’s positive adjustment to cancer [128]. However, a young person’s return to the family has been described as being maladaptive when they become dependent on their parents while they are trying to assert their autonomy and become independent. This can lead to stress in family relationships, especially those between mothers and daughters [83] (p. 625).

Physical independence was compromised for many young cancer survivors who participated in Grinyer’s study because of fatigue, muscle weakness, and impaired mobility. As a result of their physical dependence, young people who participated in Grinyer’s study sometimes experienced severe compromise to their financial independence. Loss of wages due to their inability to work compromised financial independence by threatening the young person’s capacity to service debts. Young people cared for in specialist care units felt this compromise less acutely because of the expertise of social workers and other staff in accessing compensation (such as rent assistance and travel costs). Young people treated in non-specialist centres at a disadvantage in dealing with social welfare bureaucracies because they did not know how to deal with them, and had little assistance in accessing the financial support to which they may have been entitled [85].

Studies of young people’s compromised bodily function that arises from their cancer illness and treatment emphasise two aspects of growing up. First, they emphasise the role of parents to act on behalf of and care for their children. These studies report on what other people do for young people with cancer rather than how they relate with them. This perspective can position young people as passive recipients of care rather than active collaborators in the care they receive with pro-active responses to their unusual and stressful social situation.
Second, in Western culture this has become synonymous with becoming self-sufficient and of avoiding reliance on others. Gilligan rejects this individualistic perspective, replacing it with the concept of interdependence. According to Gilligan, a progressively more adequate understanding of the psychology of human relationships ... informs the development of an ethic of care. This ethic ... evolves around a central insight, that self and other are interdependent [129] (p.74). The idea that a return to the family home is a maladaptive response to cancer illness and treatment at a time when young people strive for independence tends to miss the point that they do so in the context of a health care crisis. Cancer illness and treatment limits the capacity to act autonomously and live independently. This is true for people of all ages.

One study of young people in Taiwan helps illustrate this point. Yeh analysed interviews with sixteen 13-18 year old cancer patients using an interview based Grounded Theory methodology [130]. Findings were consistent with studies of young cancer survivors in the West insofar as the diagnosis of cancer produces an unsettled state of mind for young people: they experience apprehensiveness about adverse effects of treatment, fears for the future, and disrupted friendships. However, their parents perceived their adolescent offspring to be too young to understand their disease and co-opted health care professionals into maintaining a “conspiracy of silence” that denied young people information about their disease and treatment. No evidence is offered by Yeh that adolescent cancer survivors came into conflict with their parents over this issue in a way that might be expected of some adolescents in Western cultures. Furthermore, the adolescents perceived their parents to be supportive.

The effects of cancer illness and treatment on young people’s bodily function also has implications for the conduct of their academic studies and their relationships with their peers at academic institutions. Compromised academic results at school are widely reported by parents and teachers [48, 131]. This may be due to absences from school for treatment and follow up [112], effects of treatment such as ongoing fatigue, and fear of failure and being “left behind” in school work by peers [74, 132]. One study found that young cancer survivors are statistically more likely than their peers to have repeated a grade at school and to be frequently absent from school. Both outcomes were positively associated with treatment intensity [133].
According to Punyko *et al* young cancer survivors may be less likely than siblings to have completed high school, ever worked at a job, or to ever have been married [110]. Young people who have had cancer complete high school less often than their siblings without cancer when they experience performance limitations, a health-related inability to work or attend school, or moderate to high levels of cancer-related pain [110].

Young people with cancer miss out on their usual attendance at school or university or desired activities such as going away for the weekend [85]. They may also experience difficulty fitting in with their old peer group [74], especially when their peers misunderstand about their illness status – whether young cancer survivors are sick or well [134]. I will describe the social consequences of missing school, and of being different to their peers when they return to school, more fully in section 4.3.2.

### 4.2.2.3 Bodily Function and Romantic and/or Sexual Relationships

The disruptive effects of cancer and its treatment on normal sexual development in adolescents and young adults have been recognised for many years [80, 135-137]. These disruptions occur throughout the cancer journey from diagnosis through treatment to long-term follow up [80]. Broadly, cancer can disrupt physical, emotional, and behavioural aspects of a young person’s sexual self-identity [138]. However, studies of sexual dysfunction in young people diagnosed with cancer have been dominated by the grand narrative of puberty. As I described in chapter 2, the goal of biological transition is for a young person to reach sexual maturity. Sexual maturity can include the development of sexual relationships and the experience of sexual pleasure. Researchers of young people with cancer, however, most often describe the disruption of cancer illness and treatment as being to reproductive capacity. An exception to this generalisation can be found in the findings of one study that young men may experience changes in their sensation of orgasm and they may lack a “normal” ejaculation [139].

From the perspective of biological transition, the major adverse effect of a cancer diagnosis and treatment is that it can result in infertility [43]. The impact of cancer illness and treatment on a young person’s fertility varies according to their age and gender, the site of their cancer, and the type of treatment they receive [140, 141]. For example, the impact of chemotherapy on fertility in young women is drug and dose dependant and age related, with pre-pubertal ovaries being the least susceptible structure to gonadotoxicity [140]. Cryopreservation is the
process of removing a woman’s ovum and storing them in a frozen state for fertilisation and implantation in her uterus if and when she decides she wants to have her own children. Cryopreservation is possible for young women’s ovaries but the technology facilitating this process is currently unreliable [140]. In young men, cryopreservation is the process of collecting sperm and storing them in a frozen state for fertilisation of his partner if and when they decide to become parents. Cryopreservation and assisted reproductive technologies are clinically practical ways of preserving fertility in young men [141]. In one study, half of 27 childhood cancer survivors aged between 16 and 26 years showed delayed psychosexual maturation [142]. Compared to healthy adolescents, forty-one 12-19 year olds treated for cancer had greater concerns regarding their ability to conceive children and that their children might be born with congenital defects because of their cancer treatment [138].

One of the social consequences of the transitions to sexual maturity is that young people often become sexually active. Young people with cancer are as likely to be sexually active as their healthy peers, but discussions with them about contraception are rarely undertaken by health care professionals [143]. The use of contraception is important for young people who are sexually active generally. However, the use of contraception is especially important for young people who have survived cancer. One reason is because their fertility status may be uncertain and unprotected sexual intercourse could result in unexpected and unwanted pregnancy. Another is that their body fluids may contain cytotoxic chemicals (especially during treatment) that present a risk to their partner’s health. The use of contraception amongst adolescent and young adult cancer survivors is also variable [43, 144]. Lack of information can lead a young person to assume he or she is infertile when this is not the case [43]. Barrier methods applied by women (for example, diaphragm or vaginal sponge) are relatively unreliable methods of contraception, they require planning and they are expensive [43]. Male condom is recommended for contraception because of its protection against pregnancy, sexually transmitted infections, and exchange of cytotoxins present in bodily fluids [145]. Treatment for cancer, then, has implications for the sexual health of young people’s partners in additional to the normal concerns of sexually transmitted infection and unwanted pregnancy in young people who are sexually active.

Young women sometimes fear for the safety of their unborn children as a result of their cancer treatment. However, Hosalkar et al found no increased risk of birth defects for women being treated with chemotherapy for bone sarcoma and Fenig et al found no increased risk of
birth defects in women being treated with radiotherapy for breast cancer [146, 147]. It appears unlikely that treatment with chemotherapy increases the risk of congenital abnormalities occurring in the offspring of women or men who were treated for cancer in childhood or adolescence [148]. Women who have been treated with radiation to the pelvis can have diminished reproductive capacity due to damage to the uterus. This can result in spontaneous miscarriage or premature birth of an infant [140].

Since many variables contribute to fertility outcomes for young cancer survivors, it comes as no surprise that in one study 59% of survivors reported that they are uncertain about their fertility status, and half did not recall a parent or health care provider ever mentioning potential reproductive problems associated with their past cancer treatment [149]. Another study found that the highest incidence of sexual dysfunction occurs within the first 6 months following treatment for testicular cancer. Most patients recovered sexual function within 3 years. Long term sexual dysfunction occurs in 15% of patients [150]. This adds to the uncertainty about fertility status in young people who have had cancer.

Infertility is not a major issue for all young people treated for cancer. For example, infertility is less of an issue for those who have already had children [85, 151, 152] and have thus completed the normal biological transition to sexual maturity. It may also be less of an issue for people who do not want to have children. Some young people have easier access to options for sperm banking (cryopreservation of sperm) and ovarian cryopreservation than others but those who have access to these means of fertility preservation are disadvantaged in particular ways. Donating sperm can be technically difficult or embarrassing for young men and cryopreservation of ovaries can be invasive and painful for young women [85]. Fertility preservation requires foresight and planning because it aims to facilitate a goal that may not be achieved for years to come.

Although the grand narrative of puberty describes the normal transition to sexual maturity and reproductive capacity, the trend amongst Australian women has been to commence motherhood at an older age than in previous generations. Between 1969 and 1999 the proportion of births to young women aged 15 – 24 years dropped from 46% of all births to 20%. Between 1979 and 1999 the ratio of births to women aged 30 years and over increased from 24% of all births to 47% [153]. Therefore, young women treated for cancer are being treated years before they would normally expect to be having babies of their own.
As is the case with fertility, sexual function for young adult males across the board is less impaired than for young adult females as a result of cancer treatment [154, 155]. Some treatments and diagnoses do result in a high level of sexual dysfunction (e.g. testicular cancer) and this issue is not necessarily adequately addressed by health care professionals. For example, 67% of 264 men aged between 25 and 53 with testicular cancer or malignant lymphoma reportedly had received inadequate information about sexual dysfunction post treatment both at diagnosis and follow up [156].

A number of social and psychological factors combine with biological issues of fertility and sexual function to produce a young person’s sexual identity. Cancer illness and treatment can disrupt any or all of these processes. Some studies indicate parenting (i.e. the ability to nurture a young child rather than simply conceive one) is an area of concern for young people with cancer because of the ongoing adverse physical effects they experience as a result of their illness and treatment [74, 157].

Crawshaw and Sloper characterise infertility as one of the visible bodily effects of cancer on young people that are invisible to others. They studied the consequences of infertility on young people’s social interactions. Some young men used condoms in order to appear “normal” and to avoid disclosing their infertility to a sexual partner. One young man feared being “found out” because his girlfriend failed to conceive when he mistakenly thought she had been using oral contraception [158] (p. 612-613). The authors discuss this as a response to the stigma of infertility which is consistent with recent research on the general population [152, 159-161]. The benefits of passing as normal for these participants also carried the risk of being “outed” or exposed as being infertile [158].

A focus on reproduction that dominates the discourse of the effects of cancer illness and treatment on young people’s sexuality is limiting in a number of ways. First, infertility is pathologised and interventions to preserve it frame it as a medical rather than a social issue for young people. Second, this dominant discourse risks subordinating other discourses around young people’s developing sexuality. I have described issues of desirability briefly in section 4.2.1 and will describe the capacity of young people to develop relationships of a romantic and/or sexual nature in section 4.3.2. However, discussions in the literature of the capacity of and opportunity for young people with cancer to engage in sexual expression and
to experience sexual pleasure is subordinated by the discourse of reproductive capacity. This is a noticeable absence from the literature.

4.2.3 Summary

Many studies have focussed on the psychological impact of cancer on young people’s bodily appearance and general bodily function. These studies have also suggested some of the social implications of these psychological outcomes. A focus on psychological effects of cancer illness and treatment tends to dominate this literature by focussing on those consequences that diminished self-confidence and self-esteem.

Other studies have focused on the biological impact of cancer on young people’s sexual function. This perspective is medico-centric in that it focuses on young person’s fertility or sexual function. While medical treatment is important for both, the medical approach tends to ignore how young people negotiate the ongoing effects of cancer in relationships with other people.

The use of the grand narratives of biology and psychology has led to a detailed understanding of the adverse effects of cancer illness and treatment on young people’s normal developmental transitions. Bodily appearance and function are powerful but they are not the only influences on a young person’s experience of surviving cancer. In section 4.3 I will describe further effects of cancer illness and treatment on young people’s experiences of growing up.

4.3 Experiences of Cancer as a Disruption to Normal Life

Diagnosis and treatment for cancer alter the ways in which young people perceive themselves [162]. They perceive these alterations as having either positive or negative consequences depending on the different meanings they ascribe to them [75, 162]. Cancer is said to become enmeshed with survivors’ overall sense of identity and so form a distinctive basis for the ways in which they understand themselves and are understood by others [163] (p. 283). A cancer experience therefore becomes a central part of who a young person is. Their overall sense of self identity cannot be separated from their experience of cancer illness and treatment; and the ongoing physical, psychological, and social effects that they continue to experience after treatment finishes. Some authors have reported that young people desire to return to normal after their treatment finishes, but they have difficulty doing so because the
changes they experience to their developing self-identity as a result of their cancer experience profoundly changes what “normal” can be. In this section I will describe the experience of cancer illness and treatment as an existential crisis. Resolution of the crisis during the period of remission and recovery is complicated by the ongoing effects of illness and treatment young people experience.

4.3.1 Cancer Illness and Treatment as a Disruptive Experience

While some young people maintain a sense of self as being unchanged - or minimally changed - from the one they experienced before their cancer illness and treatment, others experience a more severe disruption to their sense of self. Consequently they can expect a more time consuming and elaborate process of creating a new normal. Grinyer has found that young people experience a biographical disruption that prevents their return to their pre-diagnosis normal way of being [164]. Bury coined the term “biographical disruption” to describe the experience of adults living with a chronic illness [165]. His understanding of the illness experience clearly applies to young cancer survivors:

... chronic illness is precisely that kind of experience where the structures of everyday life and the forms of knowledge that underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support. [165] (p. 169).

There are two primary implications of this for young people diagnosed with and treated for cancer. First, their sense of self is threatened by their confrontation with pain, suffering, and possible death. Second, cancer illness and treatment has the potential to disrupt relationships with their parents and peers as they transition towards adulthood, leave the family home and develop intimate relationships with non-family members. Certainly death may be seen by young people as a distant possibility and one that they associate more closely with elderly people than with themselves. Part of Grinyer’s point is that biographical disruption occurs within young people’s narrative biography [164]. According to Kameny et al:

... narration is an activity by which the speaker reconstructs and reinterprets past, present, and future events. Talking about one’s illness experiences aids in one’s quest for meaning, as well as in the mastery over uncertainty that follows a diagnosis of cancer [166] (p. 73).
The narrative is told primarily to position oneself in a particular way in a given social context. Therefore, when Grinyer speaks of biographical disruption, she speaks of (amongst other things) a disruption to the sequential story a young person tells others about herself as a way of sharing with them who she is. This biographical disruption experienced during illness and treatment leads to a young person to experience uncertainty about her developing identity.

4.3.1.1 Disruption Results in Uncertainty
One of the quintessential experiences of surviving cancer illness and treatment in adolescence and young adulthood is that of uncertainty. Young people frequently report uncertainty about their chances of both relapse and diagnosis with a second cancer [48, 86, 127, 134, 167, 168]. This uncertainty arises out of their fear of cancer recurrence and the unpredictable nature of late effects of disease and treatment [107, 167, 169]. Uncertainty is reportedly highest at the time of diagnosis and diminishes over time [170]. Conversely, fear of recurrence and its resultant uncertainty diminishes over time as long as young people remain off treatment for cancer [171].

Uncertainty changes during the course of young peoples’ cancer journey. While they are in treatment, they experience uncertainty about the possibility of experiencing pain, their prognosis, and their ongoing capacity for self-care [108]. At the time of relapse, experiences of uncertainty have a significant impact on their decisions about pursuit of care, treatment related decision making, and inter-personal communications with health care professionals [172]. During their period of remission and recovery, they experience uncertainty about who to approach for care for their ongoing medical concerns, their capacity to complete school, find a job and gain or maintain their independence [167]. Prouty et al provide three examples of coping strategies young people use to manage their own uncertainty. First, they use milestones to measure longevity as a way of tracking their progress through life. Second, they use memorise statistics about longevity for young people diagnosed with their type of cancer as provided by their health professionals. Third, they make a conscious decision not to dwell on their past experiences [127]. Prouty et al do not discuss how these individual coping strategies influence young people’s social interactions.

Although uncertainty is commonly linked to fear (e.g., fear of relapse), some researchers argue that uncertainty can benefit recovery from cancer in both older adults [173] and young
people [174]. Duggleby et al found that recognising the dynamic possibilities within the experience of uncertainty can lead to hope for older adults who seek to transition from a difficult present to a positive future [173]. Parry found that the experience of uncertainty was paradoxical for young people who survive cancer. The paradox she describes is that uncertainty can be a source of distress for young people as well as a source of growth, a deepening appreciation of life, a greater awareness of life purpose, and the development of psychological traits of confidence, resilience, and optimism [174].

It is clear from recent research that uncertainty about the future is a common experience for young people which they can find distressing. They remain uncertain about their future well into their period of remission. Over time, however, they can relieve the distress that uncertainty causes. Uncertainty is not only a source of negative experiences for young people. It can also create opportunities and act as a catalyst for personal growth. This fits into the broader perspective of benefit-finding in the experience of illness outlined in section 4.3.2 and of the experience of post-traumatic growth [175]. Uncertainty is a condition of modern life. Recent sociological theory suggests that all peoples’ futures are uncertain, and that this has always been the case, despite our tendency to act as though our futures are within our control.

4.3.1.2 Disruption to Relationships with Family and Friends
A young person’s efforts to achieve independence can create problems during the period of illness and treatment when parents want to discuss issues that their children do not wish to discuss or vice versa [128]. Further complications can arise during the period of remission and recovery when young cancer survivors seek to re-assert their independence from their parents but continue to experience the effects of cancer illness and treatment [169]. For example, some young people resist being positioned by others as “special” or “heroic” except when their symptoms are particularly intrusive. At these times they appreciate receiving special care and attention from their parents [132].

Young cancer survivors can also feel a sense of obligation towards their family for providing support during their period of illness and treatment or guilt for causing their parents to suffer [77] and this conflicts with their desire for independence [176]. These perspectives focus on the young person’s feelings about her own situation, however, and do not show how these feelings manifest in interpersonal relationships. During their illness and treatment the social
support that young cancer survivors receive from their friends can help them cope with their cancer diagnosis, improve their quality of life, and reduce some of the uncertainty they experienced because of their cancer illness and treatment [83].

Independence is compromised during illness and treatment (see section 4.2.2). Compromise to independence disrupts young people’s sense of who they are. Grinyer concentrates her study on three markers of independence; emotional, physical and financial [85]. Emotional independence is sometimes accomplished when young people move out of the family home. Some young men felt compromised by their need for emotional support from their parents especially if they had lived outside the family home. Some young women, however, actively sought the emotional support of their parents during different periods of their cancer journey.

Returning to their usual social worlds is a mixed experience for young cancer survivors. The timing of their return depends upon their diagnosis and the type of treatment they received. While they are pleased to have survived their treatment, they notice differences between themselves and their peers [169]. They can have difficulty explaining to their peers why their relationship has changed. They may have less in common with their peers, or feel that their peers have “moved on” while they have “stagnated” [169]. Fears of rejection or being stigmatised may inhibit young cancer survivors’ willingness to tell their friends about their diagnosis [177]. They miss out on the shared experiences of daily life with their peers while being exposed to experiences they would not normally have, such as confronting their own mortality [77]. Young cancer survivors experience fear related to their sense of a social self, for example, as a result of being left out by friends, being different to others, and being different to what they were before their cancer diagnosis [107, 128].

If young people develop a sense of what is normal in the process of growing up by comparing themselves to their peers, then missing out on interaction with their peers can inhibit their process of growing up. Missing out on individual events is reportedly inconsequential. What causes problems for young people with cancer is the combination of missed events and exclusion from usual daily activities that accumulates as time passes [85]. This is disruptive because over time they miss out on experiences that inform ongoing social exchanges with their peers [85].
One key way of missing out on being with friends is to be absent from school. Absence from school occurs in all phases of disease but is concentrated in the first year after diagnosis [83]. Teachers observe greater degrees of social isolation amongst young cancer survivors than amongst their peers [48]. Parents report that young cancer survivors have fewer close friends and use friends as confidants less often than other young people [131]. Studies of young cancer survivors suggest that they fear rejection [48] and are anxious about fitting in with peers when they return to school [112].

Re-integration programs designed to facilitate young people’s return to school after cancer illness and treatment have been formalised in some places. Because these programs have been initiated by schools and health care institutions, reports of their implementation and outcomes have been focused on institutions rather than young people. Early models of school re-integration were medico-centric. For example, Katz and Jay found six factors that facilitate young cancer survivors’ return to school. These included 1) health care professionals educating teachers about how important it is for young people to continue their studies, 2) health care professionals helping to diagnose young cancer survivors with learning disabilities, and 3) the medical team monitoring ongoing school participation to aid in continued education [96]. More recent models of school re-integration programs for young cancer survivors have emphasised program development and implementation that involves collaboration between cancer care centres, young cancer survivorship advocacy groups, and schools to ensure the implementation and outcome evaluation of effective school re-integration programs [178]. Multiple factors influence young peoples’ experience of returning to school when their treatment allows. One important factor in the process of re-integration into school for young cancer survivors is the effect of cancer illness and treatment on their bodily appearance and function.

4.3.1.3 Disruption to Relationships with Romantic and/or Sexual Partners
Adolescents and young adults with cancer find it difficult to establish intimate relationships. Friends sometimes discontinue contact during the period of illness and treatment and young people sometimes withdraw from social contact because of their cancer experience. Both factors limit the opportunity to engage in sexual activity and to develop an integrated sense of personal sexuality becomes limited. Evan et al argue that self-esteem diminishes for young people with cancer because of their limited opportunities to answer the question ‘who am I?’ in the context of romantic relationships [84]. Others locate sexual identity within the context
of other aspects of life that are disrupted by cancer illness and treatment, such as education, friendship networks, and appearance [164].

Romantic relationships in adolescence and young adulthood may be fragile [85]. For many young cancer survivors, romantic relationships survive the crisis of diagnosis and treatment but later disintegrate. It has been suggested that young people might consider leaving a partner who is seriously ill to be unethical [164]. The likelihood that romantic relationships break down after treatment has finished also suggests that the period of illness is limited for young people with cancer. If it is unethical to leave a sick partner but ethical to leave a well partner, there must come a point when a young person is considered well.

4.3.1.4 Summary
The period of illness and treatment provokes an existential crisis in young people with cancer because they are forced to confront their own mortality. This crisis disrupts young people’s usual way of being in the world leading them to feel uncertain about their future and about who they really are. The sense of uncertainty is exacerbated in social situations when young people’s developing sense of independence is altered and they become dependent on their parents again. It is also exacerbated when they return to school because peers sometimes have difficulty understanding what a young person with cancer has experienced and what their experience means. Young people therefore seek to resolve the crisis by creating for themselves a new way of being in the world.

4.3.2 Young People’s Experiences of Returning to Normal
According to Drew, young cancer survivors emphasise the ongoing, transformative effect of cancer on their lives and ways of being in the world [163] (p. 283). Drew is the only researcher in this literature review to have studied young Australians. She contrasts this with the biomedical emphasis on cure of disease and the illusion of certainty that this produces [163]. This also complements Grinyer’s description of the period of illness and treatment as one of biographical disruption. Young people’s transitions through life are temporal. Explanations of the past and intentions for the future coalesce in a present effected by their cancer experience [85]. In the present, “who I want to be now” can be disrupted by hospitalisation or medical isolation due to the risk of infection [164]. After the period of illness and treatment, young people experience a period in which they have to accommodate the effects of their illness and treatment into their daily lives and sense of self. In some ways they wish to return to normal. However, in many ways this is not possible.
Rechner found that some young cancer survivors feel as though they are the same as they have always been, but that other people respond to them as though they have changed [122]. This can result in them separating their “cancer” life from their “normal” life [122]. The prevailing goal for participants in a study by Miedema et al was to achieve what they called “normalcy.” For some, this meant major changes in their lives; for others it meant resuming life where they had left off before of their cancer diagnosis [179]. These findings conform to what Frank calls the “restitution narrative”. A restitution narrative is a story commonly told by people who are acutely unwell to make sense of their situation.12 The basic structure of the restitution narrative is “yesterday I was well, today I’m sick, tomorrow I will be well again”[180] (p. 77). The notion of biographical continuity has been refined by Woodgate who found that young cancer survivors recognise that cancer has changed them when they express feelings of not being themselves or of not being normal, but that they subordinate these feelings to ones of being “pretty much the same person” after their diagnosis as they were before [113]. From a psychological perspective, these findings assume that the self-identity young people were developing before their cancer diagnosis persists across the duration of their period of illness and treatment.

Young people who have had cancer use various coping strategies to come to terms with their experience of illness, treatment, and recovery. The coping strategies vary from person to person, depend on the stages of their illness, and resonate with those developed during their pre-cancer lives [179]. For example, Earle et al identified two alternative strategies employed by their participants in their quest to return to normal. Some of their participants played down information about late effects and the importance of follow-up care. Others carefully monitored their health and placed considerable value on attending clinical appointments [181]. The first example suggests that some young people prefer to get on with life and not to dwell on the consequences for them of their cancer experience. The second suggests that other young people focus more acutely on their ongoing embodied experience.

Drew focuses on biographical revisioning as the narrative process young cancer survivors undertake during their period of remission and recovery in order to accommodate the ongoing effects of their cancer experience into their sense of a new normal [182]. Biographical

12 The restitution narrative is less commonly deployed by people with a chronic illness because their conceptions of “sick” and “well” differ to those of people who expect to recover from their illness.
revisioning is a process in which taken-for-granted possible life trajectories and narrative pathways are regularly revisited and reconfigured as a way of making sense of their cancer illness [163, 182]. From this perspective, a young person’s self-identity is located within the stories he or she tells about who he or she is. This has also been theorised as a state of ‘expanded consciousness’ which defines health as *encompassing disease and non-disease in a process of developing awareness of self in relation to the environment* [183] (p. 154). According to Labay *et al*, this process can be difficult “even [for] those survivors who appear to have come through treatment unscathed” [86] (p. 166). The important point here is that young cancer survivors’ efforts at biographical revisioning are ongoing.

If they are unable to return to normal (in the sense of ‘the way they were before their diagnosis’) young cancer survivors embark on a quest to establish a “new normal” way of life – one that is forever touched by the experience of cancer and its ongoing and late effects [168]. Prouty *et al* refer to this as “embodiment” of the cancer experience which brings *an envelopment of past experience into present sense of self* [127] (p. 147). Survivors’ stories reflect ongoing efforts at biographical revisioning, self-reconstruction, and narrative repair years after their cancer treatment finishes [163]. Narrative repair suggests a seem-less integration of a young person’s story about their cancer experience into the broader story of their life. For young people, the “new normal” typically includes a sense of grief over the loss not only of past ways of being in the world [85], but also for plans that may no longer be achievable [113] (p. 12).

Recent research has challenged earlier conceptions of the period of remission and recovery as one of seeking to return to normal [122]. In their period of remission and recovery, young people realise that their cancer experience has changed their life-course, but they acknowledge that changes during their phase of life are inevitable in any event [113]. The process of reinventing the self has also been described as a paradox. Despite having completed treatment, young people are not well. They struggled to integrate this into their identity. Knowing they will never be the same, they mourn their past while trying to look forward to an uncertain future [77]. Young people seek to resolve their existential crisis in relationships with others.

4.3.2.1 Returning to Normal and Relationships with Family and Friends
There is little doubt in recent qualitative literature that young people experience survivorship as a quest to establish a “new normal”, having lost some of their connection to their pre-
cancer sense of self. Their “new normal” incorporates aspects of their pre-cancer lives as well as accommodating their experiences of cancer and its ongoing effects. Some authors, including Duffy-Lind et al, suggest that the “new normal” is a way of life inherent to the cancer experience [134]. Some of these relationships pre-existed cancer and therefore provided continuity with the past. Some relationships commenced either during or after cancer treatment and therefore influence a young person’s “new normal”. Despite these relational dimensions, establishing a “new normal” is most often presented as a psychological process of ‘adjusting’ [184-190] or learning to ‘cope’ [54, 191-204] with the ongoing effects of their cancer experience. Psychological perspectives tend to place the responsibility for recovery on individual young people. This diminishes the role played in their recovery by the relationships they conduct with other people.

Survivors of traumatic events seek to make sense of what has happened to them by identifying how their experience has benefited them. According to Tedeschi and Calhoun, people who survive trauma find benefit in their experience when they recognise positive changes in their perception of themselves, their relationships with others, and their philosophy of life [175]. Cancer in young people has been described as a traumatic event because those who are diagnosed repeatedly experience adverse effects of disease and treatment well into their period of remission and recovery [205]. The experience of cancer and the shift in perspective on life that results can benefit young people who have been treated for cancer as well as their family, friends, and acquaintances. In their study of young people 2 years post diagnosis, for example, Mattsson et al. explained positive changes as the result of post-traumatic growth [74]. The accrual of benefits is not inevitable, however. For example, some researchers have found that up to 30% of young cancer survivors exhibit symptoms of Post-Traumatic Stress Disorder (PTSD) linked to their evaluation of their experience of illness and treatment as being “hard” or “scary” [128]. Symptoms of PTSD include avoiding discussion of the illness experience, intrusion of the illness experience on daily life (e.g., in shaping young cancer survivors’ responses to minor illnesses), and hyper-vigilance of bodily signs [206]. The consequences of hyper-vigilance include seeking treatment for minor complaints that they are misrepresented as signs of recurrent cancer.

Nevertheless, Mattsson et al have defined post-traumatic growth as a positive psychological change experienced as a result of a struggle with a highly challenging circumstance [74] (p. 1008). Post-traumatic growth is one possible outcome from an individuals’ encounter with
death and the resultant existential uncertainty [74, 174]. The experience of cancer can result in post-traumatic growth by acting as a catalyst for a deeper appreciation for and value of life in general [74-76, 128, 183]. This, in turn, leads to greater enjoyment of life for young cancer survivors and experiences of decreased worry and concern with trivial matters [76]. This assists young cancer survivors to develop a positive outlook on life [122] including a focus on healthy living [207]. These are all benefits for the individual that resonate with the positive psychology movement. Conversely, a lack of post-traumatic growth has been associated with lower life satisfaction in adult survivors of cancer diagnosed in adolescence [209]. These perspectives are consistent with those held by survivors of cancer who were diagnosed in later adulthood [210]. One of the benefits for young cancer survivors is that they develop a sense of self as more mature than their peers – a sense of self that they value but that also has the potential to result in their experiences of social isolation [74, 76, 211].

Some young cancer survivors report a desire to help others [76, 183] and claim that their cancer experience has made them mentally stronger than they were before diagnosis [74, 76]. Mental strength can give them more self-confidence and greater independence than they had before their diagnosis [74, 211, 212]. Young people can also feel more motivated to perform and better focused on their various tasks than they were before their diagnosis [211]. They perceive resources of inner strength which they attribute to their experiences [169]. This is similar to the experience reported by older adult cancer survivors [210].

Young cancer survivors’ perception of themselves as gaining benefit from their cancer experience not only has implications for their psychological well-being but also for the well-being of those around them. Their cancer experience can result in stronger relationships between themselves and their families and friends [75, 183, 211]. This can lead them to reach out to others and express their greater feelings of empathy for other people, especially those who are suffering or in need [183]. For example, young people express a desire to help others by choosing a career as a health care professional, by donating money to charity, or by acting as peer counsellors for other young people diagnosed with cancer [127, 176, 183, 207]. Brown et al found that some participants in their study planned for careers in medicine or

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13 Positive Psychology (Seligman) links optimism and happiness with personally desirable outcomes such as good health and career success. It has been heavily critiqued (see for example Ehrenreich) as being intellectually shallow and insubstantial.


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nursing and they were interested in helping others as a result of their cancer experience. They perceived that cancer had a positive effect on their career plans because it made them more resilient and self-determined than they had been before their diagnosis [207]. This resonates with the experiences of older adult cancer survivors who come to recognise their own importance to other people [210]. This can manifest as a desire to give back to the individuals or institutions that contributed to their survival of their disease [213].

The benefits young people claim for themselves and others are reported in the literature as being positive outcomes from the cancer experience. However, these interpretations of positive outcomes are complicated in two ways. First, the benefits of having cancer in adolescence and young adulthood highlight the differences between young cancer survivors and their friends and, thus expose them to the possibility of social rejection, isolation, or stigma. Second, some of these benefits, while experienced earlier for young cancer survivors than they are for their peers, may not be directly attributable to the experience of cancer at all. For example, young people theoretically develop feelings of empathy for other people as a normal phase in their process of growing up [5] (p. 820). If this is so, then the difference between young cancer survivors is that they experience a sense of maturity earlier than their healthy peers. Despite these complications, finding benefit in their cancer experience may be a way for young people to accommodate their cancer experience into their developing sense of self rather than resisting its influence on their lives.

Not all young people receive ongoing support from their parents and friends. For example, according to Weekes, when parents and friends refuse to continue to discuss a young person’s cancer experience with them, she or he experiences a lack of support [124]. Some cope with this by adopting a role as peer counsellor to other young cancer survivors where they can legitimately engage in conversations about their own cancer experience [124]. They also experience their return to their usual social worlds as difficult when they seek verification that their cancer experience was traumatic, and yet want to be treated normally [77].

School is a central experience of young people living in Western societies where compulsory primary education has been mandated for more than a century. School provides structure and social contact and allows young people to gain the skills they need for successful functioning in later life [83]. Returning to school represents a continuation of “normal” life [128] and this has a normalising effect on young cancer survivors [54, 122]. Because a prolonged absence
from school can result in adverse psychological reactions a return to school as early as possible is recommended [54, 96]. A return to school may be difficult or daunting for young people who have had cancer. Therefore, school re-entry programs can help with this process. School re-entry programs have been shown to improve self-esteem and reduce depressive symptoms in young cancer survivors. This contrasts with the experience of home schooling which exacerbates feelings of isolation and loneliness [83]. Young people with cancer also report feelings of social isolation which they attribute to peers not knowing what to say or how to respond to them when they returned to school [74].

These effects of cancer on young people’s educational achievement have adverse consequences for young cancer survivor’s future employment prospects and independence [85]. Young people’s entry into the work force can be delayed if their academic achievement in diminished due to their cancer illness and treatment. If they have been employed at the time of their diagnosis, cancer illness and treatment can delay their advance in the workplace because of missed opportunities [85].

Complication can arise for young people who have had cancer when they return to school because of the adverse responses they receive from their peers. Some report being bullied by others at school [214, 215]. Young people with cancer may be bullied because of their unusual appearance or because of their lower levels of academic achievement. Although Smith et al found that fewer than 10% of participants in their study felt distant from their peers or experienced being rejected by their peers because of their cancer, on balance the research literature suggests that social compromise in the form of bullying and rejection is a common experience for young cancer survivors who return to school [162].

4.3.2.2 Returning to Normal in Relationships with Romantic and/or Sexual Partners
From a developmental perspective, young cancer survivors experience life transitions later than their peers or they do not experience them at all. For example, in one study young women had achieved fewer developmental milestones in their sexual development, such as having their first boyfriend, or they reached these milestones later. They also reported a significantly stronger desire to have children. Young men were more likely than their male peers to live with their parents [216]. However, equivalent proportions of young cancer survivors and their peers were living in a long-term relationship but survivors were less likely to have ever married or had children. Survivors of adolescent cancer experience some social
late effects of the disease in adulthood, such as a delayed social development as well as substantial differences in their family life and living conditions compared to healthy peers [216].

Canada et al reported that young people with cancer who experience delayed psychosexual maturity may benefit from a counselling intervention delivered by health care professionals. In their study, 21 young people who had received treatment for cancer aged between 15 – 25 years participated in a pilot study of a counselling intervention. They were given education about the effects of cancer on their sexual health, including fertility, sexual function, and romantic relationships. In a post-intervention evaluation, participants experienced a decrease in anxiety about sexual and romantic issues and also showed a decrease in overall psychological distress [217].

Young people who have had cancer feel concerned about their attractiveness or desirability to other people [84, 163]. Drew reports that, as a result, young people try to accommodate the physical changes that persist after their treatment finishes in to contemporary cultural frameworks of masculinity and femininity [163] (p. 284). However, they are not always successful in achieving this because some physical effects of cancer are difficult to disguise (e.g. physical weakness, scarring). Another aspect of the cancer experience that complicates young people’s return to normal is that they feel their experience of treatment tends to objectify their bodies and that they associate bodily contact with unpleasant or painful medical procedures. This can inhibit their desire to become physically close to other people [163]

Studies of young people who have had cancer that focus on their intimate relationships of a romantic and/or sexual nature view their participants through a hetero-normative lens. In other words, findings focus on outcomes of cancer illness and treatment that have particular resonance for young people in heterosexual relationships. This is evident particularly in that researchers tend to focus on the impact of cancer illness and treatment on fertility and marriage.

4.3.3 Summary
Recent researchers have consistently argued that young people who survive a cancer diagnosis and treatment cannot return to normal in the sense that they can never be the same
as they were before the event. This means they have to find ways of constructing a “new normal”, one in which the memory and ongoing effects of their cancer experience is an integral part. A “new normal” way of being in the world can manifest in the stories young people tell about who they are, where they have come from, and where they are going. It can also manifest in finding benefit for themselves in their cancer experience. Young people who have had cancer are often uncertain about their prognosis, however, and uncertain of how to go about constructing a “new normal”. We therefore have a broad understanding of how young people with cancer try to create a “new normal”, but the research to date has focussed on the individual perspective. Less is known about how this task is accomplished in and through relationships with others.

4.4 What We Already Know and What We Need to Find Out

Empirical research into young people with cancer has consistently recognised adolescence and young adulthood as transitional periods [48, 112, 122, 169, 218]. The transition is often said to involve significant cognitive, emotional, and physical changes [83, 169, 218-220]. Young people are said to engage in tasks that enable them to develop a self-identity [221]. However, researchers have also recognised the interaction between these changes and the social worlds of young people with cancer. Developmental tasks are achieved in and through relationships; in growing emotional and economic independence from parents [54, 83, 113, 121, 122, 221] in closer relationships with peers [112, 122, 219], and in sexually intimate relationships [113, 219]. These transitions are also reflected in normal transition from school to employment and the expression of a sense of self through choice of occupation [122, 221]. This is important because these dominant conceptions of adolescence and young adulthood, whether explicit or, more commonly implicit, have guided research into the experience of cancer for young people for more than twenty years.

Recent research into the experience of young people who have had cancer has a particular focus. It tends to focus on young people as *individuals*. The dominant discourse around cancer illness and treatment in young people is one of biological and psychological transition. As a result, we now have an extensive knowledge of young people’s experience of bodily change as a result of their cancer experience and how these changes effect young people’s adjustment to their new status as cancer survivors. It also means that we have an extensive knowledge about how young people cope with their disease and its ongoing effects. Within this framework, young people’s social development has also been individualised. We
therefore know about how their bodily and psychological disruptions effect their actions within their usual social worlds. We also know about the actions other people undertake in order to support young cancer survivor’s transitions. However, we have more to learn about the social processes that young people engage in when they seek to accommodate the effects of cancer into their relationships with other people. We have more to learn about the reciprocal nature of the relationships in which they engage that complements our current understandings of their individual experience of growing up with cancer.

I have suggested in the introduction to this thesis that the process of growing up for young Australians is similar to that experienced by those in other Western countries. However, only Drew has studied the experiences of young Australians [163, 182]. There may be aspects of the experience of growing up in Australia, and the way young Australians conduct relationships with their family, friends, and new acquaintances that are subtly different to the ways in which young people in other Western countries conduct theirs. Furthermore, the structure of the health care system in Australia may influence the experience of cancer illness and treatment for young Australians in ways that are different for them than for young people diagnosed and treated in other Western countries.

This study, therefore, aims to:
1. expand current understandings of the experience of young Australians with cancer, focussing on the period of remission and recovery; and
2. determine how young Australians conduct social interactions in light of their cancer experience.

The project will address these aims by answering the research question: “what is the impact of cancer illness and treatment on the experience of growing up among young Australians?”
Part II Methodology and Methods

Chapter 5: Methodology and Methods

5.1 Synopsis
This chapter outlines the ontological and epistemological assumptions of American Pragmatism and its epistemological successor, Symbolic Interactionism, as these underpinned and guided the analysis of interviews collected for this study. I will justify my selection of this theoretical perspective as an appropriate approach to answer my research question. I will then describe my methods of approach and recruitment, and data collection and analysis, and justify why these methods were appropriate to this study. The conduct of this study raised some ethical consideration that I will address at the end of this chapter.

5.2 Ontology and Epistemology
Previous research into young people with cancer has combined biological, psychological, and social theories of adolescence and young adulthood in study design. The advantage of doing this is that it provides new insights into the impact of cancer on different aspects of growing up. It also provides an opportunity to balance findings that are especially relevant to one disciplinary perspective with those relevant to others. By adopting this approach I can acknowledge the biological and psychological effects of cancer while focusing my answer on the social experiences of young people with cancer, which has been less widely studied than biological and psychological outcomes. I have divided this section into three sub-sections. First, I give a brief overview of the philosophy of American Pragmatism. This is to provide the philosophical background to the choice of theoretical perspective that I used to guide my data analysis – that of Symbolic Interactionism. Second, I outline the features of Symbolic Interactionism that are of particular relevance to my analysis of interview data. Third, I will summarise the appropriateness of Symbolic Interactionism as a guiding theoretical perspective for this study.

5.2.1 American Pragmatism
American Pragmatism is a philosophy aimed at “unifying … all facets of the human condition – mental and physical, subjective and objective, individual and social.” [222] (p. 2). For pragmatists, reality is dynamic, unfinished, and “in the making”. Pragmatists argue that knowledge arises from our interactions with our physical and social worlds. Knowledge is a process of giving meaning to things based on how we respond to them, and it is the product of both psychological and social interactions. For pragmatists, truth is not absolute but is characterised by ideas and beliefs that persist for as long as they allow us to adapt to our
circumstances. In other words, truth is historically contingent and results from social interaction [222] (p. 2-4). Therefore, if we were to conceptualise the process of growing up as a combination of the biological, psychological, and social perspectives outlined in chapter 2 of this thesis, this approach would be consistent with American Pragmatism.

5.2.2 Symbolic Interactionism
American Pragmatist philosopher G.H. Mead was influenced by the late nineteenth century turn in naturalistic inquiry, which held that humans might best be studied through observing them in natural settings, rather than in laboratories [223], and which advanced five basic propositions unique to the social sciences. First, individuals do not possess a constant, stable personality but are dynamic and ever-changing; they act and interact with their environments and each other. Second, society itself is not static but constantly reconstructed through the process of interaction undertaken by individual actors. Third, the two characteristics of “mind” and “self” exist within individuals but these are not static either. Fourth, many “selves” may be portrayed by individuals in response to the varying contexts of their interactions. Finally, truths, ideas, knowledge, perceptions, and perspectives are all processes that evolve in response to the contexts of individual interactions [223] (p. 27).

The tradition of naturalistic inquiry gave rise to four central characteristics of symbolic interactionism. First, symbolic interactionism does not focus on characteristics of personality in the way that the discipline of psychology does, nor does it focus upon the social structure that influences social behaviour, in the way that sociology does. Rather, it focuses on the nature of social interactions between individuals as they occur in various contexts.

Second, social interaction is not merely the product of each individual’s action in response to others in any given situation; it is also a product of an individual’s interaction with him or herself, resulting from their perceptions of their situation. I take this to mean that individuals engage in a reflective process of interpreting the situations in which they interact. Third, symbolic interactionism is focussed on the present. Both future and past interactions are seen to influence those in the present, but individuals are not seen as being controlled by the past. Finally, Mead’s conception of symbolic interactionism portrays individuals as more active in their social situation than do some other perspectives [223] (p. 23).
Blumer extends Mead’s ideas of symbolic interactionism and commences with three “simple premises”. First, human beings act towards things on the basis of the meanings that the things have for them. Second, the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows. And third, these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters [224] (p. 2). In symbolic interactionism meaning does not emanate from the things, nor does it arise through a “coalescence of psychological elements in the person” [224] (p. 4). Meaning arises from the process of interaction between people [224] (p. 4).

5.2.3 Summary
Growing up is a process characterised by a combination of biological, psychological, and social transitions. American Pragmatism is a philosophical perspective that seeks to unify all aspects of the human condition including mental and physical, individual and social. Symbolic Interactionism is a theoretical perspective based on American Pragmatism that provides a methodology for studying the social interactions in which people engage in their usual social contexts. Therefore, this methodology provides an appropriate perspective from which to study the impact of cancer on the experience of growing up.

5.3 Study Design
Qualitative research aims to develop concepts that help us understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all the participants [225, 226]. This is consistent with the methodology of Symbolic Interactionism. I therefore collaborated with the chief investigators on the research project to design a qualitative, interpretive study.

5.3.1 Justifying Methods of Data Collection
Blumer described the social act as the fundamental unit of social psychological analysis. The ideal method of data collection for a study guided by Symbolic Interactionism is, therefore, direct observation by the researcher of the social interactions that occur in participant’s usual social worlds. However, within the constraints of GUWC, direct observation of young people in their usual social worlds was potentially intrusive on them and impractical for members of the research team to undertake.

Blumer lists numerous acceptable methods of data collection in social research including ethnographic observation and interview. As a method of qualitative data collection,
interviewing is well established and widely accepted. Interview data is an appropriate method of observation of participants in this study because, according to Blumer:

[These observations] are in the form of descriptive accounts from the actors of how they see the objects, how they have acted toward the objects in a variety of different situations and how they refer to the objects in their conversations with members of their own group [224] (p. 51-52)

Research interviews may be conducted face-to-face, over the phone [227], or on the internet [228]. Different interview methods can yield different results, however. A one-on-one face-to-face interview is a conversation with structure and purpose that goes beyond outward behaviour to secure accounts of events and processes that reveal the meanings and values that participants attach to them [229]. This is not only applicable to face to face interviews. Interviews conducted over the telephone, for example, can produce a similar result, although the interviewer cannot respond to non-verbal signals from the interviewee, and this may affect the quality of the interaction.

5.3.2 Study Population
Because we aimed to study the impact of cancer on the process of growing up without conducting a longitudinal study, we identified a population of young people who would be likely to provide a retrospective, reflective account of their experience of growing up. To this end, we focused on a study population whose period of acute illness and hospitalisation for treatment had passed. Rather than collect stories of the experience of acute, life threatening illness and the chaos associated with that period (see section 4.3.1.1), we sought to study the experience when young people had had the chance to reflect on it, and attribute meaning to their cancer experience in the context of their life. We also aimed to maximise the diversity of our sample in terms of their diagnosis, their age at diagnosis, and their age at time of first interview. This was seen as important because in a previous study of young people with cancer that informed the design of this study [2, 3], it proved difficult to recruit young men.

5.4 Methods
5.4.1 Setting
Participants were recruited from three different settings. Two settings were large acute care hospitals in Western Sydney. One setting was CanTeen, the support group for young people living with cancer and partner organisation on the GUWC project.
The Children’s Hospital at Westmead delivers acute inpatient treatment to children and adolescents who are newly diagnosed with cancer or haematological malignancies between the ages of 0 and 16 years. It also provides ongoing care for young people aged up to 18 years who are diagnosed at 16 years or younger. The hospital provides an outpatient service for the care of long-term and late effects of cancer in children and adolescents. Patients are transferred to the long-term follow up clinic from acute care services five years after their diagnosis.

Westmead Hospital is a major teaching hospital that is located near the children’s hospital. It provides separate services for adult patients diagnosed with haematological malignancies or cancer over 18 years of age. The hospital provides inpatient services for acute care of patients newly diagnosed or suffering from side effects of treatment. Three months after initial diagnosis patients are transferred to the long term follow-up clinic and their long term care is delivered on an outpatient basis.

CanTeen is a national cancer support group that provides state based educational and recreational programs for the benefit of its members. Membership is open to young people 12 to 24 years old. Members are divided into three categories. Patient members are young people who have been treated for cancer. Sibling members are young people whose siblings have been treated for cancer. Offspring members are young people who have one or more parents diagnosed with and treated for cancer. Sibling and offspring membership remains open to young people after their relative has died from cancer and specific programs are dedicated to supporting these members during their period of bereavement.

5.4.2 Approach and Recruitment Processes
Eligible participants were initially approached by mail. With the consent of the heads of hospital haematology and oncology departments, Dr Mooney-Somers and I asked hospital administrative staff to identify young people who were eligible to participate, using their patient databases. We then provided hospital administrative staff with information packs containing a letter of introduction to the study, participant information forms and consent forms for one to be mailed to each patient and the parents of each patient under 18 years of age (See Appendices 3 and 4).
Young people could indicate their interest in participating in the study by phoning me on my office phone or on a mobile phone paid for by the project budget, by e-mailing me on a generic project e-mail address, or by returning a written request by conventional mail for me to contact them by whichever means they stipulated. When a young person contacted me in any of these three ways, I spoke to them by telephone to ensure they had received and read the information forms, to give them the opportunity to ask any questions they had arising from their reading of the forms, and to arrange a time and place that was mutually agreeable for me to conduct an interview. I explained that participation was voluntary and that participants were free to withdraw at any time.

Young people under 18 years old could also volunteer to participate by proxy, (i.e. one or other of their parents could contact the research team on their behalf). When potential participants who were under 18 years of age volunteered, I spoke to their parents on the phone as well as the young person to ensure their parents had also read the participant information forms, to answer any of their questions, and request consent for their child to participate. I assured the parents that participation was entirely voluntary and that they or their child could withdraw their consent at any time. I had to arrange for interviews at times and venues that were convenient for the parents to transport the participant to.

Administrative staff mailed 790 information packs (380 from the Children’s Hospital at Westmead and 410 from Westmead Hospital) to people eligible to participate and parents of those younger than 18 years. The introductory letters invited potential participants to complete an on-line psychometric questionnaire and to contact the research team directly if they wished to participate in the interview and/or self-portrait. If a young person completed an online survey he or she was again invited to contact the research team directly if they wished to participate in the interview or self-portrait. The participants were able to moderate their involvement according to their level of interest and/or their capacity to participate.

To limit the volume of data collected at any one time we undertook a two stage sampling strategy. Recruitment commenced in November 2009 when information packs were mailed from the Children’s Hospital at Westmead. In January 2010, information packs were mailed from the haematology department at Westmead Hospital. Administration officers from the two hospitals mailed follow-up letters of invitation to eligible participants four weeks after the initial mail out of information packs. Between November 2009 and May 2010 a total of
ten young people who had been treated for cancer at the Children’s Hospital at Westmead volunteered to participate in this study. No patients treated at Westmead Hospital volunteered to participate.

Expanded Approach to Recruitment: The ten participants originally recruited were a balanced sample in terms of gender, however the research team considered that the study would benefit from recruitment of young people diagnosed with a wider variety of cancers and who experienced their cancer in late adolescence or young adulthood. The research team therefore sought and was granted institutional ethics approval to broaden the recruitment strategy in three ways. The first was for Member Liaison Officers at CanTeen to e-mail letters of invitation to CanTeen members in New South Wales and Victoria followed by a phone call from CanTeen member liaison officers to young people from different diagnostic and age groups. The second was to approach other cancer support groups in New South Wales to request assistance in recruiting eligible young people. The third way was for me to approach eligible young people in person at the long term follow up clinic at the Children’s Hospital at Westmead.

Fifteen additional participants were recruited from letters of invitation that were e-mailed to CanTeen members in New South Wales and Victoria. I telephoned five cancer support groups in New South Wales two of which focussed on supporting young people with cancer. Both of these support groups e-mailed letters of invitation to their members. No members of those support groups volunteered to join the study. Few young people eligible to participate in the study attended the long-term follow up clinic at the Children’s Hospital at Westmead during the recruitment period. Most clinic attendees who were over 14 years old had been diagnosed in childhood. As a result, I approached four young people, one of whom agreed to participate. Chief investigator Kerridge also recruited one participant by personal approach at the University of Sydney. Table 3 shows progressive totals of participants recruited and where they were recruited from during the 14 month recruitment period.
Table 3: Progress of Recruitment

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<td>2</td>
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<td>4</td>
<td>5</td>
<td>10</td>
<td>2</td>
<td>27</td>
</tr>
</tbody>
</table>

The expanded approach strategy enabled us to broaden the variety of participants by recruiting young people from rural areas, young people diagnosed with brain tumours, testicular cancer, and ovarian cancer.

Mailing out information packs from hospital departments was time consuming for hospital staff and researchers and generated a very low response. It was therefore an inefficient method of recruitment. This could be due to a number of factors. Conventional mail out could be inappropriate for young people who are more accustomed to communicating via digital media [230]. Also, information packs mailed from the Children’s Hospital at Westmead were addressed to parents rather than young people and parents might not have passed them on to young people, or parents might have made the decision not to participate on behalf of their child.

5.4.3 Sampling
In this study we used a quota sampling strategy to ensure a roughly equal number of male and female participants and also to ensure that the sample represented a wide range of experience in terms of diagnosis and maturity. Table 4 outlines eligibility criteria for the participation in the study.
Table 4 Eligibility Criteria

<table>
<thead>
<tr>
<th>Eligible</th>
<th>Ineligible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosed with cancer between 10 and 24 years old</td>
<td>Diagnosed with non-melanoma skin cancer</td>
</tr>
<tr>
<td>Receiving treatment and aged between 14 and 24 years old</td>
<td>Diagnosed with cancer less than eight weeks before being approached</td>
</tr>
<tr>
<td>Post-treatment and aged between 14 and 29 years old</td>
<td>Were intellectually impaired to the extent that they could not complete any arm of the study</td>
</tr>
</tbody>
</table>

We initiated a process of quota sampling to recruit interviewees who fit the criteria outlined in table 4 [231]. We added further criteria to maximise our chances of recruiting a diverse range of participants as shown in table 5.

Table 5: Characteristics of Participants for Quota Sampling Strategy

<table>
<thead>
<tr>
<th>In Treatment</th>
<th>In Treatment</th>
<th>Post Treatment</th>
<th>Post Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 – 17 years old</td>
<td>18-24 years old</td>
<td>14-17 years old</td>
<td>18-24 years old</td>
</tr>
<tr>
<td>Bone Marrow Transplant</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Neurological Cancers</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Other Cancers</td>
<td>4</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

This sampling strategy aimed for a total number of 48 participants. We recruited just over half this number of participants. Only one participant was in treatment at the time of her interview. She had been taking oral maintenance chemotherapy at home for eleven months and her treatment was to have finished after twelve months. Our original quota sampling strategy included participants who were in their acute phase of illness and hospitalised for treatment. No such young people volunteered from the mail out of information packs. There are several possible explanations for this. If they were hospitalised they might not have received the information packs. If they did receive them, they might have felt too unwell to volunteer. This study therefore only includes young people who were in remission and had effectively finished their treatment when they volunteered to participate.

5.5 Data Collection
The full range of methods used in this study is described in the preface to this thesis. This section focuses on the process of collecting interview data, as the interviews form the basis of this thesis. I will also describe the process of creating self-portraits. The interviews and self-portraits provided a suite of reflective spaces in which products of earlier activities informed young people’s responses to later activities and ultimately the outcome of interview 2.
Digital audio recordings were made of all interviews and interviews were conducted in one of three ways according to the stated preferences of the participants: face to face, by telephone, or on Skype (Table 6). Telephone interviews were the most efficient method of interviewing young people resident interstate. I used Skype once to interview a young woman who was travelling internationally.

Table 6: Mode of Interview

<table>
<thead>
<tr>
<th></th>
<th>Face to face</th>
<th>Telephone</th>
<th>Skype</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview 1</td>
<td>13</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Interview 2</td>
<td>7</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>Interview 3</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

I conducted face to face interviews in a variety of locations including departmental offices at the University of Sydney, The Children’s Hospital at Westmead, and at the national office of CanTeen in Sydney. I interviewed one participant at his home and another one at the home of her relative. I conducted telephone interviews from private offices in the Centre for Values, Ethics, and the Law in Medicine at the University of Sydney. I conducted one interview by Skype from my own home.

**5.5.1 Interview 1: Protocol**

I initiated the first interview by asking participants about their experiences of adolescence and/or young adulthood and the impact of cancer on those experiences (see appendix 8 for an example of the interview schedule). I commenced face to face interviews by asking participants to draw a time-line using a pen and paper depicting significant events in their lives from age eleven. I retained copies of these participants’ time-lines for my own consideration in conjunction with participants’ interview data (see appendix 5). Some agreed to create a time-line, however, some preferred simply to talk. When participants did create a time line I used them in the interviews as a stimulus for discussion of the events they depicted. After a brief discussion of what participants lives were like before their diagnosis with cancer, I asked them to add to their time-line significant events in their cancer journey providing further stimulus for discussion. I intended for the time-line to assist in the process of data collection in two ways. One was to disrupt the standard cancer story that describes the participant’s experiences of diagnosis, treatment, and recovery. I used this to emphasise for participants that the project was about their experience of growing up and not only about their experience of cancer. The other was to provide a context which enabled participants to talk about other life events as being as important or more important to them than cancer.
I commenced telephone and Skype interviews by describing my general location and my immediate surroundings. I advised participants that, for the purposes of recording our interview, I would put the telephone on loud speaker and reassured them that my location was private and that our conversation could not be heard by other people. I then asked participants to describe what their lives were like at the time of their diagnosis and how they perceived that their cancer experience had changed their interactions with others.

My style of interview was semi-structured and conversational. I used my pre-prepared list of topic areas to prompt me to ask questions about areas of the young people’s lives that they did not raise themselves but that my reading of the literature suggested might be important. This type of structure was loose enough to enable me to explore topics raised by participants that impressed me as being important to them. As a result, interviews lasted between 40 and 120 minutes. This flexible approach resulted in a large volume of data that ranged across a variety of topics of interest to both participants and to my research agenda.

5.5.2 Self-Portrait Workshops
After I had completed a first interview, I asked participants if they would like to create a self-portrait as part of the study. They could choose to create a self-portrait on their own using any media they liked or they could choose to attend a workshop facilitated by chief investigator Smith at which they could discuss ideas and explore techniques for producing a self-portrait. If they agreed to create a self-portrait I passed on their contact details to Dr Mooney-Somers who acted as a liaison between participants and chief investigator Smith as well as organiser and co-facilitator of the self-portrait workshops. Three participants completed their self-portraits without attending a workshop and several others did so with minimal assistance, such as an occasional phone call from chief investigator Smith. Analysis of the creative process as a methodology and of the self-portraits as pieces of research data are beyond the scope of this thesis.

5.5.3 Interview 2 and 3: Protocol
Dr Mooney-Somers encouraged all those who participated in a self-portrait workshop to participate in a second interview when the workshop finished. If the participant agreed to a second interview at that time, she asked their permission for me to contact them to arrange a time and place for the interview. She then notified me of a participant’s willingness to participate in a second interview and I telephoned the participant to arrange a time and place
for their interview. The second interview was designed to explore their experiences of participating in the workshop and of creating the self-portrait and to discuss the contents of their self-portrait. It was also designed to allow me or the participants to discuss any other thoughts that arose from their first interview. I conducted interview 2 with participants when it suited them. This was usually within one week of the completion of the self-portrait workshop but ranged from three days to four weeks after. Some participants brought their completed self-portrait to the interview to provide stimulus for discussion. Others had not seen their self-portrait printed on paper before I brought it to the interview to show them. I conducted interview 2 in a conversational style, however I constructed a narrower list of topics for discussion than I did for interview 1.

I commenced interview 2 by asking participants if interview one had evoked any thoughts related to - or memories of - their cancer experience that they wanted to share. After discussing any topics raised by participants I asked their permission to discuss any topics that I identified as being of particular interest to my study from interview 1. After discussing these topics, I asked participants to explain the content, meaning, and experience of producing their self-portrait(s). The final phase of the interview was completely unstructured. During this phase participants often asked questions about the progress of the research, about the content of other participant’s interviews and self-portraits, or personal questions about me and my work. I responded to their questions openly and honestly without breaking confidentiality of other participants. For example, if a participant asked me whether other participants in the study had said the same things as they had, I reassured them that their answers were consistent with those I had received from other young people of a similar age and gender.

I conducted interview two in the same range of venues as described for interview 1. Second interviews lasted between 30 and 90 minutes.

Interview three was a short, structured conversation about the content, meaning, and experience of producing a second self-portrait, if a participant had created one, or about the development of a previously unfinished self-portrait.

The semi-structured nature of the interviews enabled me to elicit answers that focussed on the topic of growing up with cancer but it was also flexible enough to elicit unexpected and new responses to questions about participant’s experiences. The typical sequence of participation (interview – self-portrait – interview), formed a suite of reflective spaces during which
participants could revisit different aspects of their experience of growing up. Participants therefore had multiple opportunities within the study to reflect on their cancer experience and access to two modes of expression. Some participants also reported that they continued their reflection in conversations with their friends and family. This reflective process enriched the quality of the interview data collected during interview 2. Participants drew on their first interview, the creative, self-portrait process, and any personal reflection that they engaged in to provide deeper insights into their cancer experience than they provided in interview 1.

The conduct of the interviews presented me with some challenges. First, some participants told me stories of their treatment experience that evoked memories of unpleasant, difficult, or challenging situations I had faced in my clinical practice. I did not express emotion during the interview but sometimes I had difficulty controlling my emotions afterwards. My co-supervisor was helpful at these times by allowing me to express my emotions as a way of dealing with the challenges I met in the interviews. Secondly, one participant disclosed intimate aspects of her sexual relationships during her interview. Although these were relevant to the topic of growing up with cancer, after the interview had finished I felt uncomfortable about hearing what she had disclosed. The participant also contacted me to say she had felt uncomfortable about the level of detail she had disclosed. In hindsight, I might have managed the interview better by sensitively redirecting the conversation towards “safer” topics of discussion. This is only evident in hindsight, however, when we both recognised our discomfort at having participated in the conversation. I discussed my discomfort with my supervisors at the time and the difficulty passed. No other participants expressed regret at how they had participated and none expressed a desire to withdraw from the study or revoke their consent to allow their interviews to be analysed.

5.6 Data Analysis
My analysis of interview data focussed on the experiences of growing up with cancer reported by participants. I conducted a Thematic Analysis [232] focussing specifically on evidence of answers to the research question [233] (p. 31-32). I categorised interview data contemporaneously with data collection.

Management of Data: Recorded interviews were transcribed verbatim by employees of a professional transcription service. I printed all transcripts and I entered them into a computerised data management system - NVivo version 8. I read printed transcripts while listening to the interview recording in order to check the accuracy of the transcripts and to
recall the nuances of speech that are difficult to identify on the page. I made notes about context on the printed transcripts while listening to the recording to prompt memories of the situated interaction of the interview itself. After my initial reading of a printed transcript, I re-read the transcript and made further notes as a preliminary step towards initial categorisation.

Process of Analysis: After I familiarised myself with the transcripts, I transferred notes and preliminary categories into NVivo. I continued the process of identifying broad categories and included identification of all concepts introduced by participants in the interviews whether obviously related to the research question or not.

As single categories proliferated I developed a series of categorical groups that contained all the different single categories related to a larger concept. I made notes and memos in NVivo to explain how the single categories combined to create one conceptual category. After I had grouped all single categories I identified the conceptual categories that I took to be most relevant to my research question, given my theoretical commitment to a social psychological conception of young people, and I re-read the printed transcripts looking especially for any further evidence for the concepts that these conceptual categories represented. I explored concepts thoroughly by including in each categorical group a variety of different participant perspectives on the concepts that these categories represent.

Throughout the analytic process, I shared my developing categories with my thesis supervisors and other members of the research team. Sometimes I circulated written memos. At other times I made oral presentations to team members. Sharing this information stimulated discussion that helped guide my ongoing interpretation of the data. As I made my categories more substantial and more clearly defined, I presented my preliminary findings to colleagues outside the research team at local seminars and, eventually, international conferences. Colleagues at these meetings provided feedback on my presentations which further enabled me to refine my analysis. In these ways I shared the iterative process of data analysis with others which assisted in refining the categories that I developed into the themes I report in Part III of this thesis.
5.7 Ethical Considerations

5.7.1 Consent
In Australia, young people aged 14 – 17 years are not legally able to consent to participate in medical research. Consent must therefore be obtained from parents or legal guardians. Both prospective participants and their parents were given information sheets written in plain language to enable them to make an informed decision about whether to participate. We then asked parents to complete a consent form on behalf of their child (see appendix 4). Although the research team was not legally obliged to obtain consent from young people between 14 and 17 years of age, we did so out of respect for their developing autonomy and independence.

Participants aged over 18 years received their own participant information and consent forms. Before asking them to sign the consent form, I asked participants if they had read the information form. If they said they had read it, I asked them to tell me what activities they anticipated performing as participants in the study. If they answered my question in a way that corresponded with what I intended asking them to do, I asked them to sign the consent form to provide evidence of their consent. If they answered my question in a way that conflicted with what I intended to ask them to do, I discussed what I actually planned to ask them to do before asking them to sign a consent form.

5.7.2 Potential Harm to Participants
Asking a young person to discuss their experience of illness and their experiences of growing up has the potential to cause them distress. Likewise, attempts to engage in conversation surrounding their general experience of growing up may have been confronting for participants who had undergone an existential crisis and were in the process of reconstructing the meaning of their life when that meaning might appear transient and unstable.

My strategy for managing potential distress was to reassure participants that they may withdraw their consent at any time and for any reason, that they may choose not to discuss topics that they found too distressing or private, and that the choice whether or not to be identified by any aspect of the study was theirs alone. If participants became distressed during the interview, I planned to give them time to compose themselves before offering them the opportunity to continue the interview. If their distress persisted I planned to remind them of their options of suspending the interview, rescheduling the interview for a later date, or terminating the interview and withdrawing their consent. I also planned to provide
participants with an information sheet listing publicly accessible, self-referral counselling services in case their distress persisted and they wished to seek professional help. CanTeen staff were also available to counsel participants who experienced ongoing distress, however I never had to refer any participants to them because no participants became distressed during their interview.

To protect participant’s privacy, I stored all digital data including audio recordings of interviews, copies of transcripts, copies of self-portraits, and copies of time-lines on a password protected computer hard drive at the University of Sydney. I stored printed copies of transcripts and time-lines and signed consent forms in a locked drawer in a lockable office in the Centre for Values, Ethics, and the Law in Medicine at the University of Sydney.

5.7.3 Harm Caused by Mail-out

Approaching potential participants by mail-out from hospital departments caused potential harm that was unanticipated by members of the research team. Three letters of invitation were addressed to young people who had previously expressed a wish not to be contacted by researchers and who complained about the contact to the research team. Chief investigator Kerridge spoke with each of these young people to apologise for the distribution of the information pack. He then notified administrative staff of the department that mailed the information packs that the three young people did not wish to be contacted. He instructed the administrative staff to remove the young people’s names from the project mailing list and to append a note to their database entry that they were not to be contacted for research purposes.

Five parents phoned the research team to advise us that their child had died. We apologised for sending the information packs and assured the parents that their child’s name would be deleted from the research mailing list. None of the parents said they had been distressed by receiving the letters. They said they wished to inform us of their child’s death because of the potential inconvenience to us! The mailing of the letters highlighted a deficiency in the system of record maintenance in one hospital department. The average time elapsed since the death of these five young people was four and a half years, and all had died in the hospital department from where the information pack was mailed. Chief investigator Kerridge notified the relevant hospital department of the deaths of the young people and asked that their names be deleted from the mailing list. He also highlighted the inaccuracy of the departmental database with administrative staff and the head of department and the potential for
embarrassment and distress that this inaccuracy caused. The head of department initiated a process of updating all departmental databases.

5.7.4 Ethics approval
In accordance with current guidelines of the National Health and Medical Research Council, as a multi-site study, the GUWC project required ethical approval from a lead Human Research Ethics Committee with expertise to evaluate the scientific and ethical merits of our proposed study. Overall ethical approval was gained from the Sydney West Area Health Service Human Research Ethics Committee in 2009 (see appendix 2). Research Governance approval was then sought by the research team and granted by the Research Governance officers at Westmead Hospital and the Children’s Hospital at Westmead in Sydney. Ethical approval was ratified by the Human Research Ethics Committees at the University of Sydney, the University of Newcastle, and by our project partner CanTeen.

5.8 Validity and Reliability
The concepts of validity and reliability are contested within the context of qualitative research. However, some authors have suggested techniques to assist in the assessment of validity and reliability of qualitative data analysis [226, 234, 235]. I have used four techniques to enhance the validity and reliability of my findings. First, I ensured that my epistemological assumptions, my choice of methodology and my choice of methods were internally consistent. Second, I created audit trails through memo writing that show the genesis and development of my findings. Third, I discussed my developing categorical groups with my thesis supervisors and other investigators on this study. Fourth, I delivered regular presentations of my study findings to and received feedback from academic and clinical audiences. Finally, I have included verbatim quotes from the data in the findings chapters of this thesis to illustrate the connection between data and analysis.

5.9 Summary
This study used qualitative methods to study the experiences of young Australians who were growing up with cancer. I engaged participants in one or more conversational, semi-structured interviews that were designed to elicit their perspectives on the impact of cancer on their experience and social interactions. I conducted a thematic analysis of this interview data from a Symbolic Interactionist perspective because it provided me with a clear rationale for theorising young cancer survivors as actors within their usual social milieu. This in turn enabled me to focus my analysis on participants’ experiences of growing up in their
relationships with parents, peers, and new acquaintances during their period of illness and treatment as well as their period of remission and recovery.
Part III: Findings

Synopsis
Participants in this study experienced a period of crisis at the time of diagnosis and treatment. During this time, they were removed from their usual social worlds in order to be treated for their disease, and this disrupted their process of growing up. Some older participants returned to the care of their parents after living independently for a time, before their diagnosis.

After their crisis subsided, participants experienced a period of remission and recovery. Early in this period they re-entered their usual social worlds. This also disrupted their process of growing up. Participants were marked as different from their peers physically and socially, and as a consequence experienced heightened levels of attention from their peers.

As participants continued their process of growing up, their social worlds expanded. They met new acquaintances, formed new relationships, and had to manage information about their cancer experience in order to let others know that their cancer experience formed part of who they were. Cancer illness and treatment also disrupted the process of growing up during this period. At this time they made choices about disclosing their cancer history, and they negotiated the ways in which the ongoing effects of cancer would fit in with their new relationships.

Growing up combines the aspects of the human condition that Symbolic Interactionism seeks to unify – the biological, psychological, and the social. The aim of this thesis is to contribute to our understanding of the social impact of cancer on growing up. For this reason, Part III of this thesis is divided into three chapters, each dealing with a different relationship or set of relationships between participants and others. Chapter 6 focuses on participants’ relationships with their parents. Chapter 7 focuses on participants’ relationships with their peers. Chapter 8 focuses on participants’ interactions with new acquaintances and their development of new relationships of a romantic and/or sexual nature during their period of remission and recovery.

Participants
These findings are based on a thematic analysis of 49 interviews conducted with 27 young people aged between 16 and 29 years. Participants were aged between 10 and 22 years old at
the time of their diagnosis. Tables 7, 8, and 9 list all participants in this study by the developmental period in which they were diagnosed.

Table 7: Participants diagnosed in early adolescence (10 – 13 years old)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age at Diagnosis</th>
<th>Age at Interview</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erin</td>
<td>10</td>
<td>24</td>
<td>ALL</td>
</tr>
<tr>
<td>Jenny</td>
<td>10</td>
<td>16</td>
<td>Osteosarcoma</td>
</tr>
<tr>
<td>Dilshara</td>
<td>11</td>
<td>18</td>
<td>Pineal Gland Tumour</td>
</tr>
<tr>
<td>Kurt</td>
<td>11</td>
<td>17</td>
<td>ALL</td>
</tr>
<tr>
<td>Gary</td>
<td>13</td>
<td>23</td>
<td>Brain Tumour</td>
</tr>
<tr>
<td>Mahalya</td>
<td>13</td>
<td>22</td>
<td>AML</td>
</tr>
</tbody>
</table>

Table 8: Participants diagnosed in middle adolescence (14 – 17 years old)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age at Diagnosis</th>
<th>Age at 1st Interview</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alexis</td>
<td>14</td>
<td>16</td>
<td>ALL</td>
</tr>
<tr>
<td>Courtney</td>
<td>14</td>
<td>21</td>
<td>Hodgkin’s Lymphoma</td>
</tr>
<tr>
<td>Holly</td>
<td>14</td>
<td>23</td>
<td>Ewing’s Sarcoma</td>
</tr>
<tr>
<td>Mick</td>
<td>14</td>
<td>29</td>
<td>ALL</td>
</tr>
<tr>
<td>Rudi</td>
<td>14</td>
<td>21</td>
<td>Ewing’s Sarcoma</td>
</tr>
<tr>
<td>Talia</td>
<td>14</td>
<td>16</td>
<td>Ewing’s Sarcoma</td>
</tr>
<tr>
<td>Malcolm</td>
<td>15</td>
<td>17</td>
<td>Hodgkin’s Lymphoma</td>
</tr>
<tr>
<td>Sharni</td>
<td>15</td>
<td>20</td>
<td>AML</td>
</tr>
<tr>
<td>Yvonne</td>
<td>15</td>
<td>16</td>
<td>Hodgkin’s Lymphoma</td>
</tr>
<tr>
<td>Andrew</td>
<td>16</td>
<td>22</td>
<td>ALL</td>
</tr>
<tr>
<td>Bill</td>
<td>16</td>
<td>18</td>
<td>Osteosarcoma</td>
</tr>
<tr>
<td>Hendo</td>
<td>16</td>
<td>18</td>
<td>Testicular tumour</td>
</tr>
<tr>
<td>Lisa</td>
<td>17</td>
<td>20</td>
<td>Hodgkin’s Lymphoma</td>
</tr>
</tbody>
</table>
Table 9: Participants diagnosed in late adolescence or young adulthood (18 years and over)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age at Diagnosis</th>
<th>Age at Interview</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jo</td>
<td>18</td>
<td>20</td>
<td>Hodgkin’s Lymphoma</td>
</tr>
<tr>
<td>Mel</td>
<td>19</td>
<td>20</td>
<td>ALL</td>
</tr>
<tr>
<td>Roger</td>
<td>19</td>
<td>20</td>
<td>Medulloblastoma</td>
</tr>
<tr>
<td>Jack</td>
<td>21</td>
<td>22</td>
<td>Bowel cancer</td>
</tr>
<tr>
<td>Linda</td>
<td>21</td>
<td>22</td>
<td>Ovarian cancer</td>
</tr>
<tr>
<td>Syd</td>
<td>21</td>
<td>22</td>
<td>Testicular tumour</td>
</tr>
<tr>
<td>George</td>
<td>22</td>
<td>29</td>
<td>ALL</td>
</tr>
<tr>
<td>Alice</td>
<td>22</td>
<td>29</td>
<td>ALL</td>
</tr>
</tbody>
</table>

General Characteristics of the Study Sample
This study was based on interviews with a select, gender-balanced sample of young, mostly middle-class Australians who were diagnosed in different phases of adolescence and young adulthood with different types of cancer. Therefore, the participants in this study were all from similar socio-economic backgrounds.

All but two participants were from white, English-speaking backgrounds. This is likely due to the fact that all of the participant information packs were in English. Also, the invitation to create a self-portrait might have been culturally strange. The findings of this study therefore tell us little about the experience of cancer in young people from diverse ethnic groups.

Some participants participated in interviews years after their cancer illness and treatment had finished. This may have affected their recall of events. We do not know to what extent young people’s accounts were influenced by events and life experiences that they had during the intervening years.

I interviewed young people whose social worlds were relatively affluent and stable. The findings of this study therefore tell us little about the experiences of young people living in chaotic social situations during their illness and treatment or about young people whose situations deteriorated socially or economically after their period of treatment finished. All but one of the young people were full time students when they were diagnosed. Nineteen
were school students. These findings therefore say little about the experiences of young people who are employed (or unemployed).

Letters of invitation emphasised the creative arts component of the study. We are therefore likely to have recruited young people for whom participating in creative activities is appealing. Young people who find creative activities unappealing are unlikely to have volunteered.

The findings reported in the following chapters should therefore be interpreted in light of the particularities of the study population.

Chapter 6: “I have to cut the apron strings”: Relationships between Participants and their Parents

6.1 Synopsis
Young people demonstrate their transition to independence in the domain of relationships, and in different social settings. They do this by adopting culturally defined adult social roles, by asserting their autonomy to make decisions that affect their lives, and by taking responsibility for their decisions and actions [35]. The process of transition from dependent child to independent adult is neither predictable nor linear. Rather, the process can be accelerated or delayed by a range of life events including unemployment, breakdown of a romantic relationship, or acute onset of a health crisis [35]. Participants in this study had their transition disrupted by an acute health crisis.

All participants in this study diagnosed younger than 18 years of age lived with one or both parents at the time of their illness and treatment. Four participants diagnosed over the age of 18 years had moved away from the family home before they were diagnosed with cancer. All participants spoke of the important role their parents played during their period of illness and treatment.

One participant, George, provided a definition of “family” which I will use as a starting point to present my findings about relationships between participants and their parents:

... your family is people who’ll always be there for you no matter what and no matter how you treat them or what happens, they’re always there. And they’re the ones who will always
give you the true advice at the end, ... so if you ask them something, they’ll tell you really what they think. (George, 29 years old diagnosed at 22)

For George, family was defined by unlimited availability, unconditional acceptance, dependability, and honesty. This chapter focuses on the ways in which participants perceived their parents as “being there” for them during their period of illness and treatment and following that, during their period of remission and recovery. “Being there” influenced how participants experienced their transition to independence during these two periods of their cancer journey.

6.2 Parental relationships during the period of cancer illness and treatment

The experience of cancer can disrupt young peoples’ transition from childhood to adulthood by causing physical incapacity, by removing young people from their usual social worlds, and by placing them in unfamiliar social worlds during treatment. These disruptions had three possible outcomes for participants in different phases of their transition from childhood to adulthood. Some participants developed relationships with their parents that were more characteristic of those conducted by two adults than by a child and her parent. Some participants experienced stagnation in their transition to adulthood, and some experienced a reversal of their transition to adulthood.

Most participants in this study who were diagnosed in early adolescence (10 – 13 years old) did not talk about disruptions to their transition to adulthood because they had not achieved much independence from their parents before they were diagnosed with cancer. One who did talk about her experience spoke about how her relationship with her mother grew during her hospitalisation for cancer creating a relationship that was more equal than it had been before her diagnosis.

... when I was in the hospital and had to talk to my Mum and she just talks to me more about how she feels about my stepdad and coming from [her country] to Australia and how hard life is in [her country] ... so I could get a better perspective of that. So, it really changed the way that I saw my parents. (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

This example shows one of the ways in which cancer illness and treatment can accelerate the process of growing up during early adolescence. Hospitalisation had the potential to accelerate the transition to adulthood by creating a social space in which participants and their parents could conduct intimate conversations. One explanation for this is that more equal relationships were the outcome of participants and their parents spending a
concentrated period of time together during which they had the opportunity to achieve deeper levels of intimacy than they had experienced before diagnosis.

The transition to adulthood for middle adolescents (14 – 17 years old) is often characterised as a period of conflict between young people and their parents as young people begin to assert their autonomy and test the limits of what their parents find permissible [236]. Few participants diagnosed in middle adolescence spoke about continuing their transition to adulthood during their period of illness and treatment in this way. One participant who did (i.e. Holly), spoke about how she and her mother came into conflict as a direct result of the side effects of her treatment.

Actually they put me on the pain killer ENDONE, and I was having eight tablets a day, and it was a constant refill prescription, I could have them as long as I wanted. And I became very attached to them, and we realised what was happening and mum cut me off them. And so I was addicted to them basically, you couldn’t talk to me when I got up of a morning until I’d had them. And so I went from having eight a day to two a day. So we were going through that process, and I had to come over for a chemo, and it was maybe a week after mum had cut me off, and then I was a little monster. … I was really bitter towards her, I hated her for bringing me to [town] for the treatment, I told her I hated her and all these things…. It became very much a bit of a battle between me and Mum about getting up on time and getting in the car and it was just this ongoing fight with her. (Holly, 23 years old diagnosed at 14)

Holly and her mother had particular difficulty managing her treatment because Holly lived in a rural area and had to drive for several hours to her place of treatment. This was an additional complication to the one posed by her dependence on ENDONE.

All participants diagnosed in older adolescence and young adulthood spoke about how their transition to adulthood was effectively reversed during their cancer illness and treatment. The notion of reversal is consistent with a concept of the process of growing up as being linear. For example, a transition directed towards independence can be reversed and re-directed towards dependence. This reversal occurred when participants lost or yielded their independence during their period of illness and treatment.

Participants in older adolescence and young adulthood spoke about losing their independence when they needed their parents to care for them and when they moved back into the family home. At these times they resumed their old role of dependent child:

moving home was probably one of the hardest things to do as well.

… what was hard about it?
Losing all your independence. Even simple things like I love cooking and going to not cooking, or cooking for a whole family, which is harder and the bedroom I had made up for myself, now I’m back in my childhood room. (Mel, 20 years old diagnosed at 19)

Moving back into the family home disrupted the process of growing up by placing participants back in their childhood role as a recipient of the care of others. Moving back into one’s childhood bedroom was also a symbolic move back into the role of child within their family. Reflecting on how her role within her family had changed because of her cancer illness and treatment, Alice said:

I’ve become [my parents’] daughter again. I very much play the daughter role. So, yeah, I need to cut the apron strings again, I think. But they’re all very much my emotional support, my Mum is anyway. (Alice, 29 years old diagnosed at 22, relapsed at 23)

Alice’s quote illustrates how the reversal of participants’ transition to adulthood can be difficult and time consuming to resolve in the period of remission and recovery. She also intimates that resuming the transition to independence was a source of ambivalence for her.

Three of four participants who moved back into the family home when they were diagnosed moved from rented accommodation. One participant, Roger, moved home from his university residential accommodation.

Well, it’s a lot different from the transition of moving out of home to a home which you know you’re renting with a couple of friends, to a college where there’s 300 students, you’re socialising all the time, you’re never alone. And basically you’re given a room where food and everything is provided for you, so the transition isn’t terribly hard, but it is fairly different not living with your parents, and sort of being alone and doing things on your own. (Roger, 22 years old diagnosed at 19)

The experience of moving out of home differs for young people as they move into different social settings including rented accommodation, residential college, or “homelessness” as they travel and stay with friends. This highlights the variety of paths to independence for young people and the ways in which these paths deviate from a normal move out of the family home and into shared rental accommodation.

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14I will return to this point in section 6.4 which concerns participant’s relationships with their parents during their period of remission and recovery.
As participants diagnosed in older adolescence and young adulthood assumed the “sick role” [237], they ceded their decisional autonomy to their parents. For example, when Alice was diagnosed she immediately phoned her parents:

*I said, “I have to talk to dad,” because my dad ... would know exactly what to do, so I called him. He was very objective, he was very, “Okay this is what we’re going to do,” he didn't show any emotion but that's exactly what I needed, just someone to take charge.* (Alice, 29 years old diagnosed at 22, relapsed at 23)

Alice and Mel make explicit the reciprocity of parent-child relationships that is implied in George’s definition of family. Participants’ resumption of a dependent, child-like role enabled their parents to resume their old parental role. This perspective suggests that the goals of young people and their parents are reciprocal. It also suggests that participants played an active part in that process.

Reciprocity is central to performance of the sick role [237]. Sick role theory is framed by Parsons as a collection of rights and obligations and is based on the notion that “illness” is a form of social deviance. This collection of rights and responsibilities, therefore, aims to manage the consequences of the deviant behaviour and provide a mechanism for its resolution. The sick person has the right to exemption from their usual social responsibilities and from blame for their condition. They have the obligation to seek technically competent professional help in order to overcome their “social deviance” [237-239]. The doctor is obliged to reciprocate by applying her or his technical competency to facilitate the patients’ rapid recovery [237-239]. People who enter the sick role engage in a reciprocal process of gaining benefits in exchange for fulfilling certain obligations, such as seeking medical attention and complying with the treatment prescribed by the medical experts they consult. In sick role theory, medical experts respond to their patients’ request for treatment by applying their expertise to facilitate their rapid recovery. For participants in this study, the benefits of entering the sick role included being cared for by their parents and the obligations included compliance with treatment.

Moving home is more than a physical relocation. Moving home can symbolise young people taking a “place” back in the family – of relinquishing their new role as independent adult and taking on their old role of child to their parents. Mel’s proposed colonisation of her space in the family home was a way of resisting her old role when it was no longer relevant to her
sense of self after her treatment had finished. Alice used the phrase “cutting the apron strings” to indicate a similar type of resistance. They reflected a desire to re-establishment the independence they had enjoyed before their period of illness and treatment. I will describe this in more detail in section 6.4.

6.2.1 Parents resumed old parental roles, continued current roles, and adopted new roles during the period of illness and treatment

Participants yielded their decision making autonomy to their parents and enabled their parents to “be there” for them during their illness and treatment. “Being there” meant taking on parental roles, such as carer, comforter, encourager, and advocate – roles that had become obsolete as participants transitioned towards independence from middle adolescence onwards.

When parents resumed the role of carer, they assisted the participant in three ways. First, they provided assistance with activities of daily living:

_I got put in [the oncology ward] and the, ... occupational therapist, (OT), she came and because I had lost all use of my [hands] and I couldn’t pick up stuff and dad was feeding me and all that and [the OT] got me some hand aids so where you put your fork in because I couldn’t clench my fist._ (Alexis, 16 years old diagnosed at 14)

Second, they played a role in organising medical care:

_Well, my mum organised everything, which was fantastic. Because I’m not very renowned for my organisational skills. Um, she had all my medical appointments done ... They were just there, every step of the way. ... I wouldn’t have got past the first scan if mum hadn’t been there the whole time. And dad too. ... they did everything they could for me, absolutely everything._ (Jack, 21 years old diagnosed at 20)

Third, parents took responsibility for resolving problems that participants could not or did not want to address for themselves:

_... my parents especially are – were amazing, I was able to hand ball every problem that I had onto them, which with hindsight probably not the best thing because it was probably pretty stressful for them ... it’s been pretty stressful for my parents and to be here - them still together, is a great thing ... _ (Roger, 22 years old diagnosed at 19)

Mel (20 years old diagnosed at 19) also used the term “hand-ball” when she spoke about asking her father to tell other people of her diagnosis – a task that she said she did not want to do for herself. When participants spoke of “hand-balling” their problems to their parents they
demonstrated asking for help within the context of a dependent relationship. Mel and Roger provide examples of participants yielding their independence to their parents during their period of illness and treatment. They could do so with the reasonable expectation that their parents would respond to their requests by resuming their parental roles based on a history that they had done so in the past.

Participants received special treatment from their parents when parents comforted them in compensation for the discomfort of illness and treatment:

... my doctor said I’m one of the few people that have actually gained weight instead of losing it.... Because my diet, my mum says you can have whatever you want so I had junk food every night and stuff. (Bill, 18 years old diagnosed at 16)

Parents sometimes saw it as their role to encourage adherence to treatment:

My Dad was quite good with that in terms of when I was in hospital he’d … when I was well enough, he’d push me, just did it, go for a walk to the bathroom and down the corridor and it was a good to encourage me without being pushy or anything. Just helped me walk a bit further and stuff like that. (Mick, 29 years old diagnosed at 14)

The three roles of parenthood described above link with sick role theory in a way specific to adolescents and young adults. Illness has the potential to change relationships between any two people, for example, in the case of older adults when a spouse becomes the carer of his or her sick partner. However, in the case of adolescents and young adults, illness has the potential to reverse the process of transition to adulthood which was tenuous and partially complete in older adolescent and young adult participants in this study.

Parents also reportedly resumed the role of advocate.

This was the radiologist and the oncologist, but yeah so because the effects were, like I would’ve lost I think 20% IQ, I wouldn’t have grown any taller, I would’ve had much worse hearing damage, cataracts by the time I was 20 etc etc. So we were really tossing up whether to do it, given that my tumour was already gone. So we decided not to in the end and the doctors said, “You’re being irresponsible,” and all the rest. But thankfully - - - Did they say that to you or did they say that to your parents?

15 “Hand-balling” is an Australian Rules Football term. Australian Rules Football is the dominant code of football played where Mel, Roger, and other participants reside. Hand-balling in a football match is only possible between team mates in close proximity and is often effective as a defensive rather than an offensive strategy because it can enable defenders to evade opponents quickly and more safely than kicking the ball away. In other words, hand passing a ball is a safe way of getting out of trouble.
Oh they said that to my parents. I was quite sheltered from this like my parents didn’t want me to know too much because they thought it was, but yeah I did have a part in deciding what happens but, yeah. (Dilshara, 18 years old diagnosed at 11)

Participants were vulnerable in the health care system both because they were incapacitated by their illness and treatment and because they were in a state of transition to independence and were not in a position to assert their decision making autonomy and take full responsibility for their actions.

6.2.2 Parents continued current parental role of mentor
Few participants spoke about their parents providing mentorship for them while they were experiencing cancer illness and treatment. One who did said:

[Try, and if you fail, at least you’ve tried] that’s been the motto that me and my dad pretty much came up with as soon as I got sick was that, going back to uni, social life, every aspect of your life, like pretty much you sort of have to give it a go and if you fail, it doesn’t really matter, but at least you’ve tried. And if you apply that to your life, my dad said that most things will probably, hopefully work out for you. (Roger, 22 years old diagnosed at 19)

Young people in general who have maintained a close relationship with their parents seek advice from their parents about how to live their lives. Cancer illness and treatment does not necessarily disrupt this relationship but can provide a focus for ongoing interactions of “student” and “mentor”. In the second half of chapter 6 I will describe how participants and their parents changed the focus of their roles of student and mentor to continue participants’ transition to independence during their period of remission and recovery.

6.2.3 Parents assumed new role of companion
Participants also reported that their parents adopted the new role of companion in which parents shared information, thoughts, and feelings with participants about their own lives. This accelerated the development of a more equal relationship between participants and their parents. I have described this process earlier in this chapter using Mahalya’s example of her conversations with her mother about her mother’s migration to Australia. This development was common across all ages of participants. For example, Malcolm, who was diagnosed in middle adolescence said:

I spent every day with my mum last year ‘cause she had the baby and so we spent hours on end in chemo. She drove me everywhere, she everything, so [we are] really, really, close. (Malcolm, 17 years old diagnosed at 15)

Jo, who was diagnosed in older adolescence, said of her mother:

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I think our relationship is so, so much better since my cancer. Looking back in 2007 she was my mum but now she's my best friend … (Jo, 21 years old diagnosed at 18, relapsed at 20)

Friendship is a reciprocal relationship that is not usually used to describe a relationship between young people and their parents. Companionship during adolescence and young adulthood is normally sought with peers. However, the close physical proximity of participants and their parents during their illness and treatment and the intensity of emotion they experience could lead young people to regard their parents as friends.

6.2.4 Exceptional Case
Not all participants reported that their parents had resumed old roles of parenthood, continued their current roles, or adopted new roles during their period of illness and treatment. Erin spoke about her period of illness and treatment as a time when her parents did not continue some of their old roles or adopt new ones. Erin’s perspective was that her parents disagreed about whether to pursue conventional treatment for Erin’s cancer or to commence a regime of alternative therapy. This disagreement had a negative effect on Erin’s experience of cancer:

I felt like I was stuck in the middle, if I had chemo mum’s going to hate me. If I don’t have chemo dad’s going to hate me so I was just really stuck in the middle and they pretty much just left all of the decisions up to me. Being 10 I was like, “I don't know what to do,” 'cause I was stuck in the middle. I don’t want mum to hate me and I don’t want dad to hate me, what do I do? (Erin, 24 years old diagnosed at 10, relapsed at 15)

Erin’s transition to independence was accelerated by her cancer illness and treatment when she was forced to make decisions about her treatment that she was ill-equipped to make. Unlike participants who valued the accelerated development of their relationships with their parents, Erin experienced her accelerated transition to the independent role of autonomous decision maker as a negative outcome of her cancer illness and treatment. This type of accelerated development had adverse consequences for her relationships with her parents that were at odds with those described by other participants in this study.

6.3 Summary
In this section I have described participants’ experiences of changes to their relationships with their parents during their period of illness and treatment. I have described these changes in terms of participants’ transition from childhood to adulthood which included their transition from dependence to independence. Participants who were diagnosed in early adolescence, when they were still dependent on their parents, had little independence to lose.
Participants diagnosed in middle adolescence experienced a disruption to their transition to independence when their assertions of their decisional autonomy were over-ruled by their parents. Participants in older adolescence and young adulthood experienced a reversal of their transition to independence by being placed back in the care of their parents.

Participants valued the roles their parents reportedly performed during their illness and treatment. Participants reported that their parents resumed old roles of carer, comforter, encourager and advocate, continued their role as mentor, and adopted a new role of companion. Participants experienced an accelerated transition to adulthood because they developed a more equal relationship with their parents than they had conducted pre-diagnosis. At the same time, participants’ transition stalled or reversed when they lost or yielded some of the independence they had achieved to their parents during their period of illness and treatment.

6.4 Parental relationships during the period of remission and recovery
Participants entered a period of remission and recovery after they completed their treatment. This period incorporated participants’ transition to survivorship. Shepherd and Woodgate list eight defining attributes of cancer survivorship in adolescents and young adults of which the two most relevant to this section are the establishment of a “new normal” and the ongoing experience of “uncertainty” [168] (p. 112).

In this section I will describe how participants experienced the dual transitions from childhood to adulthood and from cancer patient to cancer survivor. Participants who were diagnosed in middle adolescence did not report that illness and treatment disrupted their transition to independence during their transition to survivorship. Participants who were diagnosed in late adolescence or early adulthood actively resumed the process of transition to independence during their period of remission and recovery. However, this process was complicated by their concurrent transition from cancer patient to cancer survivor.

6.4.1 Participants transition to cancer survivorship: establishing a new normal
Participants learnt that they could not return to “normal” during their transition to cancer survivorship:
I didn’t really go back to normal in many senses, so when I was diagnosed I thought, when I finished treatment I would be able to go back to the life I had before, and play sport and everything, but that was just one of the things that I couldn’t go back to.

(Jenny, 16 years old diagnosed at 10)

Having accepted that they could not return to normal, they were forced to revise their aspirations for the future. This was the period of transition in which cancer became “... a big part of my life but it’s not all who I am” (Mahalya 22 years old diagnosed at 13, relapsed at 18).

Participants who experienced their transition to survivorship in middle adolescence revised their aspirations and plans while they were still at school without having the opportunity to act on them in the short term:

I guess I’ve had a lot of thinking about my future, being year 11 this year and going into year 12 next year and I really want to go into the medical field, either do paediatric nursing or psychology ... I’m steering away from the active side and I’m going more for academic and I’ve realised all these things that I want to do .... I might want to do psychology, I might want to do nursing, I might ...

(Talia, 16 years old diagnosed at 14)

Future study and career symbolise transitions towards social and economic independence, and can facilitate young peoples’ departure from their family home and the broadening of their social networks. Participants who experienced their transition to survivorship in older adolescence and young adulthood acted on their revised aspirations and plans. However, they found that the process of revision was ongoing because the effects of their cancer illness and treatment continued to disrupt their plans:

The fact is I’ve changed my whole career path because I’ve had cancer and I’ve changed my whole future, like what I want to do in the future and the kind of person I want to be ... I’m doing nursing and I didn’t really consider “Oh yeah, I’m going to be with other people in my position” because I didn’t see, I didn’t remember all these things that I went through [until I attended clinical placement] ...

(Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Participants in older adolescence and young adulthood who experienced their transition to cancer survivor also experienced a disruption to their transition to independence.

6.4.2 Transition to survivorship: Uncertainty
According to Shepherd and Woodgate, adolescents and young adults who have survived cancer experience uncertainty largely because of the fear of recurrence that is common for
the survivors and their families [168] (p. 112). Participants in this study experienced uncertainty because they feared that their cancer would re-occur:

*There’s still a lot of mental things you have to deal with. Like when it does come close to a hospital appointment, what are my results going to be, am I going to be OK? I’m really scared.* (Linda, 21 years old diagnosed at 20)

However, participants also experienced uncertainty about their sense of self or who they had become as a result of their cancer experience. They described four ways of responding to this uncertainty. First, they responded fearfully:

*I feel like I don’t know anything I want, and that’s very different from this time last year. I was so focused on everything that I knew I wanted, and in my mind it was almost a certain thing. I had all these plans like; I was going to apply for the (internship) program, and do this and do that, and eventually do this, and it was like I had my life all planned out, and now nothing is certain. ... It scares the shit out of me really.* (Mel, 20 years old diagnosed at 19)

Second, they tried to take control of their situations:

*I like to have a plan now. I just want to know where I’m going and where my goal is because I don’t want any more nasty surprises on the way. Yeah, I’m a bit of a control freak in that way.* (Holly, 23 years old diagnosed at 14)

Third, they accepted their experience of uncertainty:

*I don’t know [who I am]. I’ll just say that ‘cause clearly I don’t know. Yeah, ‘cause I guess definitely before I had like a pride like ego, like “I know who I am, I know what I’m doing”, but you don’t always know what you are doing, and then maybe you don’t always know who you are, and that’s okay ...* (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Fourth, they ignored the uncertainty of their situation by keeping busy:

*To re-establish a normal life, I think I just threw myself back into everything that I used to do. Like studies – I completely filled my week with studies and volunteer work that I used to do before [cancer]. And just making sure my whole week is full of things to do, pretty much. And just keeping myself occupied and not trying to think about it, not reflect on it as much.* (Syd, 22 years old diagnosed at 21)

So far in this section I have described participants’ experience of transitioning to cancer survivorship. I will now link their experiences of survivorship with their ongoing experience of transition to independence from their parents. I have divided this section into two parts: participants interviewed in middle adolescence (14-17 years old), and participants interviewed in older adolescence or young adulthood (18 years old and beyond).
6.4.3 Participants interviewed in middle adolescence (14 – 17 years old)

A total of seven participants interviewed for this study were aged between 14 and 17 years at the time of their interview. These participants said little about their transition to adulthood with regard to their relationships with their parents compared to the twenty participants aged 18 years and older.

One participant, Malcolm, spoke about his relationship with his mother. He said that the close relationship they had developed during his illness and treatment continued during his period of remission and recovery:

... even now I tell my mum about every single aspect of my life. So I think I failed an exam this week so I told her that. I tell all my bits of my social life, I tell my friends’ secrets to my mum, we share absolutely everything now. Before it was, she’d ask me how my day was, I’d come home and say, “Ah,” but now it’s more like I’ll tell her everything. And I feel okay with that, I don’t feel any pressure between our relationship. (Malcolm, 17 years old diagnosed at 15)

This example suggests two things. On the one hand, it suggests that Malcolm’s transition to adulthood had stalled during his period of illness and treatment and remained so in his period of remission and recovery because a 17 year old would not normally tell his mother “everything” about his own social life and that of his friends. On the other hand, this example suggests a continuation of Malcolm’s accelerated social development by describing his practice of open and honest communication with his mother that characterise mature communication patterns between adults. What belies this explanation, however, is the absence in Malcolm’s report of the ways in which his mother reciprocated by telling him things about her own life. Malcolm’s experience therefore contrasts with that of Mahalya (see section 6.2).

Kurt spoke about his experience of the period of remission and recovery. He spoke of coming into conflict with his father when he tried to assert his autonomy over taking his medications:

... things just start off stupidly, like one night [my father said] “Take your meds.” I said, “In a sec.” “Take your meds now.” I said, “In a sec and if you keep asking me, I’m not going to do it.” And it went from there. [It was] an anti-depressant and that was it, pretty much. Which, it really doesn’t, something like that from what I understand doesn’t really matter if you take them 5 minutes or 10 minutes or I wanted to finish the page of the book I was reading. (Kurt, 17 years old diagnosed at 11)
Kurt was diagnosed with depression as a result of his cancer experience. Kurt’s example differs from Holly’s example of conflict with her mother (see section 6.2) in that Kurt was already in his period of recovery when what was at stake for him was not cancer remission and recovery but his effective control of the ongoing effects of cancer on his mental health.

Although participants interviewed in middle adolescence spoke about making their own decisions and asserting their autonomy over various aspects of their lives, they spoke only of achieving their independence as a goal to which they aspired rather than as a status they had achieved. Participants interviewed in older adolescence and young adulthood spoke in more detail than those in middle adolescence about achieving their independence.

6.4.4 Participants Interviewed in Older Adolescence and Young Adulthood (18 years and older)

Of the twenty participants who were interviewed in older adolescence or young adulthood, seven were interviewed less than three years after their diagnosis. Most of those seven participants had resumed their transition to independence by resuming the adult roles they had performed prior to and lost because of their cancer illness and treatment. For example, Jack moved out of his family home after his treatment was complete and back into the rented accommodation he had shared with his girlfriend and other friends prior to his diagnosis:

> And we lived together this year, I’m back up at Uni. ... So I went back up there and we’ve got a house with some other friends so she’s just helped me so much I feel that I owe her so much. I definitely see a future with [my girlfriend]. (Jack, 21 years old diagnosed at 20)

If moving back to the family home was symbolic of moving back into childhood roles of dependence on parents, then moving in with a romantic partner was symbolic of Jack’s assumption of a new adult role of romantic partner.

Some participants in older adolescence and young adulthood had never moved out of the family home before their diagnosis. Some said that their plans to do so had been delayed by their illness and treatment. For example, Jo described her detailed plans to move out of the family home. She experienced a delay in achieving her plans and this delay repeatedly placed her back into the role of child:

> ... but then the fact that my sister’s pregnant now too I'm getting kicked out of my room. I have to go back to sharing with my two younger sisters which is going to be stressful for me because, as I said, I'm doing uni next year and I'm going to be 21 next year and a 21 sharing with an 11 year old, it's a bit ... (Jo, 21 years old diagnosed at 18, relapsed at 20)
In this example, Jo’s sister, who was younger than Jo, was in the process of adopting the adult role of parent. Meanwhile, Jo was placed physically and metaphorically “with” the children. This example provides a contrast between the normal transition to adulthood of Jo’s sister with the reversal of Jo’s transition. Jo went on to provide an example of how the paradox of being both adult and child during her transition to adulthood resulted in both adult and childish behaviour within the one social setting:

I've always had a very so-so relationship with [my father]. He's very hard to get along with, but since I turned 18 it's gotten a lot better. We have our fights and our moments where he'll say I want you to move out ... but since my cancer especially since I've grown up heaps and realised that I need to grow up we've gotten along heaps well. I find if we are all together, if the family's altogether, fights tend to start. If the girls are home that's when I'll fight with the parents, but as soon as it's just me and the parents, like on a school day for example, we're fine as. We can have lunch and coffee and all that kind of stuff and joke around. It feels good and then the kids will come in and it will add a new dimension to it. Little fights will start and stresses will start, but you get over it. (Jo, 21 years old diagnosed at 18, relapsed at 20)

Jo’s story typifies the way in which participants’ transition to independence was delayed as a result of their cancer experience. It also describes how participants in older adolescence and young adulthood planned to resume their transition to independence when their treatment allowed. Finally, Jo exemplifies the uncertainty of being in transition from childhood to adulthood and how she was at once child and adult.

Participants also experienced tensions in their relationships with their parents when the old roles resumed during their period of illness and treatment became redundant during their period of remission and recovery:

How do you get on with your parents now?
We're really close, I have to say. Mum and I sometimes clash because we spend so much time together, but it's nothing big. It's more like, oh we've been with each other too much, let's get our own space. (Mel, 20 years old diagnosed at 19)

Participants described how their parents were “there” for them during their periods of illness and treatment as well as their period of remission and recovery. However, they valued their parents’ “being there” for them differently during each period. Conflict arose between participants and their parents during the period of remission and recovery if they spent too much time together.
Thirteen of twenty participants 18 years of age and older were interviewed more than three years after their diagnosis. Participants in this category experienced ongoing effects of their cancer illness and treatment. They described resuming their transition to independence. Their transition was accelerated and delayed, but also reversed when they experienced a second crisis.

Dilshara provided her own definition of “independence” that resonates with late modern Western conceptions of what independence means to individuals:

Well what's independence for you?
I don’t like relying on other people. I like to be self-sufficient and I don’t like to accept help from my family and that sort of thing. I like to do it myself and I get a lot of, I feel really empowered when I am. So I guess that's independence for me. (Dilshara, 18 years old diagnosed at 11)

A desire for self-sufficiency and its reciprocal dislike of reliance on the help of others challenges George’s model of “family” that I described at the beginning of this chapter. Dilshara’s definition provides a lens through which we can interpret the effects of cancer on participants’ transition to independence when they were interviewed in older adolescence or young adulthood.

6.5 Resuming the transition to independence
Participants resumed their transition to independence by challenging their parents’ perception of them as children. They challenged this perception by initiating conversations about how they felt:

How’s it going getting people to treat you like an adult?
Yeah, still a bit of a struggle. It’s mainly my Dad and my sister that still see me as a little kid. My sister and I had words a while ago. Just stupid little sister things that, because we’re both living back at home now, I guess they come to light a bit better. But I’ve talked to Dad and he acknowledges that he still treats me like a little kid. And that that’s his issue probably more than mine. He just said it was just a protectiveness. Yeah, that’s his way of coping with [my cancer], is just to be protective.

What’s it like hearing that point of view from him?
Oh, it’s interesting. I guess because he wasn’t around a lot when I was sick, he was working really long hours. So it’s always funny because Dad’s fairly reserved in what he says and does and things. So when you get him full of a bit of wine and sort of question him on why he does what he does, yeah, it was really interesting actually. It made me not take it so seriously now when he gets a bit protective and tells me what to do or whatever, I don’t take it as
personally now. I sort of just laugh it off and keep doing what I’m doing anyway. (Holly, 23 years old diagnosed at 14)

Young peoples’ transition to independence is often portrayed as a struggle. A struggle occurs when there is a stake worth fighting over. In the case of independence, the stake is control over a young persons’ life – including the power to make decisions on their own behalf, to act autonomously, and to take responsibility. This resonates with Dilshara’s definition of independence as something that makes her feel empowered when she does things for herself. Holly’s story reflects the idea of being empowered when she speaks of proactively questioning her father about why he treats her as a child when she wants to be seen as an adult.

Participants spoke of their struggle for independence as being complicated by the closeness they had developed with their parents during their period of illness and treatment. Some of these participants spoke in relational terms that mirror Gilligan’s concept of interdependence more than the concept of self-sufficiency [129]:

... they’re all very much my emotional support, my Mum is anyway. But also because, you know, as you grow older you actually realise your parents are quite nice people to hang out with. You know, they’re your parents. You spend that much time with them. A lot of your values are the same, and I get on very well with them. So I’ll miss them.... So I have to, certainly, stand on my own two feet before they pop off. (Alice, 29 years old diagnosed at 22, relapsed at 23)

Alice reiterated that one of the roles played by parents for participants during their crisis is that of companion. She provided an example of how participants continued to see their parents as companions or friends in their period of remission and recovery. This perspective complicated their conceptions of what was involved in becoming independent.

6.5.1 Accelerated transition to independence
As was the case for participants during their period of cancer illness and treatment, participants in older adolescence and young adulthood experienced accelerated transition towards independence. Few participants spoke about this. One who did was Courtney who described taking responsibility for her own responses to her cancer experience by protecting her parents during her period of remission and recovery:

I don’t want to talk to my parents about [my cancer experience], even though mum and dad are, I’m still really close to them, they’re willing to talk about it and they’re happy to talk. I
Courtney described her self-sufficiency in managing the ongoing effects of her cancer experience. This demonstrates one feature of the transition to adulthood – a concern for the interests of others.

6.5.2 Delayed transition to independence
The ongoing effects of their cancer illness and treatment prevented older adolescents and young adults from resuming their transition to independence. Participants experienced ongoing physical incapacity that kept them dependent on their parents for physical support. For example, Gary’s cognitive function remained impaired as a result of his treatment for a brain tumour:

... my mum’s, she pretty much takes over all the medical appointments and things like that. ... my Mum sort of looks after all the medical things... (Gary, 21 years old diagnosed at 16)

Gary was gradually resuming his transition to independence by the time of his second interview for this study with the aid of an electronic organiser that his mother had bought for him and that he was learning to use. His transition remained very slow however, because of the level of cognitive impairment he experienced.

Participants also experienced a loss of self-confidence as a result of their cancer illness and treatment which delayed their transition to independence. For example, George had never moved out of his family home:

I lack, sort of confidence that I had before I got sick, I’ve become more introverted and I’ve noticed that in myself and my parents have noted that, you don’t go out as much. (George, 29 years old diagnosed at 22)

This partly explained why George remained living in the family home more than three years after his diagnosis:

... mum still runs around like crazy. Does my lunch, does my bed, does my washing ‘cause ah, I just sometimes I don’t have time to do anything so, like even ‘till now my mum puts up with my rubbish [laughs]. ... at the moment it’s my preference [to live at home]... if I like to move out I can move out and they wouldn’t say much about it. But I think I need to be in an environment at least where I’m with people I know and you also feel safe with family so, yeah, it’s my preference at the moment and like I told you, it’s easy as well you know, things
are getting done that otherwise if I had to do myself, I don’t know if they’d get done [laughs]. (George, 29 years old diagnosed at 22)

George and Gary both described being dependent on their parents in ways that can be described as infantilising in a similar ways to their experience of illness and treatment. What these examples highlight are some of the ways in which illness and treatment delayed participants’ transition to independence.

6.5.3 Reversed transition to independence
Participants reported that their transition to independence was reversed for two reasons. First, participants who relapsed experienced a reversal of their transition to independence similar to that reported by participants during their first experience of illness and treatment (see section 6.2). Second, as participants transitioned through their period of remission and recovery, some were affected by a second crisis that reversed their transition to independence in the same way cancer illness and treatment had done. For example, Sharni became pregnant at 18 years old:

... I really didn’t want to tell [my parents] because it was just the most frightening thing in the world and even though I’d had the [cancer], I was more scared about telling them that I was pregnant [laugh]. But when I told [mum] she just laughed at me and she goes, “You’re just a chip off the old block,” ‘cause I was about exactly the same age she was [when she first became pregnant] and she just said, “Are you going to keep it or what,” and I said, “Well I’d like to keep, I’d like to keep the baby considering I didn’t think I could fall pregnant,” and all I had to do was check with my doctors in [the hospital] that there was going to be no side effects to me being pregnant and nothing that was going to happen to the baby because I’ve had the chemo and after I got the clear that I could actually go ahead with the pregnancy, that’s when I said, “Well yeah, I’ll keep it then.” (Sharni, 20 years old diagnosed at 15)

Two aspects of Sharni’s experience stand out as being relevant to young people more generally. First, when she took the frightening step of telling her mother about her pregnancy, Sharni spoke of interacting with her mother as an equal rather than as parent and child. Sharni’s mother reacted to the news that Sharni was pregnant by helping her to make autonomous decisions, to act on those decisions, and to take responsibility for their consequences. This perspective was affirmed when Sharni prepared for her role as parent by seeking medical advice about the possible threats of her cancer history to her pregnancy and by her decision to continue with her pregnancy and to become a mother. Sharni went on to describe how her mother was “there” for her during her pregnancy as she had been during Sharni’s cancer illness and treatment.


6.6 Summary
In this chapter I have argued that participants in this study experienced a paradox related to the tempo of their transition to adulthood during their period of illness and treatment. The paradox was that their transition to adulthood was accelerated in some ways while being delayed or reversed in others. Their accelerated transition meant that they developed a more equal and more adult relationship with their parents than they had experienced prior to diagnosis. Their illness and treatment also meant that they resumed old childhood roles and that their parents resumed old parental roles of dependability when participants were physically incapacitated. The effect of this was most important to participants in older adolescence and young adulthood partly because they moved back to the family home and partly because of the care they needed from their parents.

During their period of remission and recovery, participants engaged in dual transitions to both independence and cancer survivorship. Their illness and treatment had ongoing effects on their two transitions during this period and some found resuming their transition to independence easier than others.

The transition to survivorship occurred in their broader social worlds as well as in their relationships with their parents. In the following chapter I will describe participants’ experiences of relationships with their peers during their period of remission and recovery.

Chapter 7: “I didn’t want to be the person who they thought I was”: Dislocation from one’s usual social worlds

7.1 Synopsis
As a result of their illness and treatment, participants in this study were temporarily removed from their usual social worlds, for example, school, university, and sporting clubs, and placed in the unusual social world of the hospital. In chapter 6 I described participant’s interactions with their parents while they were hospitalised. As the crisis of illness and treatment receded into the past, participants’ dependence on their parents for support diminished and they began to re-engage with their friends and peers. Engagement with peers is a normal part of growing up through adolescence. This chapter focuses on how the impact of cancer illness and treatment affected relationships between participants and their peers when they returned to their usual social worlds.
“Social worlds” have been defined as groups with shared commitments to certain activities, sharing resources of many kinds to achieve their goals, and building shared ideologies about how to go about their business [240] (p. 45-46). This chapter is less concerned with organised, collective social action than with the interaction between participants and specific other individuals. For this reason, by “social worlds” I simply mean participants’ social networks and the social settings they inhabit. A social world therefore refers to both a physical space and to the social interactions conducted within it.

Participants’ experiences during their period of separation from their usual social worlds changed their bodily appearance and function as well as their values and priorities in life. When their treatment and recovery allowed, the participants returned to some of their usual social worlds and were again subject to the formal institutional rules and group norms that operated within them.

7.2 Failure to return to sports participation
Fourteen of the twenty-seven participants said that they participated in sport before they were diagnosed. Some experienced bodily changes that stopped them returning to their sporting activities. This in turn prevented them from returning to that particular social world:

... well the only reason that sport has really not featured in this part [of my life post illness and treatment] is because of the side-effect I received from the treatment, which is avascular necrosis... it pretty much means that the blood supply to my knees is gone, so it’s dead bone. So I literally can’t do any sport, which is tough because if I could have anything in the world it would be to go and play soccer. (Andrew, 22 years old diagnosed at 16)

The symptoms of avascular necrosis include pain and functional limitation. Several participants who experienced this condition and who had been active sportspeople before their treatment excluded themselves from their sporting activities during their period of remission and recovery.16

Some participants who experienced their illness and treatment in middle adolescence sought to return to the sporting field during their period of remission and recovery and to compete with their team mates once more:

16 I will describe in section 7.3.3 how such symptoms resemble the symptoms of ageing.
I tried to play netball in about Year 11. And I played one game and it was, for a no contact sport, there was a lot of elbows being dug into my hip, knowing it was my weak area. And, actually the netball committee came up to me after and they said, “Is this something you’re deadset, you really want to do? Play netball?” And I was like, oh, I was just doing it for a bit of fun. They were terrified I’d get hurt and through them their insurance didn’t cover me. So I was pretty much asked to go and not come back. Not in a nasty way. I saw it from their point of view, I found it quite funny. And I went home limping. So, I thought it’s not really for me anyway. But I still enjoy watching sport and whatever, but I know I can’t do it. I know that limitation, I know it hurts. (Holly, 23 years old diagnosed at 14)

Targeting an opponent’s weakness is a norm of competitive sport and participants’ spoke of potential physical weaknesses – for example, pain and fatigue – that could be exploited by sporting opponents. However, Holly provided an example of how sporting clubs seek to preserve their competitiveness by excluding physically “weak” team members.

7.3 Having trouble fitting back in
Participants experienced difficulty fitting back into their usual social worlds because they did not conform to group norms of attendance, achievement, and appearance. They had trouble fitting back in when they successfully passed as normal and their peers contested the “special treatment” they were receiving.

7.3.1 Norms of Attendance
The period of acute illness and hospitalisation gradually gave way to a period of remission and recovery during which participants attended hospital as well as their usual social worlds intermittently. Participants diagnosed in early and middle adolescence spoke of their experience of returning to school when their treatment allowed. School attendance is a normal part of growing up for adolescents in Australia and school attendance is legally mandated up to the age of 17 years in both New South Wales and Victoria. Full-time attendance at school is required by formal institutional rules. It is also a strong social expectation or norm. Institutional rules allow young people to be absent from school on the grounds of illness.

When they were unable to attend school, participants missed out on the daily activities undertaken by their friends and peers and this hampered their attempts to fit back into their usual social worlds:

I wouldn’t say I'm an outsider, I was an outsider at the time, but if you have been missing for three weeks you missed what happened in those 15 days of school. (Rudi, 21 years old diagnosed at 14)
All participants who returned to school when their cancer experience allowed did so on a part-time basis. Return to school on a part-time basis was gradual and began with a couple of periods per day or a few days per week. Unusual patterns of attendance could persist for months or years:

_I had a year and a half off school. And I came back half way through year nine and I was still, I mean I only came back one or two periods a day because that’s all I could manage …_ (Talia, 16 years old diagnosed at 14)

Participants who experienced their crisis in early or middle adolescence reported that a central reason for returning to school was to return to “normal” by reintegrating themselves into their friendship and peer groups:

_I think [returning to school] was good because it was a sense of routine and normality again …_ (Jenny, 16 years old diagnosed at 10)

Part of this process was to find ways to “fit in” to their usual social worlds:

_I didn’t let myself adjust to the changes that had happened and I tried to just fit back in and go back to school. I went, I got out of hospital on the 11th, we travelled home and I went back to school on the 13th and I just went back as normal, trying to work, trying to catch up on everything that I’d just missed for the last year and trying to do all of that and it just was getting really hard and like I tried to just fit in with my friends the way I used to …_ (Sharni, 20 years old diagnosed at 15)

As well as being allowed by formal institutional rules, returning to school is consistent with CanTeen’s advice to young people; that going to school promotes a sense of normality.

_When you are having chemo or radiation and are feeling sick, you will not always be able to keep up with what’s going on at school. It is not just school work you will miss out on, but also the contact with friends and involvement in different school activities … Maintaining a sense of normality by going to school as much as possible can help you get through your cancer experience. [241]._

However, returning to school was not the same as returning to normal because participants’ cancer illness and treatment had altered their attendance patterns and their ability to perform academically. Peers reportedly contested participants’ entitlement to attend school on a part-time basis:

_One of the kids said, “Oh Talia is not in our class anymore, you know, she’s gone.” Pretty much just bluntly said that I wasn’t part of the class because I hadn’t been there for ages and it wasn’t fair that I could just pop in and out how I liked. So I guess he was jealous in a way_
and now him and I, we had maths this year together, and he was talking to me like it was nothing. (Talia, 16 years old diagnosed at 14)

One way of explaining why peers contested participants’ part-time attendance at school is with reference to Parsons’ sick role theory [237]. The sick role proposes a dichotomy between sick and well. When people are sick they are entitled to special consideration, such as part-time rather than full-time school attendance. Young cancer survivors occupy a liminal space [213] in which they are “between” sick and well. The school rules apparently accommodated their liminal state more flexibly than did the social norms upheld by their peers.

Part-time attendance at TAFE and university is a more normal pattern of attendance than it is at school. Thus, older adolescent and young adult participants who returned to university or TAFE did not report that their part-time attendance attracted attention from their friends and peers. This suggests that full time school attendance for middle adolescents is strongly normative and that deviation from the norm leads participants to experience difficulty fitting back into the social setting of school.

7.3.2 Norms of Achievement
Participants had difficulty fitting back into their usual social worlds when they flouted norms of achievement. Schools, TAFE, university and sporting clubs are governed by norms of achievement and these institutional norms strongly influence social norms. During their period of separation from their usual social worlds, all participants experienced a shift in values, for example, the importance they attached to their education or their new willingness to help other people. Of those who spoke about this shift in values in relation to school, some said they attached more importance and some said they attached less importance to their education after their cancer illness and treatment.

Those who came to attach more importance to their education said that they tried harder at school and achieved results at a higher level than they had before their cancer illness and treatment. Their peers reportedly noticed this:

_I think for the first few years [after my crisis] I felt that my education performance was just a lot more important to me and I worked a lot harder paying attention in class. That was the biggest thing for me. Just being more of a listener in class because I used to get just zero marks or just not even go to school and that ... was a very big difference and all my friends_
asked me if I was taking brain steroids because just no one could believe that I had changed so much. (Mahala, 22 years old diagnosed at 13, relapsed at 18)

Those who came to attach less importance to their education said that they did not try as hard at school as they had prior to their diagnosis and they were indifferent to their level of achievement. This made it harder for them to fit back into the school setting because they did not conform to either social or institutional norms:

... it’s funny when you see that, everybody pretty much does have a new perspective in life after going through something like that because, I mean going through a near death experience, you think, “Shit, I really only do have one life, I should, you know, I should enjoy it and I should get out there.” ... I’m enjoying life a hell of a lot more than I was and I’ve learnt that school isn’t everything in life. (Talia, 16 years old diagnosed at 14)

Those who returned to school spoke of being given ‘special treatment’ by teachers who reportedly did not expect participants’ work to reach the same standards that were expected of their peers:

... the teachers still let me slack off a bit ... well they didn’t really let me slack off, but they gave me leniency of my assignments and stuff. (Malcolm, 17 years old diagnosed at 15)

Participants also reported that teachers gave them special treatment at the time of their exams to encourage their higher achievement:

Some of the insensitive things they would say, obviously not on purpose; like for example the School Certificate I received provisions for the exam, which weren't really much, just a glass of water and a separate room, which really probably disadvantaged me more than anything. But the thing is that people, some of them, were saying, "Oh, I should shave my head to get that!" And I'm thinking it's a bit insensitive, as in it's not just that I'm bald it's a lot more that I'm going through. (Rudi, 21 years old diagnosed at 14)

Participants did not comment on their peers’ response to them receiving academic leniency, but their peers did reportedly contest their entitlement to special provisions at exam times probably because being given a private room at exam time was a more visible manifestation of ‘special treatment’.

University students were given ‘special treatment’ insofar as they were given more time to complete their studies:

Oh, I was in my final year [of my undergraduate degree when I was diagnosed]. In my final year so I had to stop that. Come back for treatment. Took a year off, then went back in 2003,
yeah and finished my Degree. I had maybe four or five subjects left. I was able to complete them over the course of the year. (George, 29 years old diagnosed at 22)

They did not, however, report being afforded any concessions in terms of the level of achievement required of them to complete their course. As I will describe in section 7.4, this delayed participants’ completion of their studies but did not cause difficulty for them when trying to fit back with their peers at university.

7.3.3 Norms of Appearance
Participants attracted heightened levels of attention when they returned to their usual social worlds. This attention took two different forms; stigmatisation and overweening niceness. Both of these kinds of response contributed to the experience of living in a paradox where participants were treated as different for both undesirable and desirable reasons. Importantly, participants’ reports highlighted how their peers responded to their differences rather than their similarities.

7.3.3.1 Stigma
Participants experienced heightened levels of attention as stigmatising when their appearance was deliberately ridiculed:

We were in a class that he was actually teaching and he was teasing me about losing my hair and he was saying, “What about your armpit hair? I won’t ask you about other stuff.” He was referring to that sort of thing. He made me the butt of his joke which I didn’t appreciate. ... I would have preferred him to take it seriously. (Rudi, 21 years old diagnosed at 14)

This example provided a contrast with those who spoke of receiving special consideration from teachers because of their cancer illness and treatment when they flouted norms of achievement.

Participants’ altered appearance could also attract attention from teachers inadvertently:

I did have one incident at school when I did go back and I had my beanie on ‘cause I didn’t have hair and all the teachers had been told that there would be a girl walking around with a blue beanie and that she’s allowed to. During class change overs this one time, a teacher did walk past and whip it off and I just went into the nearest room that I could which happened to be a science room. Lucky there wasn’t a class in there, like a double period or anything, and I just cried and she came back and she felt awful. (Erin, 24 years old diagnosed at 10)

This example suggests that institutional rules governing dress were flexible for young cancer survivors but that the social norm of appearance overwhelmed that flexibility in the usual course of social interaction within the school corridors. Whether young cancer survivors
chose to go bald or wear a non-regulation head covering, their appearance marks them as different to their peers in a stigmatising way. This can result in difficulty fitting back in to their usual social worlds:

And then there was another boy that he liked me. He made it very obvious that he liked me before I left, and then when I walked up to him, when I first came back to school, kind of, as a support thing, because I ... it was a big grade. There was like 250 kids in our grade. So I went up to him, because I knew him, and he just said, “What the fuck, who are you? Get away. Like I don’t even know you.” He said that, he goes like, “Who the fuck are you? I don’t know you,” or something like that. (Courtney, 21 years old diagnosed at 14)

Courtney’s example illustrates the general norms of appearance at school and the specific norms of appearance that apply to adolescent girls. Courtney had returned to school bald and overweight as a result of her treatment for cancer. One explanation for her friend’s hostility is that he was offended by her “unattractive” appearance as suggested by his “non-recognition” of her. However, norms of appearance amongst young women were also the source of difficulty fitting back in for participants who experienced their crisis in young adulthood:

One of my friends just keeps talking about her hair and her hair straightener and, “I can’t leave the house if my hair’s not straight and my hair straightener’s broken, so I can’t leave the house.” And just things like that. I don’t know, I guess, they probably weren’t even thinking about how I feel about that, but I actually got really upset and thinking, well, I don’t even have any hair so how could you just say that to me? You know how much I miss my hair. (Linda, 22 years old diagnosed at 21)

Participants whose appearance drew adverse attention had difficulty fitting back into their usual social worlds. However, participants whose altered appearance was ignored also had difficulty fitting back into their usual social worlds. In both cases, participants occupied a social space that was inconsistent with their pre-diagnosis “normal” way of being. They resisted being positioned as cancer survivor by ignoring stigma or treating it as humorous:

... people would just pass snide comments like, “Oh, don’t go near her, she’s the cancer girl, she’s contagious,” you know? So I played along with it, I mean, I was like, “Oh yeah, better not come near me, I might touch you and you might get cancer,” you know, I thought it was funny ... (Talia, 16 years old diagnosed at 14)

7.3.3.2 Overweening niceness
Participants described how peers who they had not known well before their diagnosis responded to them with overweening niceness when they returned to their usual social worlds:
... a lot of people who weren’t my friends tried to be my friend. ... everyone was really overly nice, even if they’d never spoken to me before. (Jenny, 16 years old diagnosed at 10)

School students reported increased levels of attention generally:

*I remember there was a hype about me being sick for some reason. I became kind of like a superstar for having cancer. ... when I was 13 ... I came back to school ... and then everyone followed me around. I mean like everyone, like lots of people followed me around.* (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Participants’ returning to social worlds other than school also received heightened attention. Jo, for example, spoke about her return to the nightclub she had frequented before her cancer illness and treatment:

*I just got rid of the wig and I went to the club bald and I think everyone appreciated my honesty more. The fact that I was out there, and so many strangers would rock up to me, and I got a few lesbian comments here and there like are you a lesbian or whatever? No I have cancer but apart from that I had strangers just walk up to me and be like good on you for being out and having a drink and you look awesome because I’d be dancing and all that kind of stuff and they’d be you’re a real hero dancing and all that kind of stuff and you have cancer. Self-esteem wise it I helped heaps.* (Jo, 21 years old diagnosed at 18, relapsed at 20)

When a stranger enters our presence, it is her physical attributes that we use to categorise her. Our ensuing interactions with the person are then based upon the categorical judgments we make [242] (p.3). Jo provided an example of how people at her club trialled possible categorisations of her – such as “lesbian” – in order to determine how to interact with her. Jo’s quote suggests that she was out of place in the context of a night club and that other club patrons attempted to account for her appearance in order for her to be properly “located” within the social world of the club. Jo’s physical appearance at the club also challenged norms of feminine beauty.

Physical appearance is especially important in social worlds where young people go primarily for recreation, to meet with friends, and where there is a high likelihood of meeting potential romantic and/or sexual partners. One consequence of being welcomed into such places was to boost self-esteem. However, the special attention reportedly received by participants in social worlds other than school echoed the ways in which participants reported being out of place with peers upon their return to school.

For some participants diagnosed in older adolescence and young adulthood, overweening niceness meant being positioned as “inspirational” by other people. I described above Jo’s
experience of being positioned as a “hero” by other club patrons who she did not know and how that type of attention she said increased her self-esteem. This resonates with the acceptance George expressed about being positioned as an inspiration by his friends:

I have a couple of mates who have never been through something like this and they see my energy and see I do my job, I do my job well. I get up every morning no complaints and they go, “you’re an inspiration because somebody else would’ve just done nothing, stayed indoors but you just continue on with life and yeah you’re an inspiration to me and any tiny inspiration at work I think of you and I get this burst of energy.” (George, 29 years old diagnosed at 22)

Not all participants welcomed being positioned as an inspiration. For example, Mahalya’s objection to being positioned as an inspiration was an objection to being feted for simply fulfilling her responsibility as a sick person [237]:

... and then there’s those people who refer to you as the inspiration. Oh, I hated that [laugh]. I hate that. Like they, just ‘cause you’re, yeah I’m sick, I didn’t do anything. ... I’m just still alive. What about those people who died from cancer. It’s not their fault. Like it’s weird to refer to them as an inspiration as I just think, “What did I do?” I didn’t do anything, I’m just trying to live [laugh]. Yeah, that was really annoying. A lot of teachers say that, “You’re such an inspiration.” You’re such a fighter. All those things, it’s really clichéd and it doesn’t make sense because you had nothing else to do. (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Some participants chose to resist being positioned as a cancer survivor by embracing overweening niceness and using the attention for their own benefit. For example, Alice was feted by hospital public relations staff and had her story told in a television documentary:

I was a bit of a darling in the hospital because I was the young patient on the ward. ... [after treatment finished] everyone was saying how well I looked. I was getting all this positive feedback and then I was approached ... to do a documentary and as a result of [that] everywhere I went, shopping centres, hospital, pretty much everywhere I went people would recognise me. I’d go shopping and I’d get people coming up to me giving me a hug. Suddenly, going from being in hospital, sick person, being in the same room for months with very little contact with the outside world to strangers coming up to you like they’ve known you for years and giving you big hugs and saying, “Oh you look wonderful. I saw [you on TV] we were in tears,” and emails. ... So there was a lot of attention all of a sudden ... Invitations to speak publically, yeah. ... So I became the success story, so I went to photographers and like they did all glamour shots of a sick person [laugh]. I didn’t look very sick at that stage but my hairs never grown back ... So I was still wearing a scarf and I think that was marketable. The fact that my hair has never grown back is very marketable. (Alice, 29 years old diagnosed at 22, relapsed at 23).

Mahalya was a painter and a cancer charity arranged for an exhibition of her work to promote her career and to raise funds:
[The cancer charity] work in the [Hospital] and they do stuff in the oncology ward so they funded my exhibition, my first solo exhibition and this painter that I really loved came and opened it for me. (Mahalya, 22 years old diagnosed at 13, relapsed at 18).

Ultimately, however, Mahalya and other participants experienced overweening niceness as perplexing because of its transience:

... it’s not like there were any new friendships from you, you know. Any new bridges were built, it just goes back to the way it used to. So what does that mean? Yeah, it makes you think that it was, you are just a novelty, entertainment for people that have obviously very boring lives [laugh]. (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Others treated those who displayed overweening niceness with suspicion:

I had a benefit night held for me at the start of this year. Money was raised and bands played and all that kind of stuff. I’m friends with these bands so because of my connections to the bands [some people] thought ‘we can hang out with Jo because we can get into gigs’ ... So, that's what I felt like. I was being used almost. I don't really talk to them now. I've cut myself off from them because I've realised I don't need them in my life. It hurts a bit at the same time. (Jo, 21 years old diagnosed at 18 relapsed at 20)

7.3.4 Passing as normal

So far in this chapter I have described the ways in which participants had difficulty fitting back into their usual social worlds because they flouted norms of attendance, achievement, and appearance. As Mahalya said:

Maybe people are really afraid to stand out. I don’t like standing out. Like, it’s cool to be a little bit different but when you’re like stark raging different it’s yeah [laugh]. (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Norms of attendance, achievement, and appearance included institutional rules and social expectations. Participants spoke about returning to their usual social worlds as a way of returning to normal and I have suggested that this goal was unachievable. In seeking to return to normal, participants also attempted to pass as normal [242] by masking the ongoing effects of their cancer illness and treatment when they attended school:

[My friends] didn’t really know how to cope. I kind of masked it all with humour and like the losing the hair, all that kind of stuff, was really terrifying and I masked it with humour. And I guess I masked it too much because I don’t think they understood how hard it was for me going through what I was going through and one of my friends sort of said to me, “Well, why are you coming to school if you’re not going to try? It’s just a waste of time.” It just hit home that they really didn’t understand what I was going through. ... they didn’t understand, they tried but they just couldn’t ... (Lisa, 20 years old diagnosed at 17)
Misunderstandings between participants and their friends contributed to participants’ experiences of difficulty fitting back in. One of our strategies for presenting ourselves in every-day situations, such as school, is to “stage-manage” other people’s impressions of us [243]. One way of doing this is to “mask”, or hide, what is really going on in our lives from other people. Lisa suggested that adopting the strategy of masking was one way that young cancer survivors stage-managed the impression they made on their friends and peers upon their return to school. This represents a way of trying to fit back in by “passing” as normal [242].

Some participants who successfully passed as normal found the inattention of their friends as difficult to manage as stigma or overweening niceness:

... at school it could be either the two extremes, people would really notice me and would really stare and would really pass comments and spread rumours. But then there was also this other thing where when I was with my friends the cancer was kind of invisible, which therefore made part of me invisible (Talia, 16 years old diagnosed at 14)

One of the challenges of passing as normal at school was that school staff often drew attention to the participants’ differences before they returned:

So by the time I got back to school I went into the office to sign in and then the principal and my year advisor and a counsellor were already there waiting for me and I thought what? And then in another room was all my close friends just sitting there waiting for me and then my year advisor thought is it alright if we tell the grade ’cause we were a close grade, so I said yeah that’s fine ’cause it beats people just talking and things flying around. (Bill, 18 years old diagnosed at 16)

When peers accepted the impression of normality at face value, they tended to contest a young person’s entitlement to any ‘special treatment’ given to her by their institution on the grounds that participants were not sick, and this was a source of tension in peer relationships.

In this section I have described how participants reported difficulty fitting back in to their usual social worlds. They often felt “out of place” upon their return. They had difficulty conforming to normative expectations of attendance, achievement, and physical appearance. In the next section I will describe how participants also engaged in their transition from adolescence to young adulthood at a different tempo from their friends and peers. This different rate of transition placed them on a different life schedule to their friends and peers and can be described as being “out of step”.

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7.4 Being Out of Step
A cohort is a peer group who inhabit the same social settings and who transition through life at the same time. Sometimes they are referred to as a generation, as in “Generation Y” [32]. Young people are commonly grouped according to age and gender, for example, at school and in sporting teams. Socially significant events in this temporal transition can be marked by special rituals or rites of passage [244]. However, young people also experience this transition as an accumulation of seemingly trivial everyday interactions that contribute to the development of a sense of life experience shared with their cohort. On this basis, cancer illness and treatment marked participants as different from their peers in two ways that affected the pace of development. They experienced transitions that their peers did not and they missed out on experiences that their peers shared such as events that mark rites of passage. This resulted in participants feeling out of step with their peers by falling behind them in some areas of life and leaping ahead of them in others.

7.4.1 Being Left Behind and Missing Out
In the first half of this chapter I described how participants attended school on a part-time basis and I suggested that this could result in them missing out on the accumulation of seemingly trivial everyday events that contribute to their development of a shared sense of life experience. Middle adolescence is also a time of life when a cluster of “rites of passage” take place. Participants were sometimes excluded from these. Rites of passage are the rituals, symbols, and activities that mark a status passage from membership of one social category to membership of another. In this study, the relevant rites mark a transition from adolescence to young adulthood. Participants diagnosed in early or mid-adolescence progressed through school with their cohorts year by year. They did, however miss out on participating in some events that mark rites of passage:

*I was missing out on rites of passage, going through year 12 and stuff with my friends and everyone hates doing HSC but I really wanted to do the HSC [laugh]. I did still do it but I wanted to do it with everyone else in the hall and the whole process of going through panicking with your friends outside, just before, yeah. I missed out on those.* (Mahalya, 22 years old diagnosed at 13, relapsed at18)

Rites of passage engaged in collectively provide a source of common memory that can provide a focal point for future interactions. Those who are excluded from engaging in a particular rite of passage for any reason are automatically excluded from that future interaction. They are therefore reminded that they are “out of step” with their cohort. Being a
member of a cohort at any time of life provides individuals with a reference point, or benchmark, against which they have the opportunity to measure “normal” progress through life.

7.4.1.1 Being Left Behind At University

Participants who had commenced university before their cancer diagnosis spoke of being left behind by their cohort when their studies were interrupted by illness and treatment:

... life requires you to be 100% in working order and if you’re not you fall behind.

So do you feel like you’ve fallen behind?

Yep, absolutely.

How do you measure behind?

I measure behind as in my life, all my friends are finishing uni and I’m only in the second year uni, I’ve fallen behind in that respect, as in I have no friends basically left at uni which is a little hard to deal with. (Roger, 22 years old diagnosed at 19)

“Falling behind” and “leaping ahead” are comparisons made relative to a social norm. For participants, falling behind meant being less advanced academically, professionally, or socially than their peers who had not had cancer, and who defined the norm. Participants’ academic achievements could be maintained at both school and university with time and effort and their academic goals achieved. However, academic achievement alone did not compensate for being left behind by their cohort because keeping up with one’s cohort is also a meaningful way of measuring “progress” in life.

So far I have described cohorts that are institutionally defined – a school year or a group of university students. However, cohorts are not always institutionally defined. Cohorts tend to celebrate milestones together. They celebrate leaving formal education, 21st birthdays, getting a driver’s licence, cohabiting or marrying, and parenting at similar times of life. Participants who were diagnosed in young adulthood were of an age when non-institutional milestones were meaningful:

... the only thing that, time that it’s challenging is, well and this is a big challenge, is all my friends are having babies now and doing that. So I don’t have that kind of connection with them... (Alice, 29 years old diagnosed at 22, relapsed at 23)

Being left behind by one’s cohort can loosen social bonds and potentially has ongoing implications for intimacy with friends.
7.4.1.2 Being Left Behind and Physical Dysfunction

Participants’ were “left behind” by their peers when they could not join them in physical activities due to discomfort, pain or fatigue. Being left behind in this way could persist for years after completion of treatment:

*My friends have more, they can be more active and I get tired quicker than they do which is the biggest thing I think. ... my friends can work fulltime and go to Uni fulltime and still do all these other things. I could not do that. I'd just get so tired.* (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Participants were also left behind by their sporting cohort when their team mates continued to progress through the ranks of representative sport and they did not:

*By the end of last year I would have been a black belt if I continued going to karate, I missed out 3 months and I still haven’t done a test to get a new belt. So I would have been a black belt, I would have been with my friends at the moment who are Australia’s champions of karate. I would have been with them, they all get to fly to Japan this year to go and do like a real world karate fighting championship. So I probably would have been there with that. A few girls I know and a few guys are baseball, they represent New South Wales and that now. One person I know who’s going off to represent in nationals and do that sort of stuff. So if I continued I was hoping I could still go and do that, represent New South Wales and that sort of stuff.* (Malcolm, 17 years old diagnosed at 15)

Being left behind physically had two potentially adverse effects. For participants like Mahalya who were left behind in the course of daily routine, the potential effect was isolation and loneliness. For participants like Malcolm, whose cohort progressed through the ranks of representative sport, being left behind could signal the death of a dream to achieve sporting success at high levels.

Mahalya said she resisted isolation and loneliness by selecting friends who were sensitive to her physical limitations:

* [I choose friends who] can have fun doing other things ... Versatile friends. We do salsa dancing. We go to art exhibitions. We have picnics. We just go round and take photos. We watch movies. Just things like that.* (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

7.4.2 Leaping Ahead

Moral development commences in childhood, continues through adolescence and parallels advances in reasoning and social cognition [5]. According to Kohlberg and Gilligan young adolescents (under the age of approximately 14 years) operate at a conventional level of moral reasoning in which their decisions are made by following rules that emanate from authority figures such as parents and teachers. During adolescence, young people develop a
capacity for principled moral reasoning [245]. Moral development can be approached from two perspectives. Kohlberg proposes an orientation towards justice which holds as its ideal a morality based on principles of reciprocity and equal respect – or “fairness” towards individual social actors. Gilligan proposes an orientation towards caring which attends more to relationships with others. Elements of both of these perspectives were evident in participants’ interviews [129].

7.4.2.1 Leaping Ahead: Advanced Moral Development
Participants of all ages spoke about how their crisis had changed them in various ways. They claimed that their experience had enabled them to develop virtues that they could use to serve and benefit others. They said that they had not possessed these virtues before their experience of cancer illness and treatment and implied that they may not have developed them when they did except through their cancer experience:

*I’m more compassionate now actually. Before with charities and stuff I used to be you know like teenagers, typical teenagers would, we don’t care, we just care about ourselves. Now I feel more compassionate and I feel bad for people like I don’t know, like if there’s a charity and I’ve got money I’m going to give them money. (Bill, 18 years old diagnosed at 16)*

Accelerated moral development was constructed as a challenge to stereotypical adolescent “selfishness”. Bill implied that he had leaped ahead of his cohort by claiming a more morally advanced identity – one that extended beyond personal wants, needs, or gains. Participants diagnosed in older adolescence or young adulthood said that their experience had produced a shift in their outlook on life which expanded their repertoire of virtues:

*It’s like I said it’s not until you’ve been through something like this that your outlook on life changes and just having more patience and sympathy towards other people as well. Just anyone, doesn’t matter who they are, if you can give them a hand. If you can do something for them why not, whereas before I don’t think I went out of my way to do anything for anyone. I guess that’s how most people are because they just think the world is centred around them, yeah they’re quite selfish but after you see what people have done for you like your family, friends, and even the nurses and the doctors in the hospital, it changes you yeah. (George, 29 years old diagnosed at 22)*

Participants claimed that through their crisis they had become more charitable, sympathetic, patient, and selfless and this had implications for how they interacted with other people. Similarly, as described in the introduction to this thesis, adult cancer survivors report a desire to “give something back” to the individuals or health care systems that facilitated their survival [213]. My point here is that the participants in this study did not see themselves as
the sole beneficiaries of their experience. Their perceived virtues were said to be beneficial to others as well.

One participant who was diagnosed during early adolescence provided the following example of how she used her newly developed virtues to benefit her friends and peers:

\[
\text{I guess with my cancer I feel like it gave me a lot of wisdom, in terms of dealing with problems and it gave me a lot of insight. And in that way I find that because I’ve had that experience I’m able to relate to other people’s problems a lot better. So I found that since then, I’ve naturally fallen into the role of guidance counsellor. So, yeah I guess and people notice that I have that wisdom and that grounding from that, and so they’ll naturally come to me for advice and so because I have a lot of people that look up to me and look to me as the support ... I feel like I have that responsibility on me (Dilshara, 18 years old diagnosed at 11)}
\]

A diagnosis of cancer is an existential crisis in that it confronts people with their own mortality. One consequence of this was that participants claimed to have developed greater wisdom and insight into life’s problems. Sharing such virtues has been reported in previous research as an onerous social obligation for young cancer survivors [77]. It is not always understood as a burden, however. Dilshara described a reciprocal relationship in which young people who have survived cancer can become advisors or counsellors to their peers who recognise their greater wisdom and insight.

As I have suggested in the introduction to this section, moral development is an experience typical of all young people. Participants in this study were marked as different to their peers because they developed these virtues earlier in life than they expected to. They also claimed to have developed them earlier than their peers. Participants thus developed the sense that they had “leapt ahead” of their cohort in terms of their moral development.

Not all peers acknowledged the new wisdom and insight claimed by participants, however. Alexis provided a contrasting example to that of Dilshara:

\[
\text{I was saying before how my friends used to come to me, like some of my friends would just come to me and tell me stuff .... about them and now it’s my best friend [they go to for advice], and like if I think if that didn’t happen then it’d probably still be me ... (Alexis, 16 years old diagnosed at 14)}
\]

Friends’ and peers’ responses to young people who have survived their cancer illness and treatment are not necessarily natural or predictable. However, responses by friends and peers
could influence the social roles adopted by participants during their transition through remission and recovery.

### 7.4.2.2 Being out of step: Signs of Premature Ageing

Participants in all phases of transition experienced long term adverse effects of illness and treatment on their bodies. Bodily dysfunctions such as fatigue and infertility have been widely reported in previous research. However, participants in this study also spoke of less widely reported physical limitations resulting from their cancer experience such as failing knee joints and stroke. In this section I will focus on participants’ experiences of bodily dysfunction that are more commonly associated with ageing than with youth.

Participants experienced being out of step with their cohort when they experienced symptoms of illness and bodily dysfunction that they associated with ageing rather than youth. These symptoms were sometimes vague or “medical”:

> When I get sick I get sick with things that older people would get sick with ... my teary eyes something that elderly people usually have and I got shingles quite a few times and that’s something that elderly people are prone to, I’ve been prone to like respiratory infections like elderly people have ... Even being stiff, it’s like what older people get. (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Other symptoms were specific and subject to possible surgical intervention:

> ...when I last saw him (orthopaedic surgeon), maybe a year ago, the only option was (knee) replacement and he plainly said to me ‘Look, I’m not going to do a knee replacement in a 20 year old so you should either take up computer programming or chess’. He literally put it to me like that ... (Andrew, 22 years old diagnosed at 16)

As an aspiring soccer player, Andrew’s experience parallels that of some retired elite athletes who require repeated surgical intervention to manage orthopaedic damage sustained during their sporting careers. A surgical knee replacement often signifies obsolescence - being “washed up”, “over the hill”, or “past it”. This has implications for young people whose youthful identity can be undermined by having a medical condition strongly associated with old age. As Mick said, *most of the people that have the joint replacements are 65 plus and they only last about 15 years and you can only have about three in a life time ...* (Mick, 29 years old diagnosed at 15).

Avascular necrosis was the side effect of treatment that resulted in Andrew’s and Mick’s dysfunctional knees. Other participants in older adolescence and young adulthood also experienced this side effect.
Alexis spoke of having suffered three strokes as a side effect of her cancer treatment:

*I had my stroke. And [diagnosis] took a while, because [the doctors] didn’t know that it was a stroke, they didn’t know what was happening.* (Alexis, 16 years old diagnosed at 14)

Stroke, like cancer, is rare in young people and may be difficult to diagnose. It is much more common in older people and is associated with ageing. For a young person to suffer a stroke is potentially stigmatising as it has side effects of its own such as ongoing paralysis. Stroke also represents one of the ways in which Alexis was out of step with her cohort. Stroke in young people can have the effect of locating them within the social world of the aged.17

**7.5 Summary**

In this chapter I have described how participants in this study reported being dislocated from their usual social worlds. When they re-entered their usual social worlds they made a number of comparisons that enabled them to revise who they were in light of having cancer. Participants reported feeling “out of place” and “out of step” with their cohorts due to the differences that marked them. Tensions in peer relationships arose apparently due to a perceived inconsistency between their claims to be “normal” and their acceptance of the exemptions and benefits of the sick role. Tensions also arose because they did not conform to norms of attendance, achievement, and appearance. While participants could achieve many of the milestones achieved by their friends and peers, the fact that they did so at different times of life meant that they remained “out of step” with their cohort.

**Chapter 8: Accommodating the ongoing effects of cancer into new relationships**

**8.1 Synopsis**

In chapters 6 and 7 I described the impact of the cancer experience on participants’ existing relationships with family, friends, and peers. In this chapter I will describe the impact of the cancer experience on new relationships. This is an especially important issue for young people who are at a phase in their life in which their social horizons are expanding and they are forming new attachments. They are also forming new *kinds* of attachments, such as sexual relationships and romantic liaisons, which reflect their growing maturity and transition to adulthood.

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17For example, another young woman who suffered a series of strokes at 16 years of age and who was not part of this study speaks of playing lawn bowls as a therapeutic or rehabilitative activity with elderly women at her local bowling club. [http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0010/155647/saras_story.pdf](http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0010/155647/saras_story.pdf)
As the participants in this study progressed through their period of remission and recovery, they faced the prospect of making new acquaintances and establishing new relationships while managing the ongoing effects of their cancer illness and treatment. These ongoing effects are what sets them apart from most other young people of a similar age. I have divided this chapter into two sections. First, I will describe the processes of disclosure of their cancer experience to new acquaintances. Second, I will describe the processes of maintaining intimacy with new friends and romantic partners.

8.2 The Process of Disclosure
Charmaz defined disclosure as a form of telling in which one reveals self. [246] (p. 108). By disclosing, participants reveal their feelings and vulnerabilities which touch on their self-identity and self-esteem [246] (p. 108). Specifically in the context of young people with cancer, Hilton et al defined disclosure as the extent to which cancer patients openly discuss with others their diagnosis, and thoughts and feelings about their disease [177] (p. 744). By ‘disclosure’ I mean the process by which participants told others about their cancer experience.

Disclosure has two important implications. On the one hand it was always risky for participants because they did not know how the other person was going to react. Disclosing an illness is risky because it reveals an aspect of oneself that makes one vulnerable [246] and has the potential to be stigmatising [242]. The information disclosed had the potential to be used against the participant by another person, or it might be used by another person to discredit the participant. On the other hand, disclosure had the potential to facilitate intimacy between participants and new acquaintances. By telling someone about their personal experience, participants could become closer to them. In their interviews, participants spoke about avoiding disclosure, about how they managed disclosure, and about how they sometimes lost control of the process of disclosure.

8.2.1 Lacking Opportunity and Avoiding Disclosure
In chapter 7 I described how the experience of cancer caused participants to feel “left behind” by their peers. Some participants in older adolescence and young adulthood said that their cancer experience also limited their social opportunities:

... since I was sick a lot, when guys would have been meeting girls and that sort of thing, dating, I wouldn't have been doing that so that sort of put me backwards. (Rudi, 21 years old diagnosed at 14)
Because they experienced diminished self-confidence, some participants avoided social settings in which they might be called upon by others to disclose aspects of their cancer experience and thereby risked stigmatisation:

... it’s made me like a hermit, ever since I had the [cancer], I stopped going out. I don’t spend much time outside of home. I sort of lock myself in from the world and I think that over the last 7 or 8 years has really, how do I put it, yeah damaged my skills to communicate with people ... (George, 29 years old diagnosed at 22)

The ongoing effect of diminished self-confidence was social withdrawal that continued to affect participants’ lives, in some cases, for years after their treatment had finished.

One of the ways young people have available for integrating their cancer experience into their developing sense of self is by talking about their experience with other people. However, for some participants this led to ambivalence about how they could or should account for the ongoing physical effects of their cancer experience:

I don’t know what to [tell people]. I’ve got dry eyes. I’ve got squeaky knees. How do you [tell people] that? It’s a bit difficult. (George, 29 years old diagnosed at 22)

As suggested by George above, some participants in older adolescence and young adulthood had visible, ongoing effects of cancer that they considered would be obvious to other people. In Goffman’s terms, these participants had a discredited identity – one tainted by a stigma that was obvious to others [242]. While alteration to bodily appearance resulting from cancer illness and treatment are by definition changes to a young person that are visible to others, alterations to bodily function may be either visible or invisible. Goffman accounts for this in his theory of stigma [242]. According to Goffman, stigma is an undesirable social characteristic that results in a spoiled identity. When the stigma is obvious to others it produces a “discredited” identity. When the stigma is not obvious to others, it produces a “discreditable” identity [242] (p. 41-42).

Evidence of participants’ cancer experience was not restricted to visible stigmata. Their cancer experience was recorded photographically. Participants or their parents also kept other objects such as locks of hair or medical devices as mementos of the experience. Some young people diagnosed in older adolescence or young adulthood deliberately sought to avoid disclosing their cancer experience to new acquaintances by hiding objects that revealed their cancer history:
I had been seeing a guy for about 4 months and he would come over and I took the collage down in my room and he still doesn’t know that I’ve had it, at, like he doesn’t, it hasn’t been brought up. (Courtney, 21 years old diagnosed at 14)

Participants who possessed a discredited identity were frequently called upon by others to provide an explanation of their appearance or behaviour. Some avoided disclosure by choosing to provide no account for their appearance or actions:

... sometimes I get in an awkward situation, like I have a [new] friend at Uni, and she was following me around, I had to go to the chemist to buy some medicine and she’s like, “Why do you take that medicine for? What’s that medicine about?” Asking me too many questions about my medicine, [laugh] and I just went, “Oh, I’ll tell you next week,” and she forgot, so I didn’t get to tell her. So I think if people really want to know they’ll ask me, so. … Like she forgot about it so maybe, she doesn’t really want to know, so I’m not going to tell her. I’m not going to repeat myself because it’s very private and very personal to me. Like it’s the big thing for me … (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Mahalya’s friend may also not have questioned her about her medication because she took the hint that Mahalya did not want to talk about it. Mahalya may also have chosen to avoid disclosure for other reasons in this case. First, public settings are rarely conducive to the disclosure of private and very personal information. Second, Mahalya might have experienced her friend’s questioning as intrusive and her response was to protect her privacy. Third, because her cancer experience was potentially stigmatising, Mahalya may not have trusted her new friend to maintain her privacy.

On some occasions, participants sought to avoid disclosing their cancer experience by providing a false account for their appearance. For example, Holly said she responded to the stares of others by providing a false account for her scarred appearance, and that her account was verified by her friends at the time.

[Chuckle] I have a love/hate relationship with [my scar]. In winter it doesn’t worry me because I’m in layers and things. But it makes my hip sit out to the side. Because of all the scar tissue it’s sort of like a little extra bulge, which shits me. In summer, not that I go to the pool much, but when I went on schoolies after Year 12 and we’re up on the beach in the bikini, and everyone stared at it quite a bit. … [my friends and I] sort of made up some stupid story about it being a shark bite and, “Oh I can’t believe I’m back at this beach after that shark attack,” and things. Just for the benefit of the people that were staring. So I guess I have a bit of fun with it … (Holly, 23 years old diagnosed at 14)

This situation illustrates the relationship between knowledge and intimacy. Disclosing is a means of bonding whereas avoiding disclosure is a means of maintaining social distance.
Bonding and maintaining social distance contribute to young peoples’ developing sense of self by delineating the boundaries of where they belong socially. This relationship between knowledge and intimacy was observable in the interviews more generally in that participants who chose not to disclose spoke of protecting themselves. This highlights the risky nature of disclosure.

A major factor that shaped participants decisions about whether to disclose their cancer history was the issue of trust:

Like if somebody has the audacity, if I can say that, ‘cause I have had people like within ten seconds of seeing me you know, like oh how did you get the scar and in more vocal terms but I’ll say it’s a surgical scar, I won’t tell them like the story behind it because I don’t feel like they’ve earned my trust or that I need to tell them. Sometimes it’s really I don’t want people to have pity on me or think that I’m weaker sort of thing. (Rudi, 21 years old diagnosed at 14)

Rudi’s example provides an explicit illustration of a point alluded to by other participants. Cancer illness and treatment are potentially stigmatising so new acquaintances who inquire about the ongoing effects of cancer need to prove themselves trustworthy before they are entitled to an explanation. Participants avoided disclosing if they did not trust new acquaintances.

8.2.2 Managing Disclosure

In accordance with the reasoning outlined above, participants said they disclosed because it facilitated deeper intimacy, but (to reaffirm the riskiness of disclosure) they also said they feared being rejected on the basis of this information. Participants therefore weighed the risks and benefits of disclosing before deciding whether or not to do so. Participants sought to control the timing and content of their disclosures.

Participants of all ages sought to disclose at what they deemed to be the ‘right’ time in their relationships with new acquaintances regardless of their position on their cancer journey. They said if they disclosed too early in the relationship they might scare new acquaintances off and thereby jeopardise their chances of developing an ongoing relationship. On the other hand, if they disclosed too late they feared being revealed as dishonest and/or inauthentic and being discredited for establishing a relationship on false pretences. The content of their disclosure depended to some extent on participants’ willingness and ability to conceal ongoing physical signs of their cancer and their level of trust in their new acquaintances.
8.2.3 Disclosure during Middle Adolescence

Participants diagnosed in middle adolescence sometimes disclosed their cancer experience in the company of friends and peers who already knew about their cancer experience when new acquaintances entered an established peer group. One such participant was Bill, whose leg had been surgically amputated to treat his osteosarcoma. He now wears a prosthetic leg:

... we even tricked one of [my new] friends. I went to another room and then made a loud noise and I went down on the ground and then everyone was in on it except for this one guy and he came in and said, “What happened,” and I had twisted my leg around so it looked like [laughs] cause I was wearing really long pants so he couldn’t tell and I was just screaming my head off and he almost cried [laughs]. He was walking around. He didn’t know what to do and then he almost cried and then he was about to call 000 and then we told him and then he kind of didn’t talk to anyone for 10 minutes [laughs]. He just sat there in silence drinking a beer [laughs]. (Bill, 18 years old diagnosed at 16)

This type of disclosure could start with a false account but quickly led participants to disclose their cancer history. In Bill’s example, disclosure functioned as an initiation of the new acquaintance into the peer group, something that is more important for young people in middle adolescence than for young adults. The content of his disclosure also created an impression of Bill as a practical joker and someone at ease with the ongoing physical effects of his cancer.

In contrast to young people who spoke of disclosing after first providing a false account for their appearance, Dilshara spoke of disclosing directly to new acquaintances soon after meeting them:

... the difference is that now if I meet a new person I’ll tell them [about my cancer] pretty quickly, like I used to have this giant screening process where I had to make sure that I was close friends with them and all the rest. (Dilshara, 18 years old diagnosed at 11)

Whenever young cancer survivors choose to disclose or to avoid disclosing to new acquaintances, they are engaged in the process of impression management [243]. Participants disclosed their cancer history, or aspects of it, at times when it was relevant to the overall impression they were trying to create. Dilshara provided an example of how participants’ perspectives on the timing of their disclosure changed during their period of remission and recovery. Therefore, the “right” time to disclose changes as participants’ perspective on their cancer experience changes over time. This also has an impact on the role of trust as a catalyst for disclosure because, Dilshara suggests, adequate trust can develop quickly.
8.2.4 Disclosure in Older Adolescence and Young Adulthood

To older participants, new acquaintances were more important to older participants as possible romantic partners than as new additions to their peer group. This reflects a more general point that transition to maturity in older adolescence and young adulthood includes forming intimate relationships of a romantic and/or sexual nature. With this in mind, the development of a romantic relationship provides one scenario in which the potential benefits of disclosure can outweigh the risks:

*I was actually seeing my doctor that day for my annual check-up, and [my boyfriend] just knew that I was going to see my doctor that day, he didn’t know what for. And then later on when I saw him, I said, “Do you want to know why I [went] to see my doctor today?” and he said, “Yeah,” so I told him.* (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

In this example Mahalya controlled the process of disclosure. This contrasts with her example of being asked about her medications by her friend in the pharmacy. First, Mahalya created a private space, a dinner for two, in which she could disclose in relative emotional safety. Second, she chose a time when she did not experience her boyfriend’s interest as intrusive. Indeed, Mahalya suggests that she stimulated his interest by asking if he wanted to know why she had seen the doctor. Third, her disclosure was planned rather than spontaneous or opportunistic which maximised her control over the timing and content.

Some participants went on dates shortly after their treatment had finished and the physical effects of cancer treatment were obvious to other people:

*I think [my boyfriend] just knew [I’d had cancer] because I was bald. It kind of gives the game away a little bit.* (Lisa, 20 years old diagnosed at 17).

Baldness is widely recognised as a signifier of “cancer”. The meanings of other physical signs of cancer illness and treatment, such as scarring, were more ambiguous. This led to awkward situations for some participants. Dating at these times also intensified the requirement for participants to account for their appearance:

*... [my date] goes, “What the hell happened to your neck? Did someone kiss it with a knife?” And it was just so awkward like, I didn’t see him again because I was just like, “Oh.” So it is, it is awkward just when little things come up, that you wouldn’t think about but, why would you even say that? [laughs].* (Courtney, 21 years old diagnosed at 14)
Dating was not an awkward experience for all young women. When ongoing physical effects of cancer were accepted by young men as part of the participants’ identity young women spoke of experiencing enhanced self-esteem:

*I even went on my first date ... which spun me out because you think, you go through all the self-esteem issues and all that stuff, and it spun me out that here I was, I was bald. I remember it was winter I went to the club and I was wearing my jacket and a beanie and all that and met this guy. Three days later we went to the movies and dinner and all that kind of stuff and it just spun me out that he was interested in me. Despite the fact here I was bald and all that kind of stuff, and that was nice. That was a booster for my self-esteem.* (Jo, 21 years old diagnosed at 18 relapsed at 20)

The development of new relationships between participants and new acquaintances was influenced by the ways in which new acquaintances responded to the ongoing effects of cancer. If ongoing physical signs resulted in awkward interactions with to new acquaintances, the development of a new relationship could stall or be delayed by the focus on the participants cancer identity. However, if ongoing physical signs were accommodated into interactions between participants and new acquaintances – that is, if they were present but not the focus of an awkward interaction – then the new relationship had the opportunity to progress. This suggests that cancer remains a part of young cancer survivors’ sense of self but is not the sum total of who they are. I will describe the implications of this for the ongoing development of new relationships below.

Participants’ perspectives on their cancer experience changed with time, and this shaped and influenced the accounts of their appearance they gave new acquaintances. For example, Holly reported that her perspective on her scarred body had changed in the years since her cancer treatment finished. Her scars have become a source of pride that contributed to her sense of self as a resilient person and to her accommodation of her cancer experience into her self-identity:

*I’ve got a few scars on my neck from where the portacath came out, so if [new acquaintances] ask me about that then [my cancer history] comes out. I don’t get upset telling people about it, I guess now I’m working through it more than ever before. After the chemo was finished I didn’t want to think about it, I didn’t want to know about it, it hadn’t happened as far as I was concerned. And now I guess, sort of I like my scars, I’m proud of what I’ve been through and that I’m still here. So, talking about it doesn’t upset me the way it used to ...* (Holly, 23 years old diagnosed at 14)

Scarring and amputation can also be interpreted through a gendered lens. What can be interpreted as heroic, adventurous, or attractive on a male body can also be interpreted as
disfiguring and unattractive on a female body. These perspectives tap into particular stereotypes of masculinity and femininity. The type of masculinity that values the presence of scarring on a male body would be likely to interpret those effects of cancer as heroic, dangerous, or exciting. The type of femininity that is repulsed by scarring and amputation would be likely to interpret those effects of cancer as stigmatising. Feminine beauty from this perspective is likely to be defaced by a cancer history and its ongoing effects. Scars tell a story as Lisa said.

Participants in older adolescence and young adulthood described managing their disclosure to new acquaintances for two reasons; One was to test the moral character of their new acquaintances. For example, the new acquaintance could fail the moral test by stigmatising the participant or by showing no interest in that aspect of the participants’ identity:

... my view of it is, if I tell them, and they run away then they’re too gutless. If they can’t handle it, I don’t want to be with someone like that anyway. (Courtney, 21 years old diagnosed at 14)

The new acquaintance could pass the moral test, for example, by developing a relationship with the participant and accepting the part that cancer contributes to the participants’ sense of self.

Erin provided an example of a more explicit moral test when she disclosed her presumed infertility to her new boyfriend:

I gave him the option to leave, to go find someone who he could have a family with. He stuck around. He was disheartened but he was like, “I’m here for you. I’m with you for the long run. So whatever the circumstances are, we have to live with it.” I’m like, ”Alright then.” I might have been 17 when I had this testing, when I was 18, I fell pregnant. (Erin, 24 years old diagnosed at 10)

Participants spoke of the valuable contributions they could make to a relationship while being hamstrung by the stigma of cancer:

.... how do you market (yourself)? This lovely person, I actually think that I’m fun to be around and you can have a decent conversation with me and damn, I’m great in bed but [laugh] I’ve had cancer. You know, you just can’t have that in brackets at the end of it all but I need to say that. (Alice, 29 years old diagnosed at 22, relapsed at 23)

By reducing her experience to one word – “cancer” – to make her point in the interview, Alice highlighted some of the assumptions implicit in participants’ accounts of disclosing
their cancer history to new acquaintances. The assumptions are that making the disclosure “I’ve had cancer” immediately and comprehensively conveys the range of meanings the young cancer survivor attaches to that experience, enables the new person to share those meanings, and enables the new person to understand how those meanings will shape and influence the relationship into the future. The only meanings readily available to new acquaintances are culturally normative ones, such as that cancer is always fatal. Alice’s youthful and life-affirming qualities of fun and sexiness are also uncomfortably juxtaposed with the dark side of cancer which contributes to her ambivalence about the content of her disclosure. She cannot “put it in brackets” because it will not be contained, but nor can she remain silent about it because she “needs to say it”.

Second, participants sought to maintain their personal integrity by managing the content of their disclosure in order to represent themselves as honest. Again, Mahalya provided an example of proactively choosing to disclose to a new acquaintance:

*I thought, I really like this guy, and I want to be honest with him, and I think it’s a – I feel like it’s a big ask for me to have somebody that close in my life and ... to have them know that. ‘Cause they become part of it too, because you’re building relationships with them, and they have to accept that part of your – kind of, some instability of your health. So there is that death elephant in the room, or you could get really sick and – ‘cause you’re bringing them into that and I’m responsible for that. I feel responsible. So I felt it was a really big ask, and I told him that, and so I really wanted him to know that I’d been sick. I was thinking about [telling him] for a while. Should I tell him now, or should I just wait a little while? I told him quite early on. (Mahalya, 22 years old diagnosed at 13, relapsed at 18)*

Another way participants spoke of representing themselves was to be authentic:

*When I came out of cancer one of the biggest revelations, epiphanies that I had was authenticity. If people don’t know you for who you are what’s the point. (Alice, 29 years old diagnosed at 22, relapsed at 23)*

This has implications for young cancer survivors generally. The intrusion of serious illness or death into a romantic relationship is antithetical to youthful ideals of fun, flexibility, and adventure. One reason for young people to give new romantic partners the opportunity to make an informed decision about whether to end or to continue their relationship was that the relationship may not be as fun, adventurous, or frivolous as young people typically expect. Prioritising the fostering of intimacy with new romantic partners is part of the process of creating a “new normal” for young cancer survivors because it is one of the ways in which they transition from the role of cancer patient to survivor. In this way, however, young cancer
survivors are similar to their peers who have not had cancer. Establishing new romantic relationships is one way for any young person to demonstrate their transition to adulthood.

Participants in young adulthood also spoke about their disclosure as a natural part of the progress of their new relationships:

... [my new boyfriend] sort of knew of a story of a girl having cancer [at school], 'cause he’s 2 years older than me. And we were just talking and I guess it came up. He asked about the scars on my neck so I told him. And he was really accepting and, I don’t know, he reacted differently to the way most people do....most people sort of get all, a little bit embarrassed maybe and don’t want to upset me or offend me. Whereas he just kept asking questions and was really ... He didn’t pity me, or feel sorry for me, or anything. He was just very open about it and very comfortable asking me questions. (Holly, 23 years old diagnosed at 14)

Holly’s example highlights the importance of her new partners’ reciprocal openness and comfort when discussing her cancer history and its ongoing effects. Mick was the only male participant who had established a new romantic relationship in his period of remission and recovery and he spoke of his cancer experience as emerging naturally during the course of his relationship:

And then [my wife] ... would have asked me as our relationship progressed. ... I had an 18th video that was put together for me with a whole lot of home videos from when I was younger and things and part of that had pictures of me in hospital and things and I think it was just a gradual thing. Like, I didn’t sit down with her and say, “Oh, look this is me, I had this cancer and that cancer,” and just went through it. It was progressively, yeah, just talked about. (Mick, 29 years old diagnosed at 14)

Like Holly, Mick spoke of engaging in discussion with his new partner about his cancer experience rather than informing his new partners about the “facts” of his cancer experience. A policy of early disclosure paved the way for nine participants to establish new romantic relationships during their period of remission and recovery. I will describe the experiences of those nine participants below. However, to complete this section of chapter 8 I will describe the consequences for participants who lost control of the process of disclosure.

8.2.5 Losing Control of Disclosure
Not all participants kept control of their disclosure all the time. Three participants provided examples of the consequences for them of losing control of the timing and/or content of their disclosure. Participants lost control when someone else disclosed their cancer experience without their consent.
Alexis’s father told new acquaintances about his daughter’s cancer experience. Alexis objected to the content of her father’s disclosure on the basis that she found her father’s version of her story boring:

Well dad normally tells people [laughs].

What do you think of that?

Well it’s okay like the first time you hear it, because like when I meet someone and he’s there he goes oh this is my daughter Alexis and then he starts telling the whole story of the diagnosis and I’m like oh come on, I’ve already heard this story so many times … (Alexis, 16 years old diagnosed at 14)

Mahalya’s friend told new acquaintances about the Mahalya’s cancer experience. Mahalya objected to the timing and content of her friends’ disclosure because she saw the disclosure as a violation of trust and privacy.

I had a really good friend and she used to tell everyone. I was so shocked that all these people had, that never, that don’t know anything about me know such private information. It’s really private and for, it’s actually offensive to do that. You have no right to be telling stuff like that to people, and just because you think it’s so inspirational. (Mahalya, 22 years old diagnosed at 13, relapsed at 18)

Erin said that her mother told new acquaintances about her cancer history. She objected to the content of her mother’s disclosure because her mother became the focus of the story:

… we were going to the shops and she runs into an old friend and she’ll tell them how I was sick and that, but she’d turn it around as if she was the patient. Like she was the victim and I was standing there like, “Hello. I was the one who was actually sick.” (Erin, 24 years old diagnosed at 10)

8.2.6 Summary

Participants made deliberate choices about whether or not to disclose their cancer experience to new acquaintances. Disclosure presented participants with both risks and opportunities. By disclosing, participants risked being stigmatised because of their cancer experience. Stigma can reduce self-esteem and self-confidence, thus making disclosure more difficult as time passes. Disclosure also provided participants with the opportunity to show trust in and develop more intimate relationships with new acquaintances. It was an important step in participants’ dual transitions towards intimacy and cancer survivorship. Disclosure meant identifying oneself as being a cancer survivor and this potentially made participants vulnerable in their new relationships. It also meant dealing with rather than avoiding their sense of self as a cancer survivor and being prepared to negotiate the implications of their cancer experiences for their new relationships.
8.3 Accommodating the ongoing effects of their crisis into participants’ new relationships
In this section I will describe how participants managed their ongoing effects of cancer as they actively engaged in new romantic relationships. Few participants in middle adolescence spoke about starting new romantic relationships in the future. One explanation for this is that young people in middle adolescence are focussed on developing relationships with their friends and peers as I have suggested above and in chapter 7. One of the functions of peer groups is to provide a safe space in which young people can explore their sexuality without necessarily developing serious or long term romantic partnerships.

Participants in older adolescence spoke about seeking a partner who was fun and flexible and a relationship that was more serious than those for middle adolescents, though not necessarily any more durable. One explanation for this is that participants in older adolescence rehearse different aspects of their sexuality with different partners without making long term commitments to durable, monogamous romantic relationships. Participants in young adulthood spoke about coupling in the long term and having their own children. They spoke about this without explicit regard to their possible infertility, presumably because marriage and children are strong social expectations.

Nine participants (eight women and one man) interviewed in older adolescence and young adulthood had commenced new romantic relationships during their period of remission and recovery. In this section I will focus on two aspects of new romantic relationships that these nine participants, as a subset of the whole sample, spoke about; establishing intimacy and fertility.

8.3.1 Establishing Intimacy
Participants spoke about the effects of their cancer illness and treatment on the process of establishing intimacy with their new romantic partners in two ways. First, ongoing medical surveillance and monitoring caused participants anxiety which manifested as withdrawal or short-temperedness. These responses were potentially destructive to participants’ new romantic relationships and they learnt to communicate their feelings to their partners more effectively in order to limit possible adverse effects:

*I’m trying to learn to communicate more; I haven’t been the best communicator so trying to be really open and actually just saying, “I have an appointment, I’m getting quite scared. Sorry if I take it out on you.” I have to sort of express that.* (Linda, 22 years old diagnosed at 21)
Participants reported that their partners reciprocated their efforts to communicate effectively:

_When I do go for blood tests I do talk to him and a little bit about it but just tell him that I’m scared of what’s going to happen and he always just says, “We’ll deal with it if it happens. When it happens.”... But I know, he’s told me it scares him to think about it as well. He’s told me that._ (Erin, 24 years old diagnosed at 10)

Reciprocal sharing of feelings is a marker of intimacy with a romantic partner.

Second, participants and their romantic partners actively planned for a future together as though participants’ ongoing effects of illness and treatment were inconsequential:

_[My partner’s] got to finish uni. He went in as a mature age student, so he finishes his degree next year. And then we’re hoping to go New Zealand next year, travelling. And then hopefully, the year after that, we’ll do a Contiki Tour around Europe, and maybe stay over there for a few months. And then I guess, hopefully, come back and move down near Mildura or Echuca, somewhere down there, and set up home there._ (Holly, 23 years old diagnosed at 14)

This suggests that, for some, the consequences of their cancer experience did not impede the achievement of their life goals. Also, that the ongoing management of the effects of illness and treatment were subordinate to achieving their life goals.

However, some participants spoke of making plans that required their more careful consideration of the potential impact of cancer on the achievement of their goals:

_[My boyfriend and I plan to travel to] Thailand, Vietnam and Cambodia. So hopefully we can get there. I’m hoping I’ll be able to cope [physically]. Because it’s a holiday, I can take it at my own pace._ (Mel, 20 years old diagnosed at 19)

Travelling in developing countries is challenging for young cancer survivors because of ongoing effects of their crisis, such as fatigue and continued need to take medication, as well as their continued engagement with health care services unavailable in remote areas of the world and because of the increased risk of infection present in developing countries that particularly threaten people with compromised immunity.

These findings suggest that the process of transition to survivorship for young people in the context of developing intimacy with a new romantic partner is in some ways similar to and in some ways different from the process of establishing intimacy with a new romantic partner for young people who have not had cancer. The process is similar in that it depends on open and effective communication about their relationship. It is different in that young cancer
survivors have to deal with uncertainty about how cancer will affect them in the future, especially bodily.

8.3.2 Fertility
Parenthood is often regarded as a marker of adulthood [244]. However, young people generally make decisions about whether or not parenthood is a role they will adopt based on their assumption that they are fertile and that pregnancy will be achievable without complication. Cancer illness and treatment has an impact on participants’ aspirations and capacity to become parents. This is widely reported in reports of research conducted with young cancer survivors (see for example Crawshaw [158]). Describing participants’ experiences of infertility or parenthood also makes explicit an aspect of a “new normal” [168] that include the adoption of adult roles and their implications for family life.

For some young people engaged in romantic relationships fertility was an issue because they were planning to have children (or assumed they would in the future) but they became infertile because of their illness or treatment. Fertility was an issue for others because they assumed they were infertile but this proved to be untrue. This was the case for two women who became teenage mothers. Both actual and assumed infertility required participants to negotiate ways of accommodating cancer into their new romantic relationships. The former had to deal with demands of In Vitro Fertilisation (IVF):

*I can still actually have children of my own in that sense. So, yeah, in the next few years we’ll look at having children but we’ve just gone through that working out the whole fertility clinic and IVF process. … while we were down at Christmas we had an appointment at the clinic there just to, so we could find out the whole process in terms of … so, I guess, that we could best plan that, particularly being [interstate] and not knowing where we’ll be in the future, just so we can kind of have a bit of a rough plan as to when you need to start and all those things. It’s reasonably flexible but part of it will have to be at the clinic; but a lot of it can be done away but it’s probably easier to do it, if you’re based where you’re getting all the treatment and the specialist is.* (Mick, 29 years old diagnosed at 14)

The latter had to decide whether to continue an unexpected pregnancy:

*I was very shocked [laugh], very, but like considering I was still, I was 18 ½ I was a bit worried about what people were going to think and then umm, and then when I sat down and thought about it I’m thinking, “What am I going to tell people. My whole life I’ve told them I never want kids and now I’m pregnant,”…[Mum] just said, “Are you going to keep it or what,” and I said, “Well I’d like to keep, I’d like to keep the baby considering I didn’t think I could fall pregnant,” and all I had to do was check with my doctors in Sydney that there was going to be no side effects to me being pregnant and nothing that was going to happen to the baby because I’ve had the chemo and after I got the clear that I could actually go ahead with the pregnancy, that’s when I said, “Well yeah, I’ll keep it then.” Because if there was going
to be really bad things that were going to affect me or the baby I was a bit unsure whether or not to keep it. (Sharni, 20 years old diagnosed at 15)

Those who decided to keep their children embraced parenthood for two reasons. First, when they were told they were infertile they realised how much they wanted to have children:

*I thought the test was lying. The pregnancy test was lying, ... and I told [my mum] I hadn’t had a period for a while and she had a spare pregnancy test. She goes, “Oh just do it,” and I’m like what’s the point? It’s just going to be a negative. So I did it and I didn’t want to check it so she went and checked it and she comes in and goes, “Oh, I think you better make a trip to the doctor.” So we went to the doctor and it was confirmed that I was pregnant and I didn’t know what to believe. The doctor told me that I couldn’t have a baby and so I was really happy. I was over the moon. The whole family was. It was such a buzz ...* (Erin, 24 years old diagnosed at 10)

Second, adopting new adult roles of parent and partner provided direction in participants’ lives when they remained chaotic and uncertain as a result of their cancer experience:

*... [motherhood] gave me something more to look forward to in life. Like I now get to watch him grow up and have his kids and their kids and so on how life goes, but yeah, it’s given me something to do. I don’t just sit around wondering, “What’s next,” and that. I can now give him a life and in order to give him a life I need to give myself a better life. So it’s also helping me to actually want to get on track ...* (Sharni, 20 years old diagnosed at 15)

All participants who spoke about their fertility status, and who knew themselves to be able to conceive, spoke of it as life affirming rather than stigmatising. This is counterintuituitive in a society like Australia where teen pregnancy is still stigmatised. This explains Sharni’s ambivalence about what to tell people. However, her ambivalence was also linked to the sense of self she had developed: embracing a role that one has previously rejected has the potential to undermine one’s credibility. If, for example, participants who rejected the role of parent before their cancer illness and treatment come to embrace the role afterwards, they risk being seen as inconsistent, dishonest or inauthentic. Embracing a role as parent also shapes the range of other roles available to both partners. Roles of employee, partner, even cancer survivor can be subordinated to the role of parent. Parenthood is a powerful contributor to a developing sense of self and one that participants in this study embraced.

8.3.3 Not all Relationships Lasted
Early disclosure, establishment of intimacy, and discussions of fertility did not guarantee successful relationships. Two young women spoke of establishing new romantic relationships that ended during their period of remission and recovery. For example, Courtney spoke of her
relationship with a young man to whom she had disclosed her cancer experience early in a relationship that ended after one year:

*I told him. It was on one of the first nights I met him. He was telling me how he got run over by a car when he was younger and things like that. So I told him. But, so I was open kind of from the, from early on. And then it wasn’t really spoken about …* (Courtney, 21 years old diagnosed at 14)

Relationships between young cancer survivors and their new romantic partners are subject to the same pressures encountered by young people engaged in new romantic relationships more generally. However, the transition to intimacy for participants in this study was complicated by their concurrent transition to survivorship.

**8.4 Summary**
Participants established new romantic relationships after building intimacy with open and honest disclosure about the ongoing effects of their cancer experience. Their disclosures did not guarantee the success of their relationships but they did provide a basis upon which the ongoing effects of their cancer experience could be negotiated and accommodated into their new relationships.

The two most intrusive ongoing effects of illness and treatment on new romantic relationships were the anxiety provoked by ongoing surveillance and monitoring of participants’ health and their fertility status. Both of these provided occasions for ongoing negotiation to accommodate the cancer experience into new romantic relationships. New romantic relationships also had the potential to enable participants to imagine and structure a future life that the chaos of cancer illness and treatment had prevented them from imagining.
Part IV: Discussion and Conclusion

Chapter 9: Discussion and Conclusion

9.1 Introduction
This study aims to describe the impact of cancer illness and treatment on the experience of growing up. It was based on interviews with a select, gender-balanced sample of young, mostly middle-class Australians who were diagnosed in different phases of adolescence and young adulthood with different types of cancer. The methodology of the study has focused my analysis of interview data on the participant’s social relationships. The findings reported in the three previous chapters reveal how the impact of cancer manifests in young people’s relationships. They clearly suggest that the impact is different in early adolescence, mid-adolescence, and later adolescence/young adulthood.

For participants in early and mid-adolescence, the impact of cancer was particularly evident in relationships with parents. Some impacts were evident during illness and treatment. Others were delayed until later in life. At the time of illness and treatment, participants developed closer bonds with parents than they had experienced before diagnosis because of the concentrated time they spent together. They used their time together to discuss weighty topics. Their cancer experience tended to make their parents over-protective, and this became a problem for the young person later in life when he or she sought to establish her independence. For participants in mid-adolescence, the negative impact of cancer was particularly evident in relationships with peers, and it was acutely experienced when participants returned to school between treatments or after treatment had finished. For participants in older adolescence and young adulthood the impact of cancer was particularly evident in their relationships with their parents and in the new relationships they forged, especially intimate relationships of a romantic and/or sexual nature.

These patterns of relationship reflect how young people’s social priorities shift as they grow up. During childhood and the early years of adolescence, the family lies at the centre of the child’s social world. During the course of adolescence, this focus typically changes in two ways. The centre of the young person’s social world shifts from parents to peers (and later to intimate relationships of a romantic and/or sexual nature), and she becomes independent of her parents and family.
By the middle years of adolescence, young people’s social worlds have typically extended well beyond the family, and peer relationships become central. As is clearly evident in the findings reported above, however, cancer marks young people in ways that set them apart from their peers. This is a problem particularly for those in middle adolescence because it places them outside of peer group norms. Returning to school is a pivotal moment in their experience because at this point their difference is most obvious to others, and most keenly felt by them. The interviews with participants in this group reveal both the problems that arise from being different and the opportunities their difference presents. They also reveal the different ways that young people manage these problems and opportunities. These issues are discussed in more detail in section 9.2.2 and 9.2.3 below.

In later adolescence and early adulthood, young people typically strive for independence from their parents and family, and they begin to explore and establish romantic attachments and/or sexual relationships. Again, however, as is clearly evident in the findings reported above, cancer makes young people highly dependent on their parents and family, especially while they are ill and undergoing treatment. This dependence figured as a troubling issue in the lives of older adolescents and young adults because they had attained a measure of independence, lost it, and were faced with the task of regaining independence. Relationships with parents were clearly implicated in this process.

Finally, compared to younger participants, older participants were less focussed on issues arising from non-conformity to peer group norms than on issues arising from the quest for independence, and the task of establishing an individual identity. Their accounts of relationships with non-family members focused on the impact of cancer on the prospects of forming and maintaining intimate relationships of a romantic and/or sexual nature, and on negotiating the ongoing effects of cancer on actual relationships of this kind.

In summary, the impact of cancer on the experience of growing up needs to be understood in terms of the main relationships and priorities that young people have during the early, middle and later phases of adolescence. I will now discuss this thesis in more detail, and what it might mean generally for the experiences and care of young people who have had cancer. I will then discuss the significance of my findings in relation to the extant literature on the experience of growing up with cancer. I will conclude by making some practical recommendations.
9.2 The Impact of Cancer on Growing Up in Relationships with Parents, Peers, and New Acquaintances

9.2.1 The impact of cancer on relationships with parents
Growing up means (among other things) developing relationships with one’s parents that are more equal than those normally conducted between a child and parent. This is a gradual process but is normally noticeable from the time young people enter late adolescence onwards. However, some participants diagnosed in early adolescence developed more equal relationships with their parents than are normally conducted between child and parent.

Parents remained at participant’s bedside during their hospitalisation for treatment. Some cancer treatments, such as bone marrow transplant, require long periods of hospitalisation and some require periods of medical isolation to guard against infection. At these times, both parties were confined to the hospital room, effectively sharing the experience of acute, severe illness, intensive treatment, and the daily routines of living in hospital. Sharing such an intense experience in a concentrated period of time and being confined to a small physical space evidently created a social space in which parents could communicate more openly with their children about their thoughts and feelings and participants and their parents could discuss weighty topics concerning life and death. Some participants consequently saw their parents from a new perspective – as individuals with their own life history and dreams for the future. As a result, they began to relate to their parents in a more mature way than they had before their diagnosis. Thus in some cases the impact of cancer on relationships with parents was to give them a new depth and a degree of equality characteristic of relationships between adults.

Growing up also means gaining independence from one’s parents. Most participants in this study were school students living with their parents at the time of their diagnosis and treatment. They had gained little independence before they were diagnosed. Therefore when they were diagnosed and treated for cancer, they had little independence to lose. Gaining independence was a task that lay ahead of them. Some of these young people experienced a tension when they later came to negotiate their independence from their parents during older adolescence or young adulthood. In particular, some said their parents were over-protective. This manifested in feelings of being treated like a child rather than the young adult they felt they had become.
Participants managed the issue of negotiating independence in two stages. First, they discussed it with their parents and developed an understanding of their parent’s perspective. This gave them insight into the different issues faced by their parents and those they faced themselves. They did not always share the same issues. Young people subsequently asserted their autonomy in areas of their lives over which they sought to assume control. The key to this was for participants to try to understand their parent’s perspective. This led them to conclude that their parent’s behaviour towards them might be a result of their parent’s own perspective on their cancer experience and that it need not inhibit their search for independence.

The benefits of this are that both young people and their parents learn to see the situation from the other’s perspective, thereby providing a solid basis upon which to negotiate the young person’s independence. Young people can also formulate a clear idea of what their own issues are around their cancer experience compared to the issues that belong to their parents. The risk is that the process is likely to be time-consuming and that this may cause frustration for a young person who is keen to get on with life.

Other participants sought to advance their independence by rebelling or by asserted their autonomy by making and executing their plans and telling their parents about what they were doing afterwards. Some of these plans were risky for young people who were still suffering adverse effects of cancer illness and treatment. The benefit of rebelling is that a young cancer survivor can assert her or his autonomy quickly and decisively. In other words, they provide a clear statement to their parents that they are taking responsibility for themselves. The risks of adopting this strategy are that conflict between young people and their parents might escalate in the short term and that the choices of activity young people make might prove to be detrimental to their ongoing recovery from cancer.

All of these strategies contributed to the process of growing up by enabling participants to assert their autonomy in their relationships with their parents and continue their transition to independence. This reflects Arnett’s theory of Emerging Adulthood in that participants sought ways of taking responsibility for oneself and making independent decisions (see section 2.3.2) [23]. Whether they choose a conciliatory management strategy or a rebellious one, the important thing for young cancer survivors is that it is their own choice and not one imposed by others.
Some participants diagnosed in older adolescence or young adulthood had moved out of the family home before their cancer diagnosis, and they moved back into the family home during their illness and treatment. These participants were thrown back into the care of their parents. The resulting loss of independence was frustrating. All of these participants moved back out of the family home when they had achieved a level of physical and financial independence that enabled them to do so. Some young people who lose their independence during illness and treatment can expect to regain it after their treatment finishes. Once they regain their physical independence they have the opportunity to pursue financial independence and ultimately emotional independence from their parents. This process is most likely to be enhanced if a young person has some meaningful activity to undertake outside the family home and if they have a close friend or romantic partner with whom they can share accommodation when they move out.

Their newly acquired independence is likely to be different from the independence they lost, however. One reason is that they may experience ongoing feelings of emotional attachment to their parents after they have moved away from their family because of the bond they developed during illness and treatment. This bond is likely to develop for many young people for the same reasons that young people in early and mid-adolescence grow closer to their parents – they share an intense period of their lives in which they confront a severe health crisis together. Another reason is that they realise that their independence is fragile and can be lost when they experience adverse and life threatening events such as cancer. Young people are likely to experience a tension around regaining their independence if they conceptualise independence as a state of self-sufficiency (i.e. a state of having no reliance on others) rather than a state of interdependence. The former idea arguably predominates in the modern Western world [129].

The impact of cancer on young people’s relationships with their parents occurs across all periods of adolescence and young adulthood. They do not occur in isolation, however, they occur within the context of other relationships conducted by young people with their peers.

9.2.2 Growing up with Peers: Returning to one’s usual social worlds
When participants returned to their usual social worlds, they did not conform to group norms of appearance (e.g. hair loss, fluctuations in body weight), attendance (part-time for those at
school), and achievement (e.g. on the sporting field or academically). This was experienced in the short periods between receiving intermittent treatment and/or immediately following completion of treatment and was a problem particularly for participants who were diagnosed in middle adolescence.

When they returned to school participants received heightened levels of attention from their peers. Some attention was indirect such as when peers whispered to each other or pointed at the participant making him or her feel uncomfortable. Some attention was direct and consisted of peers commenting directly on their usual pattern of attendance at school, or on their appearance. Participants often characterised this type of interaction as insensitive or derogatory. Both indirect and direct attention were stigmatising for participants because they singled participants out as being different to their peers in a socially undesirable way. A spoiled identity usually requires management [242]. One way participants managed their spoiled identity was by refusing to engage with the indirect attention they received. Another strategy was to engage with their peers directly by making their comments into a joke and treating the interaction flippantly or humorously. Two young women experienced this heightened attention as bullying. One attended a school in rural New South Wales and had no choice but to stay at school and manage the situation with the help of her parents and school staff. The other managed it by changing schools.

Young people also received lionising attention. Lionising attention was experienced directly, but in a minor way, from peers who did not know them well before their diagnosis. Some participants found this confronting. Young people experienced lionising attention in a major way when peers described them as “heroic” or inspirational”. Being treated as heroic or inspirational is not stigmatising because it leads to development of an enhanced identity rather than a spoiled identity. Therefore, we need an alternative theory to help explain the phenomenon of lionising attention received by young people with cancer.

Becker cautions against the use of metaphors to shed light on social phenomena unless the metaphor is taken seriously [247]. With this in mind, I propose understanding participants experience of being treated as heroic or inspirational when they returned to school using the metaphor of celebrity. Monaco listed three types of celebrity in a hierarchy from most local to most public, namely, quasar, star, and hero [248]. The category of “hero” is not represented
in this study\textsuperscript{18} but I will discuss the categories of quasar and star. On the least public tier of fame, quasars are people who attract initial attention through no fault of their own and through a process over which they have no control. Participants in this study who returned to school resembled “quasar” celebrities when they claimed that the attention they received was undeserved, intense, superficial, and ephemeral.

Participants said that they considered the attention they received to be undeserved because they had not done anything to warrant it. They were famous (in a local way) for having had cancer, not for what they have achieved [249]. Participants found the experience intense because their peers, especially those they did not know well, constantly approached them to interact with them. This reflects the celebrity experience of dealing with the attention of fans. “Fans” followed young people around and sought their attention in return. This fandom is linked to superficiality which, for celebrity interactions, has been described as false intimacy [250] or parasocial interaction [251]. False intimacy is the sensation of knowing another person, a celebrity, even though one’s only interaction with that person has been mediated, for example by television [250]. The knowledge peers developed about a young person with cancer was mediated by normal cultural discourses of cancer and by the announcements of school teachers. Finally, participants experienced the attention as ephemeral because it passed quickly. This corresponds to the experience of celebrities who are “consigned to the shadowy limbo of oblivion” [251] (p. 72). Once the attraction of a celebrity has outrun its course, she or he is discarded [251]. For young people, this meant that the heightened attention they had experienced disappeared. Participants who returned to school after their treatment therefore had to contend with both spoiled and enhanced identities. Both marked them as different from their peers in a period of life when similarity with peers is critically important.

Young people who return to school can expect to receive heightened levels of attention from their peers. Some of this attention is likely to make them feel uncomfortable or resentful because it marks them as different from their peers when it is important for them to be similar. Being singled out by others or being different to their peers in ways that both spoil and enhance identity complicates the process of growing up by disrupting the usual shift in priorities from family relationships towards relationships with their friends and peers.

\textsuperscript{18} According to Monaco, a hero is someone who has actually done something to attract the attention they receive. He cites the example of an astronaut.
Although being marked as different can be difficult to deal with at school, it can be resisted by ignoring it, making fun of it, or rejected it as unwarranted.

The experience of receiving heightened levels of attention was different for older adolescents and young adults than for those who returned to school. They received heightened levels of attention from hospital PR staff and cancer charity workers rather than from their peers. Some young people in middle adolescence also received attention from cancer charity workers, but their experience of this led to heightened attention from their peers, for example, when they participated in cancer fund raising activities at their school. Some young people in middle adolescence also embraced the lionising attention they received. Participants in older adolescence and young adulthood engaged with different organisations to celebrate their own survival and the survival of others like them, to raise public awareness of the issues faced by young people who have had cancer, and to raise funds for ongoing research into and treatment of young people with cancer. To extend the metaphor of celebrity, these participants became “stars”. A star is someone who achieves prominence through the cultivation of a public persona in addition to and more important than their professional profile [248]. Older adolescents and young adults who embraced the attention they received from others capitalised on the attention they received by using it to mark themselves as special (to be different in a desirable way). Cancer illness and treatment therefore facilitated the process of growing up for some young people by providing them with opportunities to showcase their individuality.

Receiving heightened levels of attention from peers was not the only way in which middle adolescents were marked as different from their peers. They were also marked as different when they experienced arrested and accelerated development, that is, when they fell behind or leapt ahead of their normal process of growing up.

9.2.3 Growing up with peers: The paradox of arrested and accelerated development
One impact of cancer illness and treatment on the experience of growing up was to both hold back development and to accelerate it. This was especially evident in participants who were diagnosed during middle adolescence. Being held back was a process of arrested development that produced an unusually slow transition towards a peak of physical development. Leaping ahead was a process of accelerated development that produced an unusually rapid transition towards a peak of physical development.
Participants experienced arrested development when they missed out on both day-to-day experiences and the events that marked their rites of passage that they would normally have shared with their peers. Day-to-day experiences characterise the pursuit of daily life and each one appears insignificant in isolation from the others. However, for participants who were denied access to those experiences over a prolonged period this meant that the interactions of daily life that relied on sharing a common experience were also denied. Rites of passage, on the other hand, are marked by special rituals or events that indicate a young person’s progress through adolescence to adulthood. They also missed out on these events which meant that they could not relive the experience with their peers later in life.

When they miss out on attending events that mark rites of passage because of illness, many young people will have opportunities to experience them for themselves after their treatment finishes. However, they may experience significant events and rites of passage differently to how they expected if they do not share them with their cohort. Under these circumstances, young people are likely to feel “out of step” with their peers because they do not have access to the collective memories - and the feelings they evoke - of experiencing special events together. This feeling of being “out of step” is likely to persist for as long as a particular peer group remains important to a young person.

Some participants managed their loss by attending social events that marked different rites of passage. These included higher school certificate examinations and “schoolies week”. They generally did so with a cohort with whom they had little experience in common, such as members of a different year at school. Their experience of those events was unsatisfying.

Participants diagnosed in early or middle adolescence experienced accelerated development because of the wisdom and insight they gained from confronting a life threatening illness. Accelerated development was marked by a desire to help others both informally and professionally. It manifested through feelings of empathy in participants for the suffering of others – an empathy that they did not see in their peers. Accelerated development had the potential to enhance identity when young people’s wisdom and insight was acknowledged by their peers.

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19 Schoolies week is an interstate holiday marketed by tour companies as a celebration of the end of schooling. Middle class young people migrate to the beach to party.
Participants responded to their accelerated development by offering to share their wisdom and insight with their peers and to plan for careers in social work and health care (where their insight into the experience of illness might prove valuable). Sharing their wisdom and insight was a way of marking themselves as special. They were able to offer their peers access to the lessons they had learnt during their cancer experience. Claiming to be special carried risks, however, because claims of wisdom and insight were not always accepted by others. This demonstrated how social identities are constructed in social interactions. In other words, participant’s claims to possess a special identity were validated only if their peers recognised them as special.

“Falling behind” and “leaping ahead” marked participants as different to their peers. When both occurred simultaneously it was experienced as a paradox. Being different was felt most acutely in mid-adolescence for reasons I have outlined above. The paradox produced a number of outcomes. Some tried to maintain contact with their peers in order to limit the cumulative effect of missing out on day to day experiences. Others tried to recapture the experiences they had missed out on during their cancer illness and treatment. They did this by going out and doing some of the things that their peers had done but that they had no opportunity to do during their illness and treatment. However, the day-to-day experiences cannot be recaptured. They had to learn to live with this particular difference.

9.2.4 Meeting New Acquaintances
Growing up means (among other things) entering new social worlds, making new acquaintances, and forming new kinds of relationships (i.e. intimate relationships of a romantic and/or sexual nature). Young people who survive cancer can expect to experience ongoing adverse physical effects of illness and treatment that are more or less obvious to others. They acquire a “discredited” identity when the effects of cancer are obvious to others and a “discreditable” identity when the effects are not obvious to others [242]. This affected young people interviewed in older adolescence and young adulthood regardless of when they were diagnosed. Therefore, participants took steps to manage information about their stigma by deciding how, when, and where to disclose their cancer experience.

All participants suffered ongoing adverse physical effects from their cancer illness and treatment. One of the things they had to deal with was signs of premature ageing. Premature
ageing is always stigmatising, whereas accelerated development has the potential to enhance one’s identity. Normally, young people rise towards a peak of physical strength and ability as I have outlined in section 2.2. After young people reach their peak, a long period of physical decline ensues. Participants in this study experienced this decline without having experienced the peak of physical strength and ability that they would normally expect to experience and that their peers experienced. Premature ageing signifies redundancy and participants had this in common with elite sportsmen and women whose sporting careers end in their thirties when they still look “young” but when their bodies can no longer perform to the standard required of them [252]. The implications of premature ageing were that young people feared being stigmatised by others. Some feared that this might reduce their chances of meeting a new romantic partner and forming new intimate relationships. This resulted in consternation about how and when to tell new acquaintances about their cancer history.

Participants managed the process of disclosing their cancer experience in various ways. All participants said they made their disclosure soon after meeting a new acquaintance so that their cancer experience did not become an issue later on. Some participants involved their friends in the process of disclosure and made a joke of the ongoing physical effects of illness and treatment to show that their cancer experience was no big deal. Others chose a private location to disclose their cancer experience one-on-one to another person. The location and the level of privacy young people chose for their disclosure sometimes reflected their aspirations or the importance of the issue for the development of the relationship. Participants chose settings that were most private when disclosing to acquaintances with whom they hoped to enter into a romantic and/or sexual relationship.

The risks of not disclosing their cancer experience are that they will be “outed” as a cancer survivor in the future, and this might threaten a new friendship. The risk of being outed for young cancer survivors is that the aspects of their cancer identity that are stigmatising might dominate those that enhance identity. Being “outed” might also make them vulnerable to allegations of inauthenticity, dishonesty, or duplicity which are all potentially destructive to a romantic or sexual relationship of any duration and in any age group. Further risks of disclosing are that their cancer experience will scare off a potential romantic partner. Disclosing a cancer experience taps into culturally dominant discourses of cancer such as the perception that cancer is necessarily fatal. New romantic partner’s responses to a young person’s disclosure of his or her cancer experience will likely be informed by dominant
cultural discourses such as these. The dominant cultural discourse of cancer as stigma has the potential to scare a new partner off before he or she has had time to understand what the disclosure means to them, to their partner, or to the relationship they are seeking to establish. For this reason and the others I have outlined above, the choices young people make about their disclosure of their cancer experience will influence the course of an acquaintanceship as it progresses into a relationship.

9.2.5 Growing up in New Romantic Relationships
Growing up in older adolescence and young adulthood normally includes exploring one’s sexuality and forming romantic relationships. Some participants formed new romantic relationships when the acute effects of cancer illness and treatment had passed. This worked best when their prospective partner accepted their cancer experience as part of who they were and were able to accommodate the ongoing effects of cancer illness and treatment into their relationship.

Many of the ongoing effects of cancer were more predictable than the acute effects had been. Follow-up hospital visits were planned in advance and medical treatment stabilised many of the ongoing physical effects of cancer illness and treatment. Some participants managed ongoing mental health issues with regular counselling sessions. During these sessions they developed communication skills that enhanced their ability to manage their emotions and to communicate their feelings to their partner. The ongoing effects of cancer were therefore more easily integrated into the routines of daily life than the acute effects of illness are.

Despite their predictability, some ongoing effects had an impact on new romantic relationships. Some participants continued to attend regular follow-up appointments and medical surveillance procedures that required planning and time commitment. Young people and their partners had to negotiate how the requirements of follow-up would fit into their daily lives. Young people also felt anxious about the possible outcomes of these procedures. Their anxiety sometimes made them short tempered and sometimes led to social withdrawal. They had to discuss the reasons and strategies for managing their changes in mood with their partner.

Couples were also required to discuss aspects of sexuality that they would normally have put off until later in life. This was especially important when young people were uncertain about
whether they were fertile. Some women were fertile when they had been told by health care practitioners that they were infertile. They therefore became pregnant when they did not expect to. Fortuitously, pregnancy and child birth gave some young women a direction in life that they felt they had lacked as a result of illness and treatment. Managing the ongoing effects of cancer contributed to the development of intimacy between some young people and their partners which helped increase the security of their relationship.

Young people spoke about other aspects of sexuality, such as the impact of cancer on sexual desirability and behaviour, much less explicitly than they did about fertility. Sexual desirability was discussed by some young women in terms of their feelings about their physical appearance, especially with regard to hair loss and scarring. One participant spoke about the challenges she experienced initiating sexual encounters with her boyfriend shortly after treatment. No young women spoke of the impact of cancer on their sexual behaviour in the longer term (i.e. years post treatment), however. One young man spoke of his desire for a girlfriend at the time of his interview. Others spoke only of a desire to find a sexual partner at an unspecified date in the future.

In summary, accommodating the ongoing effects of cancer into a romantic relationship made the relationship more serious than young people believed it would have been if not for their cancer experience. This meant that participants and their partners had to interact in mature ways, by practicing effective interpersonal communication, to make the relationship work.

9.3 Significance of the Study Findings

9.3.1 Relationships with Parents

9.3.1.1 Social Support Provided by Parents

Parents provide social support to their children during illness and treatment, especially during early and mid-adolescence [117-119, 121-124, 205, 253]. This support is framed in terms of what parents do for their child. What they do can be as simple as “being there” for their hospitalized child to provide comfort, hold their child’s hand, to prevent loneliness, to foster a positive attitude and to treat their child as normal in a serious and abnormal social situation [126]. It can also be as complex as learning how to carry out medical procedures for their child and providing advice about life [127]. Cantrell and Conte report that their participants experience a paradox in which [young people] want others to talk with them about their

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20 I use the term children in this section to indicate the parent’s perspective of the young person with cancer.
experiences, but they are disappointed when others treat them different [77] (p. 318). Findings from this study support those of Cantrell and Conte in that participants were projected forward emotionally in relationships with their parents because of their hospitalisation and treatment. My findings support the notion that parents attend hospital and stay at their child’s bedside in order to provide care for them in various ways. Sometimes they also mediate interactions between their children and the health professionals caring for them. Young people rely on their parents to fulfill these caring and supportive roles during illness and treatment. “Being there” to provide care for a sick child is a strong cultural expectation. As I described in section 6.2.4, the exceptions to this cultural norm are unusual and remarkable.

Findings from this study expand our understanding of what it means for a hospitalized child to experience their parents as “being there” for them during illness and treatment. My findings highlight interactions between parents and their children beyond those that can be explained with reference to cultural norms. They highlight the new ways in which parents relate to their children when they share the intense experience of cancer illness and treatment. Parents initiate or take part in conversations that facilitate a more equal relationship between them and their child. This adds a dimension to the child-parent relationship: it suggests that sharing the experience of cancer illness and treatment fundamentally changes the nature of the relationship from that of child and parent to that of equals. This provides opportunities for further research into the nature of this changed relationship, including its longevity, from the perspectives of young people and their parents.

9.3.1.2 Parental Over-Protectiveness
Confronted with a serious and potentially fatal illness in their child, parents can become over-protective [48, 254]. Over-protectiveness is sometimes described as being problematic for young people because the increased time they spend with their family compromises their privacy [218]. Parental presence in hospital can also stifle a child’s developing independence. Descriptions of parental over-protectiveness relate to the period of illness and treatment and recommend creating a social space in which young people can assert their autonomy and continue their struggle for independence [48]. This is a particularly medico-centric perspective as the aim of young people asserting their autonomy during hospitalization is to improve compliance with treatment. I have described how this shapes health policy regarding
the transition of young people from paediatric to adult health care institutions in New South Wales in section 3.6.

Findings from this study add insight into the impact of parental over-protectiveness on young people in the period of remission and recovery. The protection of a child normally associated with concerned parenting may be experienced as overly protective by a young adult struggling for her independence. This contrasts with findings from previous studies that describe the impact of parental over-protection on young people as being especially relevant during the period of illness and treatment. It does so by expanding the concept of independence to those social processes normally undertaken by young people within their usual social worlds.

9.3.1.3 Loss of Independence

The notion of independence in Western culture typically focuses on individual self-sufficiency and non-reliance on other people [23]. I described the theoretical basis for this in chapter 2 when I referred to the concepts of individualization, “do-it-yourself biography”, and the Reflective Project of Self [27, 29, 31]. From this perspective, the major concern for young people with cancer is their capacity to engage in the process of making their own decisions related to their care (see section 3.6 above). Independence in these terms is about the young person taking responsibility for her own illness and treatment. Participants in this study expressed views about their independence that were consistent with this perspective.

Loss of independence is therefore a problem for young people diagnosed with cancer. However, the problem is exacerbated in late adolescence or young adulthood. Cancer illness and treatment can effectively throw young people in this stage of development back into the care of their parents [85]. They can also experience difficulties re-establishing their independence after treatment has finished and before their physical and financial resources are restored [169]. Findings from this study support these notions of independence as being lost and regained.

Independence is experienced in physical, emotional, and financial domains of life both during and after treatment [85]. Grinyer argues that each of these aspects of independence is inter-related. Grinyer carried out her study in England where the cost of treatment is covered by the National Health Service (NHS). The loss of financial independence for participants in her
study is not, therefore, related to the financial cost of treatment as might be expected in a privately funded health care system such as that of the United States. Rather it is related to the loss of employment and subsequent income that cancer illness and treatment brings about. The Australian health care system is funded by a combination of public (state-funded) and private insurance. We might therefore have expected financial independence to be compromised by participant’s cancer illness and treatment in this study. However, this was not obvious from the interviews. One explanation for this is that only one participant was in full time employment when she was diagnosed. The rest were enrolled in full-time study at various institutions. Those students employed on a part-time basis before their diagnosis spoke about leaving their jobs during illness and treatment, but not about the financial impact of doing so. Some spoke about receiving social security benefits to supplement their income, but most did not talk about their financial independence at all. We can infer therefore that participants were financially dependent on their parents during their period of illness and treatment but that this dependence was of little concern to them.

Findings from this study contribute new insights into the inter-relationship between physical and emotional independence experienced by young people who have had cancer. Late adolescent and early adult participants regained the capacity to care for their own physical needs which enabled them to move out of the family home after treatment finished. However, a tension arose at this time because of the strong emotional bond young people developed with their parents during illness and treatment. This emotional attachment may have caused tension by challenging late modern conceptions of independence as self-sufficiency rather than as interdependence with others. These findings would be enhanced by more research into the process of renegotiating independence that uses a framework that conceptualises independence as explicitly relational rather than as self-sufficient and self-reliant.

9.3.2 Relationships with Peers

9.3.2.1 Stigmatising Attention and Social Support
Findings from this study in some ways support those of previous studies that describe young people’s experiences of returning to their usual social worlds, especially those diagnosed in mid-adolescence who return to school. Young people who return to school fear social isolation, being left out by their peers, and have difficulty fitting back in with their peer group [74, 107, 128]. This was the case especially for participants in this study diagnosed in mid-adolescence and has been explained as a response by young people to their altered
embodiment and existential fear [107]. Previous studies have found that young cancer survivors report being bullied or victimised [214, 215]. This threatens one of the central reasons for returning to school – to regain a sense of normality [214].

Previous studies have also found that peers play a central role during the period of illness and treatment by treating young cancer survivors as normal and by helping young cancer survivors return to normal during their period of remission and recovery [83, 126]. The “peer shield” is designed to protect young cancer survivors from being singled out as different (i.e. abnormal) in certain social situations [93]. These studies describe what peers do for their friend with cancer rather than how they relate with them however.

Findings from this study support those of previous studies. Participants evidently experienced bullying behaviours ranging from insensitivity to their condition to harassment that was so severe that they felt it necessary to change schools. They were ostracised for violating norms of appearance, attendance and achievement. However, young people received two types of attention from their peers when they return to school: stigmatising attention and lionising attention. It is not only stigmatising attention that participants experienced as uncomfortable or threatening. Both mark young people as different from their peers. Lionising attention is thus less than helpful to young people diagnosed in mid-adolescence because similarity to peers is critically important to young people in this age group.

This study is the first to explain the phenomenon of lionising attention in terms of “celebrity”. The concept of support focuses on the benefits to the young cancer survivor of returning to normal. Support is seen as a good thing that is provided by people who have the best interests of the young cancer survivor at heart. The concept of celebrity deliberately positions young cancer survivors as special. Quasar celebrity holds no particular benefit for young cancer survivors and is experienced negatively by some. However, some young people capitalised on their stardom for their own benefit as well as for the benefit of other young people with cancer. We can speculate that the “fans” derive some kudos or social capital from providing such attention. However, this contention would need support from further research that explored the phenomenon from the “fan’s” perspective (i.e. the peers who provide the lionising attention).
9.3.2.2 The Paradox of Falling Behind and Leaping Ahead
Recent research has described young peoples’ experience of cancer survival as a paradox [77, 78, 171, 255]. Cantrell and Conte, for example, report that their participants had been “projected forward” in their emotional development despite spending a portion of their adolescence in treatment [77]. My findings support these findings of the experience of growing up with cancer as one that is characterised by the paradox of simultaneously accelerated and arrested development.

Grinyer has argued that cancer illness and treatment disrupts young peoples’ life trajectories because they gradually miss out on developing a sense of common experience with their peers [85]. The significance of this according to Grinyer is that reintegration into usual social worlds is more difficult for young people after their treatment finishes. In other words, Grinyer focuses, like those described in the section above, on the difficulty young people experience returning to normal after their cancer experience. She recommends ways for health care teams to facilitate ongoing social contact between patients and their peers and the benefits this has for young people during illness and treatment and during their return to their usual social worlds. However, findings from this study suggest that the impact is more far reaching than this. Missing out on sharing day to day experiences and events that mark rites of passage with their cohort denies young people common experiences that form the “currency” of social interactions in later life. Some topics of conversation and the memories and feelings they evoke that are available to their peers are subsequently unavailable to young cancer survivors. Therefore, they continue to miss out during social interactions that rely on a set of common experiences.

9.3.2.3 Wisdom and Insight as Benefits of the Cancer Experience
Surviving a life threatening event can result in a process of finding benefit in the cancer experience. For young cancer survivors, this manifests in feelings of greater empathy for those who are suffering and, for some, in pursuing careers as health care professionals [176, 183, 207]. Young people have also been reported as feeling more mature than their peers [74, 76, 211, 212]. These are reported as positive outcomes of having cancer, the negative side of which is potential social isolation and difficulty fitting in with peers.

The younger participants in this study also described being more mature than their peers because they believed they had more wisdom and insight into life than their peers did. Greater wisdom and insight is usually described as a positive outcome of or a benefit found in
the experience of cancer illness and treatment for people diagnosed in middle early or middle adolescence. However, findings from this study suggest that it also marks a point of difference between these young people and their peers. As I have described, being marked as different from peers is undesirable and can be distressing for young people growing up in this phase.

Being different is not however the same as being socially isolated from or rejected by peers. Participants in this study used their wisdom and insight as a catalyst for negotiating new ways of fitting into their old peer group. Fitting back in is problematic when peers do not accept young cancer survivor’s newly developed wisdom and insight. According to Goffman, the credibility of our identity is limited by the extent to which others accept our “performance” of a particular role [243]. For young cancer survivors to credibly perform the roles of wise and insightful person therefore requires their peers to recognise and accept them as such.

9.3.3 Physical Effects of Cancer are Ongoing

9.3.3.1 Physical Dysfunction and Signs of Premature Ageing
Physical effects of cancer can be ongoing and include fatigue and pain [99, 107]. These effects can reduce self-esteem and confidence in social situations [101, 105]. These adverse outcomes are usually linked to young people’s physical dysfunction that excludes them from participating in social activities with their peers. This perspective focuses on disability which is stigmatising in a particular way. Disability focuses on a person’s deficits or inadequacies. Disability can be distressing for young people, especially those who have led an active life before their cancer diagnosis. Findings from this study support those of previous studies that emphasise the pain and fatigue that is especially associated with illness and treatment which can persist for years after treatment finishes.

Findings from this study frame the ongoing effects of cancer illness and treatment as stigmatising but not as a disability. This is the first study to equate the ongoing physical effects of cancer with premature senescence and the stigma associated with premature ageing. Like disability, premature ageing is associated with decreased sexual desirability which is especially problematic for young people. Having a disability is compatible with being young, but signs of ageing are not. Living with a disability is therefore not paradoxical for young people who have survived cancer in the same way that living with signs of ageing is. For example, young women diagnosed with premature menopause can forgo their chance to be a
mother and this can challenge her anticipated identity as a mother [256]. Premature menopause is, like cancer, regarded as pathological and conforms to a deficit model of health and illness because it focuses on the loss of the physical capacity to bear children.

It is important to recognise signs of premature ageing as the ongoing effect of cancer as including pain, fatigue, and cognitive impairment are well known and predictable side effects during treatment. Dry eyes and aching knees are less well known and emerge as problems as recovery progresses.

9.3.3.2 Sexuality and Reproduction
Sexuality is almost always dealt with in terms of the impact of cancer on bodily function, puberty, and fertility [135, 137]. Studies have focussed on the risks of infertility associated with treatment and the various options for preserving the fertility of both young men and young women [140]. A medico-centric focus on the effects of cancer illness and treatment on the reproductive aspects of sexuality tends to marginalise the consequences of this for relationships. I have described Crawshaw and Sloper’s study which focuses on the risks to a sexual relationship of attempting to conceal one’s infertility (see section 4.2.3.2 [158]). Crawshaw and Sloper found that young men feared being “outed” as infertile when their partners failed to conceive. Findings from this study support those of Crawshaw and Sloper by highlighting how the stigmatising effects of cancer illness and treatment complicate the processes of disclosure to new acquaintances and the processes of developing new relationships.

Findings from this study also add new insights into the experience of young people whose fertility status is uncertain after their treatment of cancer. Specifically, findings from this study provide new insights into the experience of young women who become teenage mothers when they assumed they are infertile. Having children can provide direction in life that is often absent for young cancer survivors.

Findings from this study also provided new insights into the experience of conducting relationships of a romantic and sexual nature by highlighting the reciprocal processes involved in accommodating the ongoing effects of cancer into a new relationship. While it is well known that cancer illness and treatment forms part of a young cancer survivor’s self-identity, the implications of this for conducting new relationships are less well known.
The impact of cancer on young men’s and women’s fertility has been widely studied (e.g. Sweet and Karow [141], Zebrack et al [149]. However, there is a gap in our current knowledge about the experiences of young men who have survived cancer in the area of new relationships of a romantic or sexual nature that requires further research.

9.3.3.3 Sexuality: Sexual Expression
The development of a young person’s sexual identity has been reported in two ways. One has been to report the adverse impact of cancer on body image and subsequent decrease in self-esteem and self confidence, especially for young women [87, 216]. Young people have also reportedly experienced delays in reaching their psychosexual milestones, such as dating, masturbation, and sexual intercourse [115]. Young women in this study spoke at length about the new romantic relationships they had formed since their treatment for cancer had finished which was to be expected given findings from recent studies. However, few young women spoke about the impact of cancer on their libido or on their sexual behaviour. None of the young men who participated in this study had commenced a new relationship of a romantic or sexual nature after their treatment had finished. This is unsurprising given the findings of other recent studies of young men who have survived cancer [216].

9.4 Study Limitations
There are several possible reasons for the difficulty we experienced during our initial recruitment phase. First, we invited participants to engage in a number of different activities that took place in different locations, some of which might have been inconvenient for young people to attend either because of their timing or location. Some participants were under 18 years old and might have been reliant on parents or older siblings for transport, and the latter might not have been available at the required times. Second, the multiple arms of the study might have proved daunting for recipients of the information packs and may have discouraged them from volunteering. The idea of creating a “self-portrait” might also have discouraged some people from volunteering. One participant suggested that she found the idea of creating a visual representation of herself to be confronting. Third, we promoted the self-portrait activity as an artistic process. Some participants warned the research team that they did not consider themselves to be “artists”. These potential participants therefore might have feared that their self-portraits would be judged on artistic merit and found to be unacceptable. This fear might have deterred them from participating in any of the activities proposed by the research team.
The resolution we chose to overcome our recruitment problem might also have added to the study’s limitations. The success of our recruitment strategy by CanTeen staff members meant that 14 of 27 participants were active CanTeen members (three others said they were members but did not participate in CanTeen activities). This was a potential problem for the balance of the sample because CanTeen members are likely to have a different perspective on the role of peer support in their cancer experience than non-members. The experience of participating in activities run by CanTeen might also shape how young people learn to talk about their cancer experience because of the opportunity CanTeen gives young people to “rehearse” their story. This could reduce generalisability because CanTeen members are a small subset of a broader category of young people with cancer. However, there was no obvious difference between CanTeen members and non-members in the interview data collected.

The time elapsed between diagnosis and participation in the study was likely to be significant in that time provides people with opportunities to reflect on their cancer experience. I did not explore the effect of “time since diagnosis” on the interview, however. Nor did I explore the experience of relapse with participants, which is also likely to be significant for different reasons.

Like all interviews, my data was limited by what the participants chose to tell me at a given time and in a given place. Some interviewees had to finish their interview earlier than they would have liked in order to attend social engagements. Some were distracted by having to care for their children. One participant conducted her interview between appointments in a hospital outpatient clinic which caused us both to be distracted from time to time.

Finally, some participants might have more or less insight into their experience than others. Some participants had clearly reflected deeply upon their experience over many years and still had trouble making sense of their cancer experience in terms of its effect on their experience of growing up. Others could recount a well-rehearsed, cogent, linear narrative which addressed this issue explicitly and in detail.

9.5 Practical Implications
My conceptualisation of young people is informed by the disciplines of biomedicine, psychology, and sociology. This thesis, therefore, is a cross disciplinary examination of the impact of cancer illness and treatment on the process of growing up. My thesis has practical implications for young people, their family members, and members of their peer group.
While I have focussed on the social implications, my findings are likely to provide insights for researchers and healthcare practitioners in nursing, medicine and psychology who are concerned with the effect of cancer on the experience of growing up. I will conclude by outlining how these findings might be used by those directly involved in the care – informal and formal, medical and social - of young people who have had cancer.

9.5.1 Implications for Families
Children depend on their parents when they are sick. This is especially so during serious illness and hospitalisation. Parents of young people with cancer can respond by being dependable and by “being there” for their child. “Being there” means being physically present in the hospital or wherever treatment is being carried out. Being physically present gives parents the opportunity to provide care for their child and children usually appreciate this. It also means being present emotionally. Findings from this study suggest that relationships between parents and their children who have cancer can become more equal during illness when they share the experience together. Sometimes a child who has grown into young adulthood and has moved away from the family will need to come back home because he or she has trouble caring for herself. Cancer can be physically debilitating. Returning home is often a process undertaken during the crisis of cancer illness and treatment. Whilst it can enrich family life, it can also make regaining lost independence difficult for young people as their period of remission and recovery progresses.

Later, when an older adolescent or young adult recovers from their cancer, she may take steps towards regaining her lost independence, for example, by moving away from the family again. This can be a stressful time because children and their parents are likely to experience a strong emotional bond as a result of sharing the intense experience of cancer illness and treatment. Findings from this study suggest that their second separation from the family might be easier if both children and parents acknowledge and value the bond they have developed. Parents may also need to resist the temptation to continue playing the role of protector of their child, lest they hamper the process of growing up.

9.5.2 Implications for Peers
A friend who has had cancer will return to school when she is well enough. This does not always mean she is cured or that she has stopped being treated for cancer. For these reasons, she is likely to return to school on a part-time basis. It also means that she is likely to be physically and emotionally fragile. Being fragile can include being fatigued or having muscle
weakness as a result of illness and treatment. A young cancer survivor is likely to claim that she has returned to normal, however, and she need not be treated differently to how she was before her diagnosis. These conflicting messages may be difficult for the peers of young people to understand and they may not know how to respond to them.

There is no easy way to deal with this. However, some strategies may help. It is important to help young people join in physically strenuous activities when they can, but it is also important to enjoy quiet activities with them when they cannot. Findings from this study suggest that quiet nights at home with a DVD are a good way for friends to support a young person who has had cancer without worsening the symptoms of fatigue. However, it is best for friends to be guided by what the young person feels capable of doing. Friends need not feel guilty about enjoying physically strenuous activities that a young cancer survivor is unable to participate in.

Friends also need not be afraid to talk about the cancer experience. Findings from this study also suggest that they can ask questions about the experience of illness or treatment or they can tell the young person about some of the events that have taken place while she has been away. Friends can also talk about how they feel about the young person and her cancer experience. The important thing is to talk about the cancer experience sensitively. What this means will vary from person to person, but findings from this study suggests that talking about the cancer experience at the right time and in the right place can be beneficial for both young people and their friends. For example, a good time to talk about the cancer experience is when young people and their friends are relaxing. A good place to talk about the cancer experience is somewhere private where the possibilities that other people might intrude on the conversation are minimal.

9.5.3 Implications for Cancer Support Groups
Joining a formal cancer support group does not suit everyone. However, these findings have practical implications for the types of services cancer support groups can provide. Most participants valued their membership of a formal cancer support group. They especially valued the support they received when they were acutely unwell and when it was important for them to talk about their cancer with other people who shared a similar experience to them. Some also spoke of valuing the opportunity to provide support for other young people with cancer through their participation in a formal support group. Nevertheless, there may be
opportunities for formal groups to support young people in different phases of life and disease.

Cancer support groups may be well situated to facilitate school reintegration when the ongoing effects of cancer illness and treatment are primarily social. When social effects are combined with ongoing adverse medical effects for a young person, school reintegration could be facilitated by a cancer support group in collaboration with the multi-disciplinary health care team. The risk of the multi-disciplinary health care team alone facilitating school reintegration is that ongoing effects of illness and treatment can be inadvertently portrayed as pathological when, as findings from this study suggests, they are aspects of a social process that requires ongoing negotiation between young people and their peers, teachers, and parents.

The opportunity also exists for cancer support groups to play a more prominent role in helping young cancer survivors accommodate the ongoing effects of cancer in their usual social worlds. They could do this by including friends and romantic partners in some of the support group’s activities. For example, groups that support middle adolescents who have survived cancer could facilitate activities to which members can invite a friend (or two friends). Such activities could bridge a gap between the world of the cancer support group and the member’s usual social worlds and perhaps help to demystify aspects of the cancer experience for those removed from it. Groups that support young adults who have survived cancer could facilitate activities, for example, weekends away that support their member’s developing romantic relationships. Discussion groups could be conducted about the impact of cancer on sexuality including the impact on communication about sex, fantasy, bodily sensation and pleasure, as well as the impact of treatment on reproduction. Activities such as these might provide practical support for the relationships that are most important in members’ lives.

**9.5.4 Implications for Health Care Professionals**

Findings from this study have implications for clinical practice for health professionals caring for young people with cancer during illness and treatment and when young people return to their usual social worlds when treatment allows.
Acute illness that requires hospitalisation and different treatment regimes may limit young people’s opportunity to interact in their usual social worlds. Young people in middle and late adolescence may miss out on significant events that mark their rites of passage as a result. Missing out is likely to be a disadvantage to them during social interactions in later life because it denies them access to the social “currency” that these events provide.

Every effort should therefore be made by health professionals to facilitate the young person’s attendance at any important social event. Young people can never recapture the experience of participating in significant events with their peers when the opportunity to do so has passed. Health professionals may therefore have opportunities to negotiate the modes and the timing of treatment delivery in order to maximise their patient’s chances of attending various social events outside the hospital. This is likely to involve being flexible about the mode and timing of treatment. It may also mean collaborating closely with parents to ensure patient care can be safely managed outside the hospital.

The ongoing effects of cancer can highlight the differences between young people with cancer and their peers. This is problematic for young people being treated in mid-adolescence because identification with a peer group is important to the process of growing up in this phase of life.

School staff and patient’s peers may benefit from education around the range of issues faced by a young person with cancer. However, education of peers should proceed cautiously in order to limit the impact of differences on the relationships conducted between patients and their peers. Health professionals may have to withdraw from directly telling peers about the patient’s cancer experience by preparing patients to discuss their own illness and treatment with their peers. Health professionals could continue to educate teachers about the impact of cancer on young people emphasising that the ongoing effects of cancer illness and treatment mark young people as different to their peers and that this difference should be minimised.

Acute illness and cancer treatment is likely to result in loss of independence for late adolescents and young adults. The period of acute illness and hospitalisation may therefore be a suboptimal time in which to promote autonomy in this group of patients. Health professionals could promote patient independence by adopting a model of relational
autonomy that places at its centre the interdependent relationships between patients and others instead of a model of independence that focuses on self-sufficiency.

The implication for health professionals of promoting relational autonomy instead of self-sufficiency is that the strategy is most likely to succeed when it is supported by a model of care that explicitly included care for people important to the patient as well as to patients themselves. This may prove more challenging for health professionals working in the adult health care sector than for those working in the paediatric sector because paediatric health care delivery is dominated by a model of family centred care that is not prevalent in the adult sector.
References


Appendix 1: Growing Up With Cancer ARC (Linkage)
Grant Application
E1 Growing up with Cancer: A mixed methods examination of how cancer influences the transition from adolescence to adulthood

E2 AIMS AND BACKGROUND

During adolescence, young people develop an independent identity and the capacity to make and enact choices. It is also when their autonomy is recognised. A cancer diagnosis can have a profoundly disruptive effect on these crucial developments. This is a significant problem in Australia: from 1992 to 2001, almost 10,000 of Australia’s adolescents and young adults were diagnosed with cancer (Australian Institute of Health and Welfare data). Although there is increasing recognition of the need for cancer services that are tailored to the needs of adolescents, there is only one dedicated adolescent oncology unit in Australia. In order to develop such services further, we need to understand this population and the ways in which health services can facilitate maturation. In order to generate this knowledge, a partnership between CanTeen (the premier Australian organisation for young people living with cancer) and a multidisciplinary team researchers at the Universities of Sydney and Newcastle propose to investigate the effects of cancer on the psychosocial development of adolescents. The team will use mixed methods (established and innovative, qualitative and quantitative) to investigate the impact of cancer on the transition from adolescence to young adulthood. This study will provide important insights into adolescents’ experience of cancer and its treatment, and will generate multimedia resources that will contribute to knowledge and education of patients and lay and professional carers, and inform the design and delivery of cancer services for this patient population.

Aim: To generate insights that will inform the design and delivery of cancer services for young people, to help them cope with the transitions of adolescence and thereby maximise the likelihood of a healthy and fulfilling future. To this end, the research is designed to answer these questions:

- How do adolescents/young adults with cancer describe their experience of illness & healthcare?
- What are the effects of illness and treatment on the young person’s developing identity, relationships, capacity to act (agency) and autonomy?
- How does the experience of cancer and its treatment impact on the transition from childhood to adolescence, and from adolescence to adulthood?
- What are the specific needs of adolescents and young adults (AYAs) with cancer?
- What are the effects of providing AYAs with an opportunity to share their experience of cancer through creative expression?
- How do patients, parents and health professionals describe the involvement of AYAs in decisions about their care, and how do these descriptions change with transition to adulthood?
- How do the design and delivery of cancer services influence the identity, agency and autonomy of AYAs so as to scaffold the transition to adulthood?

Background and rationale

Adolescence is a period of promise and growth, and of changes that encompass every facet of life, including physical and sexual maturation, cognitive and emotional development, shifts in familial, social and vocational roles, acquisition of culture, and the establishment of an independent conception of one’s place in the world. These transitions are accompanied by changes in moral, legal, political and economic rights and responsibilities. Adolescence is thus a critical phase during which identity is constructed and reconstructed, agency is developed, and autonomy is recognised.

Achievement of and commitment to a coherent identity is the critical “developmental task” of adolescence (Erikson, 1968; Marcia 1966). Identity has been theorised as a psychological self-representation—the image of oneself as a unique, discrete entity with particular attributes that persist across space and time (Little et al. 2001; Gillies et al. 2004), an image that guides and motivates, and that manifests itself in a variety of roles in different social contexts (Adams et al. 1996; Harter 1999, Little et al. 2001). Identity is (re)constructed socially through relationships and language (dialogical exchanges and narratives) and shaped by socialisation and enculturation processes (Adams et al. 1996; Rose 1996). Adolescent identity is (re)constructed through changing relationships with authority figures and peers, and through rituals that demand self-transformation.
Adulthood (Gavaghan et al. 1987, Madan specifically address the impact of cancer on the development of identity and the transition to adulthood (Gavaghan et al. 1987, Madan Swain 2000). A developing adolescent gradually achieves agency (the physical, mental, relational and moral capacity for realistic choice and its enactment). As maturation of identity and development of agency come to be recognised, adolescents gain the moral and legal status of an autonomous person.

Adolescent development can be profoundly disrupted by major life events such as serious illness. The experience of cancer and its treatment has a profound effect on young patients and their families. Treatments typically involve prolonged hospitalisation and repeated medical procedures that are risky and invasive. Patients must cope with the effects of the disease itself, complications of therapy, isolation, uncertainty about survival, and changes in appearance and body image. Even if treatment is successful, survivors may have to live with secondary cancers, infertility, sexual dysfunction, neurocognitive and/or cardiovascular problems (Dickerman 2007; Meadows 2006).

Cancer can have profound psychosocial effects by threatening self-efficacy and fulfilment of social roles, physical and existential security, memory, imagination of “possible selves”, and sense of continuity (Fitzpatrick 2002; Little et al. 2001; Ruvolo et al. 1992). These challenges are doubly difficult for adolescents who have to navigate, while seriously ill, the most significant transition period of their lives. Cancer illness may preclude normal developmental tasks of adolescence (developing self-worth, peer relationships, independence from parents) and prematurely confront adolescents with issues such as mortality and fertility. Ongoing treatment is a daily reminder of difference from peers and the possibility of further health problems or death (Dobbels et al. 2005). Many survivors curtail their lifestyle to minimise the risk of recurrence (Cox et al. 2005). Physical and psychological effects of cancer may disrupt identity formation and the development of agency and capacity (Madan-Swain et al. 2000; Gavaghan et al. 1987; Smith et al. 1991).

The experience of cancer in adolescence also raises a number of ethical issues, particularly around decision-making. Assessments of adolescents’ “best interests” and “capacity” to make decisions may affect how much they are told about their prognosis and the short- and long-term effects of therapy, and may also determine whether they are allowed to make their own treatment decisions. Where adolescents are not deemed to be autonomous, parents play a key decision-making role – with significant long-term effects. For example, some parents may shield their children from information that may cause stress and anxiety about potential future problems at a time when their child is already sick and scared. Yet information about long-term effects – especially infertility – can be especially important to adolescents (Earle et al. 2005; Zebreck et al. 2004), and withholding it deprives them of options (e.g. taking steps to preserve their fertility). This can engender feelings of betrayal, undermine trust and lead to non-compliance with ongoing surveillance and treatment.

Given these complexities, adolescents need services that are socioculturally appropriate and ethically robust, and that provide the necessary psychosocial and fiscal support, physical resources and research (Barr 1999). This is difficult to achieve: few health-care facilities have the infrastructure to provide psychosocial support services of adolescents or programs assisting transitions to adult facilities (Thomas et al. 2006), and patients are treated in hundreds of non-specialist hospitals dispersed throughout Australia, where the adult hospital system does not currently have age-specific psychosocial supports for young people with cancer (Thomas et al. 2006). The need for such services is recognised by CanTeen, the NSW Cancer Institute, the Greater Metropolitan Clinical Taskforce and the Commonwealth Senate, yet there is but one dedicated adolescent oncology unit in Australia at the Princess Margaret Hospital in WA.

For adolescent cancer services to adequately meet the needs of this population, we need a detailed understanding of the impact of cancer on this population. While the literature is replete with descriptions of the acute and physical late effects of cancer (McGregor et al. 2007; Meadows 2006), little is known about the adolescent experience of cancer (Bleyer 2005) and very few studies specifically address the impact of cancer on the development of identity and the transition to adulthood (Gavaghan et al. 1987, Madan-Swain 2000).
E3 SIGNIFICANCE AND INNOVATION

E3.1 Significance
This project will generate specific recommendations about how cancer services should be tailored to the needs of adolescents and young adults so as to facilitate their transition to adulthood. Over the last 30 years, improvement in relative survival for 15-30 year olds with cancer has been the lowest of all age groups (Bleyer et al. 2006), and in recent years the number of people diagnosed with cancer in the age group has risen by more than 30% in Australia and throughout the world (Reis et al. 2001). Despite this, few health care facilities have the specialized infrastructure needed for dedicated psychosocial support of adolescents and/or programs assisting transition of younger patients to adulthood. The importance of these problems, and of the important role that health services can play, have been recognised by a recent Senate Inquiry and by the Greater Metropolitan Clinical Taskforce. Our industry partner, CanTeen (Australia’s leading support organisation for young people with cancer) is advocating for a new model of care for young people with cancer. This project creates a platform for collaboration between CanTeen and a multidisciplinary team of researchers, to create the knowledge that is needed to construct this model of care.

This research will provide a rich account of the many ways in which cancer affects the transition from adolescence to adulthood. This project foregrounds a central aspect of adolescence: that it is a time of physical, sexual, and psychosocial transition in which individuals forge an independent identity that allows them to take up their place in the wider community. It is also a time of ethico-legal transition, as individuals develop agency and cognitive maturity and come to be recognised in law as autonomous individuals. The findings will have broad implications for the design of health care services, for our understanding of illness, and for the measurement of outcomes of care.

E3.2 Innovation

Conceptual innovation. This project is innovative because it examines the effects of cancer on the transition from adolescence to adulthood, the development of identity and agency, and recognition of the capacity to be involved in decisions about care (autonomy). This is conceptually significant because it recognises: that identity and agency are the chief developmental tasks of adolescence and their disruption is likely to have significant psychosocial, moral and legal impacts; that issues relating to identity and agency underpin ethics; that understanding the impact of cancer on a young person’s identity will add much to our knowledge of the specific needs of cancer survivors; and that attending to the impact of illness on a young person’s identity and ‘place in the world’ shows more respect for them than assuming they can be understood simply by reference to their disease.

Methodological innovation. This research is methodologically innovative firstly because it combines methods of visual arts research with methods of qualitative and quantitative social research to produce a rich description of the impact of cancer on an adolescent’s transition to adulthood. Secondly, by studying the views of both AYAs with cancer and also of their peer-group, carers and parents, this project will provide the most comprehensive account of the adolescent cancer experience to date. Third, the project recognises the increasing visual literacy of young people, and their preference for electronic multimedia as means of self-expression and communication. Finally, the research will create multimedia resources that will ‘live’ beyond the project, be relevant to different populations, and contribute to the lives of study participants.

How the research advances the knowledge base of the discipline
This study will expand understandings of the psychosocial, cultural and moral impact of illness in childhood and adolescence. Cancer research often focuses on a narrow range of outcomes and studies people in isolation from community and social context. In contrast, this study explicitly
focuses on the important social, psychological, sexual, biological and ethico-legal transitions that occur in adolescence and the ways that these may be altered by the experience of cancer. This will provide a much richer account of illness in adolescence and will provide a model for future studies. The findings of this study will make a significant contribution to evidence-based bioethics. This study will move beyond the dichotomy between principle-based bioethics and empirical social science. It will present a research model that socially contextualises ethics by operationalising key ethical and legal concepts such as agency and autonomy in empirical social research.

**E3.3 Relationship to Priority Areas**
This project will contribute to Australia’s National Research Priority of Promoting and Maintaining Good Health by ensuring that adolescents and young adults (AYAs) with cancer are provided with the support they need to make the transition into adulthood. It will provide a psychosocial and ethical evidence base for policymaking and clinical practice around adolescent cancer care, generate improvements in health services delivery for AYAs with cancer and support programs for AYAs who have survived cancer, and thereby help to endure that young Australia with cancer have the best possible chance of leading independent, productive, and fulfilling lives.

**E4 APPROACH AND TRAINING**
This project is a 3-year mixed-methods study of the experience of adolescents and young adults (AYAs) who are currently being treated for cancer or who have completed treatment and are in remission. The project will focus on the impact of cancer and its treatment on transition to adulthood. A variety of qualitative data will be generated. Some will be used for educational materials (ideally including a documentary film) and an art exhibition. Qualitative findings will be ‘triangulated’ using validated quantitative psychometric measures of identity, anxiety and depression and quality of life. To capture the range of views about AYAs with cancer and their involvement in treatment decisions, we will investigate the views of four different groups using a variety of methods (Table 1). Methods are described in detail in sections 1-8 below.

### Table 1. Summary of groups and methods in the study by year

<table>
<thead>
<tr>
<th>Groups</th>
<th>Methods</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescents &amp; young adults (AYAs) with cancer diagnosis</td>
<td>Interviews with ‘self portrait’, surveys</td>
<td>1</td>
</tr>
<tr>
<td>Parents of AYAs with cancer diagnosis</td>
<td>Focus groups</td>
<td>1</td>
</tr>
<tr>
<td>Healthy AYAs (no cancer diagnosis)</td>
<td>Focus groups</td>
<td>2</td>
</tr>
<tr>
<td>Health professionals</td>
<td>Semi-structured interviews</td>
<td>2</td>
</tr>
</tbody>
</table>

1. **Interviews and ‘self portrait’ for AYA with a diagnosis of cancer**
Forty-eight AYAs aged 14-24 who have been diagnosed with cancer will be recruited to complete an interview and “self portrait” (see below). Participants will be selected from three populations: AYAs who have previously had a bone marrow transplant (BMT) for a haematological malignancy, those with a neurological cancer, and those with another common paediatric cancer such as Ewings Sarcoma and Germ Cell (Gonadal) Tumour. These populations have been chosen because in each the transition from adolescence to adulthood is challenged in different ways: BMT has high mortality and requires strict compliance with medical care for many years after transplantation; neurological cancers are associated with significant changes in behaviour and cognitive status and patients with these diagnoses may be particularly stigmatised; while other cancers common in adolescence may impact on identity, body image and/or relationships in different ways, by impairing fertility, appearance or bodily integrity. We will recruit 16 participants from each of these population sources in samples stratified by age group and treatment status (Table 2). AYAs with a significant pre-existing disability will be excluded as they are likely to have very different needs.

### Table 2. Adolescent and Young Adult (AYA) Participant Cohorts

<table>
<thead>
<tr>
<th>AYA population</th>
<th>Currently in treatment</th>
<th>Post-treatment (in remission)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>14-17 years of age</td>
<td>18-24 years of age</td>
</tr>
<tr>
<td>BMT</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Neurological cancers</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Other paediatric cancers</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>
**a) Recruitment.** Eligible participants will be identified through the haematology-oncology department databases of the Children’s Hospital Westmead and Westmead Hospital. An invitation letter will be mailed with a form to return giving consent to be contacted by the researchers. Details of the study will then be sent with consent forms for participation in the interviews and survey. The letter will include a copy of the ISI-6G instrument (see section 5d) to complete before their interview, along with a brief questionnaire about their interests and skills in art, photography, digital media and IT.

**b) Interviews.** In an initial interview of up to 45 minutes, the researcher will collect the completed ISI-6G surveys and questionnaire and then ask the participant to briefly recount their cancer experience. The participant will then be asked to provide (by an agreed deadline and using any combination of text, audio-recording or visual images) a ‘self portrait’ that describes/represents the impact that cancer has had on their experience of growing up. A prompt sheet will be provided that lists (in age-appropriate language) a range of possible issues to cover, such as: effects of illness and treatment on identity, self-esteem, body image, social role(s) and relationships; ethical issues; communication with families, friends, health professionals and other patients; unmet needs (particularly in relation to information, psychosocial support, and involvement in decision making), and perceptions of support services. The researcher will also establish the participant’s preferred means of expression. This may include a recorded interview, conventional written forms and use of images (e.g. diaries, cartoons, visual displays on walls of bedrooms or hospital wards); less conventional forms (e.g. graffiti art, avatars for online games); digital text, audio and images (still or moving, as a video diary or story in digital stills with audio commentary), online resources (Blogs, Wikis, YouTube, Flickr) and web-based social networking software (Bebo, MySpace, Facebook). All interviewees will then be invited to commence their ‘self portrait’ by recording their own interview (with or without the assistance of the researchers) using a digital camera tethered to a laptop computer. At the completion of the interview all participants will be offered the use of a camera with still, video and audio capability for use in the self portrait, provided with a fact sheet describing how to make the best use of each image capture technique, and invited to a workshop aimed at developing and extending the AYAs skills in portraiture.

In a follow-up 45-minute interview, participants will be asked to show their ‘self portrait’ to the interviewer and discuss what it was like to do the exercise, choices they made in the process, and what they were trying to communicate by means it. Participants who failed to produce a ‘self portrait’ will be given a further opportunity to work one up in a group run by CI Smith.

**2. Focus groups**

Four focus groups will be conducted with parents of AYAs from each of the interview groups (per column headings, Table 2). To capture peer attitudes, three focus groups will be conducted with healthy AYAs who have neither a diagnosis of cancer nor a sibling with one.

**a) Recruitment.** Parents of AYAs previously treated for cancer will be identified through the haematology-oncology department databases of the Children’s Hospital Westmead and Westmead Hospital. Potential participants will be mailed an invitation letter which includes a form to return giving consent for the researchers to contact them. Parents of AYAs currently receiving treatment for cancer will be identified through patient lists of the hospitals named above, pending approval from the patient’s attending medical officer. Healthy AYAs will be recruited from a high school in Sydney’s mid-West: one group from year 8, one from year 10 and one from years 11/12.

**b) Approach.** Focus groups will run for 2-3 hours. Adults will first be invited to reflect on personal experiences of caring for adolescents and young adults with cancer. This will be followed by a more structured discussion of issues raised on the interview prompt sheet. Focus groups with high school students will elicit stereotypical attitudes to young people with cancer, and discussion of how young people with a cancer diagnosis might fit or not fit into various peer groups.

**3. Interviews with health professionals**

Fifteen semi-structured interviews up to one hour long will be conducted professionals involved in providing care to AYAs with cancer, including paediatric and adult oncologists, haematologists, infectious diseases physicians, oncology/transplant nurses, transplant coordinators, outpatient
cancer care workers, social workers, clinical psychologists, reproductive health workers and general practitioners. We will identify health professionals from oncology, haematology and transplant units in children’s and adult hospitals in Sydney and general practitioners from urban divisions of general practice. Intensity sampling will be used to ensure participants have experience working with AYAs with cancer and their families. Interviews will explore professionals’ experiences of caring for AYAs with cancer and their views about issues mentioned section 1(b) above.

4. Analysis of qualitative data
Interviews and focus groups will be digitally recorded, transcribed and checked. Transcripts will be imported into NVivo7 for analysis using standard methods of content, thematic and discourse analysis in order to generate a rich description of issues that emerge through adolescent transitions.

5. Survey of AYAs with a diagnosis of cancer
We will conduct a quantitative survey of the 48 participants recruited for the interviews plus a consecutive series of 72 additional AYAs diagnosed with cancer, using validated instruments (see a–d below). Participants will be patients from Westmead Children’s Hospital and Westmead Hospital who are aged 14-24 and diagnosed with neurological, gonadal or other cancers, or who have had bone marrow transplantation. Participants will be mailed an introductory letter that will direct them to a website housing the questionnaires. Unique usernames and passwords will be used to ensure that instruments are completed only by invitees. The homepage will serve as an information sheet for participants describing the purpose of the study and reassuring participants that confidentiality will be secured (No surveys require names or other identifying information; all responses are entered directly into a database in which the participant is assigned a number). It will also reassure participants that the information provided will be used for research purposes only and will not be made available to any third party. If participants do not have access to the WWW or prefer not to use it, we will seek consent to administer questionnaires via telephone.

a) Demographics: Participants will be asked for basic data about their disease, prognosis, treatment, family situation and health service utilisation.

b) Quality of Life (QOL) will be assessed using SF-36, the most widely used QOL measure in health research (Sanson-Fisher & Perkins 1998). Validation of SF-36 for assessment of QOL in adolescents and adults with cystic fibrosis indicated a robust domain structure (Gee et al. 2002).

c) Anxiety & Depression will be assessed using the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). The validity, reliability and utility of the HADS has been demonstrated in assessment of depressive and anxiety-related symptoms in cancer populations (Trask, 2003) and in studies with adolescents (White et al. 1999).

d) Identity will be assessed using the Identity Style Inventory 6-G (ISI-6G). This is a revision of an earlier instrument (Berzonsky 1992) to suit a sixth-grade reading level. It is a short (40-item) inventory that classifies respondents in to one of three identity styles: informational (tends to create a coherent and revisable sense of self); normative (tends to construct a rigid, inflexible sense of self) and diffuse-avoidant (tends to construct a fragmented, haphazard sense of self). The instrument has been shown to be reliable and valid, comparable to Berzonsky’s original ISI and suitable for use with adolescents and young adults (White et al. 1998).

e) Analysis. Data will be entered into SPSS and inferential statistics will be used to test for relationships between identity states, QOL and anxiety & depression. For the 48 survey respondents who underwent interviews, we will compare pre- to post-interview results on the ISI-6G to test whether the interview process increased levels of exploration (White et al. 1998).

6. Accumulation and use of assets for educational resources
The project team includes a multimedia producer (Susan Cornish) who will advise how the project should be documented, and how the ‘assets’ generated by the interviews – and by the process of documenting the project itself – should be managed with a view to producing educational multimedia resources. Ideally, this will include a documentary film featuring individuals recruited through the qualitative arm of the project. This outcome is subject to securing additional funding.
that will be sought during the first year of the project. If such funding is not secured, we will still have a range of “assets” that will be used for educational resources, and an expert on the team who will advise how these should be tailored to suit a range of different audiences (see E7 below).

7. Accumulation and use of images (self portraits) for art exhibition

a) Self Portrait: At the first interview each participant will be provided with a simple illustrated fact sheet that outlines image capture strategies and provides sample images using each technology. Participants without access to suitable image/audio capture equipment will be offered the short-term loan of a camera with audio, still and video capability and all participants will be invited to a preliminary self portrait workshop to develop and extend their skills in image capture using various technologies. (To enable consistency of image capture, and for ease of technical support, 16 identical cameras will be purchased for this project.

b) Interview self documentary: All interviewees will be invited to commence their ‘self portrait’ by participating in an informal ‘self documentary photo shoot’ of their first interview (with or without the assistance of the researchers) using a digital camera tethered to a laptop computer.

c) Self Portrait Workshop: A workshop will be conducted to enable interested AYA’s to develop and extend their image capture skills prior to undertaking the image-based self directed aspect of the portrait project. An online forum will be established to answer questions and/or exchange ideas related to image capture, be they technical or conceptual. Cameras would continue to be made available for all participants to extend their self portrait collection of images following the follow-up interview should they wish to do so.

d) Display and translation (Year 3): Initial contact with galleries will occur once a portfolio of images has been produced. With permission, some existing portraits would be used to promote the exhibition proposed for year 3. Venues approached for displaying the final portfolios may include artist run galleries, health and educational institutions, educational institutions, and other public access spaces equipped for the professional display of artworks.

8. Development of recommendations for design & delivery of support services AYAs

In the third year of the project the team will focus on completing data analysis, ‘triangulating’ findings from the qualitative and quantitative arms of the study, writing up findings for publication, and formulating recommendations for the design and delivery of services for AYAs with cancer. Recommendations will include how to use educational materials for a range of different audiences. With CanTeen’s support, CI Smith will organise an exhibition of artistic work based on the process and outcomes of the ‘self portraits’ generated in year 2. This event will be used to launch the educational materials, publicise the project’s recommendations, and give exposure to funders.

9. Training

The Post-Doctoral Research Fellow will conduct interviews and focus groups, manage the psychometric study of identity, and coordinate the project. S/he will; gain an in-depth understanding of the experience of AYAs who have survived cancer, and ethical, cultural, and legal issues associated with this experience; develop research expertise in adolescent and developmental psychology using novel methods and working within a diverse multidisciplinary team; learn how to translate research findings into a range of outcomes including recommendations about the design of services and support programs, educational materials and cultural events; learn about advocacy in research by working with Canteen and with cancer survivors and people with expertise in adolescent psychology, social work, counselling, communication and research

The APAI, Peter Lewis, will assist with recruitment and interviews, and will coordinate the self-portrait phase of the research (with CI Smith), co-supervised by CI Kerridge and CI Jordens. The P/T research assistant working on the self portrait exercise will be supervised by CI Smith.

E5 PARTNER ORGANISATION COMMITMENT AND COLLABORATION

CanTeen is the only national Australian organisation specifically for AYAs living with cancer. It’s mission is to support, develop, and empower young people living with cancer. This study aligns with CanTeen’s strategic goals of better understanding the needs of all young people living with
cancer in Australia and identifying how these needs can be better supported, with their commitment to the principles of participatory research with children and young people as stated by the NSW Commission for Children and Young People (2005) and with their advocacy for specific adolescent cancer services. CanTeen has demonstrated its enthusiasm for this study by committing more than $300,000 in cash and in-kind for three years. The extent of CanTeen’s commitment is evidenced by the large in-kind contributions in terms of staff assistance for this project. Dr Pandora Patterson, National Research and Evaluation Manager at CanTeen, will contribute 10% of her time for the duration of this project and be involved in research data collection and analysis, dissemination and translation of results, co-supervision of the APAI, and mentorship of the Post-Doctoral Research Fellow. Ms Jodi Gacitua, Communications and Media Manager, will devote 10% of her time through construction and maintenance of the study website for the three years and through assistance with the exhibition of self portraits in Year 3. Ms. Francesca Pinzone, National Programs and Projects Officer, will contribute 10% of her time to recruitment, interviews and focus groups, and implementing research outcomes through enrichment of peer support programs and development of CanTeen members. Mr. Ben Jones, Member Liaison Officer, will spend 15% of his time liaising with health professionals to build relationships, plan interviews, and communicate outcomes through workshops alongside Ms Pinzone and Mr Michael Lovett, Programs Officer, who will contribute 10% of his time. Ms. Xanthe Collins will devote 10% of her workload to designing and disseminating study information and newsletters. Br Brett Millar, Research Officer, will devote 35% of his time to assist with recruitment, data collection and analysis and dissemination of results and a Senior Researcher with CanTeen will also contribute 10% of their time to these tasks. Given this significant investment of time and staff resources, this project will likely lead to further joint research activities between CanTeen and the University of Sydney.

E6 NATIONAL BENEFIT
This project will provide important insights into young people’s experience of cancer, its treatment and aftermath. It will generate novel multimedia resources, including artworks and a documentary film that, along with scholarly publications, will contribute to knowledge and education, and inform the design and delivery of cancer services for this population. Ultimately, the results of this research will improve the lives of adolescents and young adults (AYAs) with cancer by facilitating the design and delivery of health services appropriate to their needs.

The educational and artistic resources created through this research will increase the sensitivity of others – and especially of peers – to the issues facing AYAs with cancer. Modification and dissemination of these resources through different media will also increase the understanding of these issues among health professionals and the wider public.

This study will enable advocacy groups such as CanTeen, to use their resources more effectively to ensure that AYAs throughout Australia who are dealing with, or have survived, cancer are adequately supported through their transition to adulthood. This will be achieved through discussion about the impact of cancer on the identity, agency and autonomy of adolescents, through incorporation of our study methods into peer support activities, through training of CanTeen staff and members, and through contribution to the recommendations for the establishment and maintenance of transitional care and adolescent cancer services.

By providing a richer and more coherent account of the transition from adolescence to adulthood in the context of cancer this research will provide important insights into the meaning, construction and maintenance of identity, agency and autonomy. This, in turn, will provide a moral, cultural and psychosocial framework that will guide health professionals in treating adolescents with cancer, lawyers in assessing young persons capacity to engage in decisions about their own care, parents and carers in knowing how to communicate with adolescents with cancer, and other members of the public, particularly adolescents, in understanding the experience of cancer.

This study will contribute to Australia’s research capacity in bioethics, adolescent health, health sociology, research into illness experience, cancer medicine and psychology. The APDI and the APAI will gain valuable generic research skills and substantive interdisciplinary knowledge of the personal and socio-cultural dimensions of biomedicine.
The outcomes of this project will contribute to Australia’s National Research Priority of Promoting and Maintaining Good Health by providing AYAs with the knowledge and support they need to make the transition into adulthood. It will also generate improvements in planning, delivery, and uptake of health promotion and disease prevention programs for young cancer survivors, and help them lead independent, productive and fulfilling lives.

**E7 COMMUNICATION OF RESULTS**
Research findings will be published in international peer-reviewed journals in oncology, psychology, ethics, adolescent health, visual arts, law and sociology. Target journals include *Journal of Adolescent Health, Social Science and Medicine, the Journal of Medical Ethics, Health Education and Behavior, Philosophy and Medicine, Psycho-oncology, Pediatrics, Journal of Law and Medicine, and Cancer*. Results will also be presented at national and international meetings of the International Association for Adolescent Health, the Australasian Bioethics Association, the International Psycho-oncology Society and the Clinical Oncology Society of Australia.

CI Smith will work with the research participants and CanTeen to develop a range of artworks from the self portraits created in the course of this research. These will be exhibited in a range of venues with the support of Canteen and relevant health providers. They will also provide a rich multimedia resource that will be used to develop educational resources (including a documentary, pending additional funding) about the experience of cancer in adolescence and the development of identity and autonomy in the context of serious illness. Educational multimedia will be tailored to a range of different audiences and practice settings including schools, health professionals, health lawyers, social workers and AYAs diagnosed with cancer, their friends and families.

A Discussion Paper summarizing the research findings and recommending strategies for reform of cancer, adolescent health and transitional care services will be prepared in collaboration with CanTeen and the participating health services. This paper will be distributed to all paediatric and adult cancer services in Australia and to the peak Australian cancer research and support organizations including the GMCT, the College of Physicians (and Paediatrics), and state Cancer Councils and Cancer Institutes. CanTeen will communicate the results of the research to its members though workshops, camps, newsletters, and their website.

**E8 DESCRIPTION OF PERSONNEL**

**Chief Investigators**

A/Prof Ian Kerridge (15%) – *Expertise*: ethics, haematology, bone marrow transplantation (BMT), health policy. *Contribution*: overall coordination of the project, research design, research oversight, participant recruitment, data analysis, translation and dissemination of research findings.

Dr Chris Jordens (15%) – *Expertise*: philosophy, ethics, qualitative research, discourse analysis, previous research on cancer survival. *Contribution*: research design and data analysis.

Kris Smith (10%) – *Expertise*: visual arts, portraiture and digital photo-media. *Contribution*: responsible for the self portrait phase of the research, accumulation of images of the adolescent cancer experience, exhibition of the portrait portfolio.

**Partner Investigators**

Prof David Bennett (10%) – *Expertise*: adolescent health, health services research and advocacy. *Contribution*: participant recruitment, clinical project coordination, data analysis and development of recommendations for reform of adolescent cancer services.

Dr Pandora Patterson (10%), Canteen National Research and Evaluation Manager – *Expertise*: extensive knowledge of adolescents and young adults living with cancer. *Contribution*: research design, data collection and analysis, dissemination and translation of results into practice through Canteen publications, workshops and camps.

**Collaborators/Research Team Members**


*Education and Multimedia*: Susan Cornish (Multimedia Producer) – *Expertise*: learning design and documentary film-making. *Contribution*: advice about how the project should be documented and the research results translated into educational resources.
Health Professionals: Dr Helen Somerville (Paediatric Oncologist, Director of Transitional Care Services, Children’s Hospital, Westmead) – Expertise: late effects in paediatric oncology. Contribution: recruitment of participants for the qualitative portion of the study; guide translation of findings into the design and delivery of transitional care services for AYAs living with cancer.

A/Prof Peter Shaw (Director BMT, Children’s Hospital Westmead) – Expertise: adolescent transitions following cancer and BMT; Contribution: recruitment, data analysis and dissemination and translation of findings into clinical services. Dr Nicole Gilroy (Infectious Diseases Physician, Westmead Hospital) – Expertise: risk assessment and modification following chemotherapy and BMT, and with non-compliance with antimicrobial prophylaxis post-transplant. Contribution: recruitment of BMT patients, data analysis and incorporation of research findings into design of infection control policy and information for survivors about avoiding infection after BMT.

E9 REFERENCES


Appendix 2: Institutional Ethics Approval
Our Ref: HREC2008/12/4.12 (2897) AU RED 08/WMEAD/290

24 February 2009

A/Prof Ian Kerridge
Department of Haematology
Westmead Hospital

Dear Professor Kerridge

Project title: 'Growing up with Cancer: A mixed method examination of how cancer influences the transition from adolescence to adulthood'

Thank you for your letter dated 10 February 2009 addressing the matters raised in the HREC's letter dated 8 December 2008 following single ethical review of the above project at its meeting held on 1 December 2008.

This HREC has been accredited by the NSW Department of Health as a lead HREC to provide the single ethical and scientific review of proposals to conduct research within the NSW public health system. This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research and the ICH Note for Guidance on Good Clinical Practice.

I am pleased to advise that the HREC has now granted ethical approval of this multicentre research project to be conducted at:

- Westmead Hospital – Co-ordinating Principal Investigator A/Prof Ian Kerridge and
- The Children's Hospital at Westmead – Principal Researcher Prof David Bennett

The following documentation has been reviewed and approved by the HREC:

- Protocol Version 1, dated 7 November 2008
- Revised Participant Information and Consent Forms – Young People with Cancer 18-24 years old, Master Version 2, dated 10 February 2009
- Revised Participant Information Sheet – Adolescents with Cancer 14-17 years old Version 2, dated 10 February 2009
- Revised Participant Information Sheet – Parents of Adolescents with Cancer 14-17 years old, Version 2, dated 10 February 2009
- Participant Information and Consent Forms – Healthy Adolescents, Master Version 2, dated 10 February 2009
- Revised Participant Information and Consent Forms – Parent of Healthy Adolescent, Master Version 2, dated 10 February 2009
- Revised Participant Information and Consent Forms – Health Care Professionals, Master Version 2, dated 10 February 2009
- Revised Participant Information Sheet – Parents of young people with cancer, Version 2, dated 10 February 2009
- Flyer
- Participant invitation letter, Version 1, dated 11 November 2008
- Interview Schedule for Adolescents and Young Adults with Cancer 14-24 years old, Version 1, dated 27 October 2008
- Interview Questions Health Care Professionals, Version 1, dated 27 October 2008
- Psychometric Measure, Version 1, dated 10 November 2008
- Artskills Questionnaire, Version 1, dated 10 November 2008

Please note the following conditions of approval:

- The coordinating investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project.
- Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, are provided to the HREC to review in the specific format. A copy of all proposed changes is also provided to the relevant research governance officer.
- The HREC must be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
- The coordinating investigator must provide an annual report to the HREC and a final report at completion of the study, in the specified format. HREC approval is valid for 12 months from the date of final approval and continuation of the HREC approval beyond the initial 12 month approval period is contingent upon submission of an annual report each year. A copy of the Annual / Final Research Report Form is attached and can be obtained electronically from the Research Office on request.
- It should be noted that compliance with the ethical guidelines is entirely the responsibility of the researcher.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained. A copy of this letter and the approved Participant Information and Consent Forms must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

A summary of the HREC Standard Operating Procedures is attached for your reference. Should you have any queries about the HREC's Terms of Reference, Standard Operating Procedures or membership, please contact the HREC Executive Officer through the Research Office on 9345 8183 or emailing researchoffice@wmi.usyd.edu.au.
The Committee notes your advice that this letter of approval is required before a submission for ethical consideration by the Department of Education can be made.

In all future correspondence concerning this study, please quote your approval number HREC2008/12/4.12 (2897) AU RED 08/WMEAD/290

The HREC wishes you every success in your research.

Yours sincerely

Ms Tina Goodenough  
HREC Executive Officer  
SWAHS Human Research Ethics Committee (Westmead Campus)
Appendix 3: Participant and Parent Letters of Invitation
November 2009

Dear Young Person,

I am writing on behalf of a research team from Westmead Hospital, the Children’s Hospital at Westmead and the University of Sydney to invite you to participate in the Growing Up with Cancer project.

The aim of the project is to examine the experience of growing up with cancer for adolescents and young adults from a variety of different points of view. As part of this study we are conducting a survey of young people with cancer aged 14 – 24 years (or 29 years if you were diagnosed before age 24). Some of these young people will then participate in a conversation and make a self portrait about how cancer has affected their experience of growing up. We will also interview health care professionals involved in the care of young people with cancer and have group discussions with parents of young people with cancer and with young people who do not have any diagnosed diseases.

If you would like to get involved in the Growing Up with Cancer project, the first step is to complete the online survey.

Go to: www.canteen.org.au/GUWC

It will take about 30 minutes to complete the survey. If you do not have access to the internet or need help filling in the survey (English may not be your first language or you may have difficulty using a computer), the research team can help. Phone Peter Lewis on 02 9036 3433, Julie Mooney-Somers on 02 9036 3412, or text your name and contact number to 0421 567 895 and someone will call you.

If you would like to participate in a conversation and make a self portrait about growing up with cancer, or just hear more about these activities, contact Peter or Julie in one of these ways:

- Email your name and contact number to GUWC.research@usyd.edu.au
- Phone 02 9036 3433
- Text your name and contact number to 0421 567 895
- Return the Contact Me form at the end of this letter.

Peter or Julie will contact you with further information about the study and answer any questions you may have. Having received this additional information you can decide to participate further. But, you should not feel obligated to participate in this study or to continue your involvement should you wish to withdraw at any stage. Remember, it is up to you to decide how much time you would like to give to the Growing Up with Cancer project.

Included in this letter is a Participant Information sheet with further details about the project and what you’ll be asked to do if you get involved. Before participating in the Growing Up with Cancer project, you might like to discuss the project with someone close to you. If you are between 14 and 17 years of age, we have also included a Participant Information sheet for your parent or guardian.
If you have any questions please do not hesitate to contact one of the investigators named on the Participant Information sheet, or speak to Julie or Peter using any of the contact details above.

Thank you for considering our request.

Sincerely,

Associate Professor Ian Kerridge
Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital
Director, The Centre for Values Ethics and the Law in Medicine, The University of Sydney

----------Contact Form ----

Yes, I would like to hear more about participating in a conversation and making a self portrait about growing up with cancer. Please contact me on:

Name ____________________________________________

Phone number ______________________________________

Email address _______________________________________

Cut out and return to: The Growing Up with Cancer Project
The Centre for Values, Ethics and the Law in Medicine
Level 1, Medical Foundation Building K25
University of Sydney NSW 2006
Dear xxxx,

I am writing on behalf of a research team from Westmead Hospital, the Children’s Hospital at Westmead and the University of Sydney to invite you to participate in the Growing Up with Cancer project.

The aim of the project is to examine the experience of growing up with cancer for adolescents and young adults from a variety of different points of view. As part of this study we are conducting a survey of people who had cancer between the ages of 14–24 years (or 29 years if they were diagnosed before age 24). Some of these young people will then be asked to participate in a conversation and make a self portrait about how cancer has affected their experience of growing up. We will also interview health care professionals involved in the care of young people with cancer. There will be group discussions with the parents of young people with cancer.

If you would like to get involved in the Growing Up with Cancer project, the first step is to complete the online survey.

Go to: www.canteen.org.au/GUWC

It will take about 30 minutes to complete the survey. If you do not have access to the internet or need help filling in the survey (English may not be your first language or you may have difficulty using a computer), the research team can help. Phone Peter Lewis on 02 9036 3433, Julie Mooney-Somers on 02 9036 3412, or text your name and contact number to 0421 567 895 and someone will call you.

If you would like to participate in a conversation and make a self portrait about growing up with cancer, or just hear more about these activities, contact Peter or Julie in one of these ways:

   Email your name and contact number to GUWC.research@usyd.edu.au

   Phone 02 9036 3433

   Text your name and contact number to 0421 567 895

   Return the Contact Me form at the end of this letter.

Peter or Julie will contact you with further information about the study and answer any questions you may have. Having received this additional information you can decide to participate further. But, you should not feel obligated to participate in this study or to continue your involvement should you wish to withdraw at any stage. Remember, it is up to you to decide how much time you would like to give to the Growing Up with Cancer project.
Included in this letter is a Participant Information sheet with further details about the project and what you'll be asked to do if you get involved. Before participating in the Growing Up with Cancer project, you might like to discuss the project with someone close to you. If you are between 14 and 17 years of age, we have also included a Participant Information sheet for your parent or guardian.

If you have any questions please do not hesitate to contact one of the investigators named on the Participant Information sheet, or speak to Julie or Peter using any of the contact details above.

Thank you for considering our request.

Sincerely,

Associate Professor Ian Kerridge
Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital
Director, The Centre for Values Ethics and the Law in Medicine, The University of Sydney

Yes, I would like to hear more about participating in a conversation and making a self portrait about growing up with cancer. Please contact me on:

Name

Phone number

Email address

Cut out and return to: The Growing Up with Cancer Project
The Centre for Values, Ethics and the Law in Medicine
Level 1, Medical Foundation Building K25
University of Sydney NSW 2006
Oncology Department

February 2009

Dear Young Person,

I am writing on behalf of a research team from the Children’s Hospital at Westmead, Westmead Hospital, and the University of Sydney to invite you to participate in the *Growing Up with Cancer* project.

The aim of the project is to examine the experience of growing up with cancer for adolescents and young adults from a variety of different points of view. As part of this study we are conducting a survey of people who had cancer between the ages of 14–24 years (or 29 years if they were diagnosed before age 24). Some of these young people will then be asked to participate in a conversation and make a self portrait about how cancer has affected their experience of growing up. We will also interview health care professionals involved in the care of young people with cancer. There will be group discussions with the parents of young people with cancer.

If you would like to get involved in the *Growing Up with Cancer* project, the first step is to complete the online survey.

**Go to:** [www.canteen.org.au/GUWC](http://www.canteen.org.au/GUWC)

It will take about 30 minutes to complete the survey. If you do not have access to the internet or need help filling in the survey (English may not be your first language or you may have difficulty using a computer), the research team can help. Phone Peter Lewis on 02 9036 3433, Julie Mooney-Somers on 02 9036 3412, or text your name and contact number to 0421 567 895 and someone will call you.

If you would like to participate in a conversation and make a self portrait about growing up with cancer, or just hear more about these activities, contact Peter or Julie in one of these ways:

- Email your name and contact number to **GUWC.research@usyd.edu.au**
- Phone 02 9036 3433
- Text your name and contact number to 0421 567 895
- Return the **Contact Me** form at the end of this letter.

Peter or Julie will contact you with further information about the study and answer any questions you may have. Having received this additional information you can
decide to participate further. But, you should not feel obligated to participate in this study or to continue your involvement should you wish to withdraw at any stage. Remember, it is up to you to decide how much time you would like to give to the Growing Up with Cancer project.

Included in this letter is a Participant Information sheet with further details about the project and what you'll be asked to do if you get involved. Before participating in the Growing Up with Cancer project, you might like to discuss the project with someone close to you. If you are between 14 and 17 years of age, we have also included a Participant Information sheet for your parent or guardian.

If you have any questions please do not hesitate to contact one of the investigators named on the Participant Information sheet, or speak to Julie or Peter using any of the contact details above.

Thank you for considering our request.

Yours Sincerely,

Doctor Luciano Dalla-Pozza
Senior Staff Specialist
Head, Oncology Unit
the children's hospital at Westmead

--------------Contact Form --

Yes, I would like to hear more about participating in a conversation and making a self portrait about growing up with cancer. Please contact me on:

Name

Phone number

Email address

Cut out and return to: The Growing Up with Cancer Project
The Centre for Values, Ethics and the Law in Medicine
Level 1, Medical Foundation Building K25
University of Sydney NSW 2006
Appendix 4: Participant and Parent Information Forms
PARENT INFORMATION SHEET
Parents of Adolescents with Cancer 14 – 17 years old

Growing Up With Cancer

Investigators:

Associate Professor Ian Kerridge, Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital, (02) 9845 7073 and Director, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3405

Dr Christopher Jordens, Lecturer and Research Fellow, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3406

Clinical Professor David Bennett, Head, NSW Centre for Adolescent Health. Children’s Hospital at Westmead. (02) 9845 2512

Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen, (02) 8296 6313

Mr Kris Smith, Associate Lecturer in Photomedia, University of Newcastle, (02) 4921 7230

Dr Julie Mooney-Somers, Senior Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3412

Mr Peter Lewis, PhD Candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3433

We would like you to consider allowing your child to participating in a research study that will be conducted in The Oncology Department at The Children’s Hospital at Westmead in conjunction with The University of Sydney.

What is the study about?
This study is about how young people with cancer experience adolescence. Adolescence can be a difficult time for some people and we’d like to find out more about whether having cancer makes it even harder. For others, adolescence is not a particularly difficult time, and we’d also like to hear from these people about growing up with cancer. Adolescence is a time when young people are growing up and learning about who they really are. We’d like to find out if having cancer has any influence on the process of growing up for young people.

We plan to find all this out by talking to your child about what it has been like for them to have cancer and also to find out how this influences the choices they make in participating in their health care.
Who can participate in the study?
Young people aged 14 to 17 years old who are currently or have been treated for cancer at the Children’s Hospital at Westmead, are eligible to participate.

What will the study involve?
If you agree to your child’s participate in this study, you will be asked to sign the Participant Consent Form.

This whole study will be conducted over a total of three years, but your child will only be required to participate for a very short period during that time. Your child will be invited to participate in a number of activities. They can just complete a survey about how they feel or they can complete a survey as well as talk with us and create a “self-portrait”. However, not everybody who is interested will have the opportunity to talk with us and create a “self-portrait”. Your child doesn’t have to decide before they do the survey.

Part 1: Survey
The online (computer based) survey tells us about how having cancer makes your child feels about cancer, their overall health and how they perceive themselves. This survey will take about 45 minutes to complete. The survey will be anonymous, which means we won’t know who has completed it.

Part 2: First Conversation
Your child will be invited to participate in one conversation lasting about 45 minutes with one of our researchers to discuss their experience of adolescence and young adulthood while having a diagnosis of cancer.
The conversation can be arranged at a time and in a place that is convenient for you and your child. The conversation will be recorded on a digital recorder so the researchers can remember what was discussed.

Part 3: “Self-Portrait”
At the end of the first conversation your child will receive information about the “self-portrait” and have an opportunity to ask questions.

Your child will be invited to participate in a creative process to provide a “self-portrait” about the impact that cancer has had on their experience of growing up. Your child will be invited to attend a workshop(s) in Sydney with one of our research team, the artist Kris Smith, and some other young people with cancer, where they will learn about photo and video techniques used to make a “self-portrait” and to receive assistance to plan and create their own “self-portrait”.

Part 4: Second Conversation
After creation of a “self-portrait” your child will be asked to a second conversation to discuss their “self-portrait”. The second conversation will be conducted at a time and in a venue that you and your child choose and it will be recorded so we can remember what was discussed and compare your child’s experience with the experience of others. The second conversation is likely to be longer than the first. We will also ask your child to repeat the survey so that we can see if anything has changed.

Part 5: Exhibition of “Self-Portraits”
We plan to display these “self-portraits” in public galleries as works of art. Viewers of the exhibition will have the opportunity to learn about experiences of adolescence and cancer. The purpose of this is to celebrate your child’s creativity and generous contribution to our research. You and your child do not have to agree to exhibiting your child’s “self-portrait”, like the other parts of the research project, this is voluntary. The “self-portrait” your child creates will belong to them.

Part 6: Documentary Film
Throughout the whole research process we will be collecting film and voice recordings to be used in various ways including for educational purposes or for a documentary film (for which we are seeking funding). We will ask your permission to contact you and your child at a later date about using their image or voice in the film if we get the money to make it. Agreeing to be contacted later does not mean you agree for your child to be in the film. We will provide separate information about the film and ask you to sign a separate consent form if we get funding.

Are there any benefits for my child participating in the study?
There are no known benefits for your child in participating in this study but we hope that the results from this study will help healthcare workers to understand what it is like for adolescents who have cancer to experience growing up at the same time. We also hope to use this information to make some suggestions about how caring for adolescents with cancer might be improved. Your child may also enjoy the process of creating a “self-portrait”, which they will be allowed to keep, and they may enjoy meeting other young people and sharing experiences.

Are there any side-effects and risk associated with this study?
Sometimes talking about personal things can be distressing. The researcher conducting the conversation is experienced in caring for children and adolescents in hospital and has also conducted conversations with children and adolescents for other research projects. He is experienced at identifying when a child or adolescent is becoming upset and will check with your child if it is OK to continue talking or if they’d like a break or to talk about something else. If your child does become upset, the researcher conducting the conversation will negotiate who your child would like to support them and he will reassure your child that it is common to become upset when talking about personal things and that it does not necessarily mean that something is wrong with them.

At a later date, your child may regret how they are identified in their “self portrait”. It is important that you discuss this possibility with your child before consenting to their participation.

Other information
Recordings of the conversation will be kept in a locked filing cabinet at the Centre for Values, Ethics and Law in Medicine at the University of Sydney. Recordings will be kept for five years and then erased. The conversations will be typed out and the paper copies will be kept for five years and then shredded.

Your child will be recognisable to other people in the “self portrait”. Please consider this when deciding whether or not to grant consent for participation in this study. We will always seek your permission to display your child’s “self portrait” or include their image or voice in an exhibition, documentary film, educational resources or in any research dissemination (such as conferences presentations or journal articles).
If you have any questions about the conduct of this study, please do not hesitate to discuss them with A/Prof Ian Kerridge or any of the other investigators named at the top of this form.

This project has been approved by The Children’s Hospital at Westmead Ethics Committee. If you have any concerns about the conduct of this study, please do not hesitate to contact Eleanor Thackray, Secretary of the Ethics Committee (02 9845 3017).

This Information Sheet is for you to keep. We will also give you a copy of the signed consent form.
CONSENT TO PARTICIPATE IN RESEARCH

Name of Researcher:

1. I understand that the researcher will conduct this study in a manner conforming to ethical & scientific principles set out by the National Health & Medical Research Council of Australia & the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.

2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks & inconveniences which may occur to my child during the study have been explained to me by ____________________________ ("the researcher") & I, being over the age of 16 acknowledge that I understand the general purposes, methods, demands & possible risks & inconveniences which may occur during the study.

3. I acknowledge that I have been given time to consider the information & to seek other advice.

4. I acknowledge that refusal to take part in this study will not adversely affect & child in any way.

5. I acknowledge that my child is volunteering to take part in this study & my child may withdraw at any time.

6. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.

7. I acknowledge that I have received a copy of this form & the Participant Information Sheet, which I have signed.

8. I acknowledge any regulatory authorities may have access to & to monitor the research in which I am agreeing for my child to participate. However, I understand my child’s identity will not be disclosed to anyone else or in publications or presentations.

9. I understand my child’s identity will be disclosed if they choose to display their “self portrait”.

10. I agree to be contacted at a later date about possible use of audio and visual material collected during the research project in an exhibition, documentary film, educational resources or research dissemination. □Yes □No

Before signing, please read ‘IMPORTANT NOTE’ following.

IMPORTANT NOTE: This consent should only be signed as follows: Where a participant is over the age of 16 years, then by the participant personally.

Name of participant __________________________________________ Date of Birth __________________________

Address of participant __________________________________________

Signature of participant __________________________________________ Date: __________________________

Signature of researcher __________________________________________ Date: __________________________

Signature of witness __________________________________________ Date: __________________________
PARENT INFORMATION SHEET  
Parents of Adolescents with Cancer 14 – 17 years old  

Growing Up With Cancer – Filming in self portrait workshops

Investigators:

Associate Professor Ian Kerridge, Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital, (02) 9845 7073 and Director, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3405

Dr Christopher Jordens, Lecturer and Research Fellow, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3406

Clinical Professor David Bennett, Head, NSW Centre for Adolescent Health. Children’s Hospital at Westmead. (02) 9845 2512

Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen, (02) 8296 6313

Mr Kris Smith, Associate Lecturer in Photomedia, University of Newcastle, (02) 4921 7230

Dr Julie Mooney-Somers, Senior Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3412

Mr Peter Lewis, PhD Candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3433

We would like you to consider allowing your child to participate in a self portrait workshop where they learn photo and video techniques used to make a “self-portrait” and receive assistance to plan and create their own “self portrait” about the impact of cancer on their experience of growing up. They will be filmed at this workshop by a documentary film team.

What is the study about?
This study is about how young people with cancer experience adolescence. Adolescence can be a difficult time for some people and we’d like to find out more about whether having cancer makes it even harder. For others, adolescence is not a particularly difficult time, and we’d also like to hear from these people about growing up with cancer. Adolescence is a time when young people are growing up and learning about who they really are. We’d like to find out if having cancer has any influence on the process of growing up for young people.

We plan to find all this out by talking to your child about what it has been like for them to have cancer and also to find out how this influences the choices they make in participating in their health care.
Who can participate in the study?
Young people aged 14 to 17 years old who are currently or have been treated for cancer at the Children’s Hospital at Westmead and have indicated that they would be interested in creating a “self portrait” are being invited to participate in a filmed workshop.

What will happen in the filmed workshop?

If you agree to your child’s participation in this workshop, you will be asked to sign the Participant Consent Form and the Model Release Form.

Your child will attend a workshop in Sydney with one of our research team, the artist Kris Smith, and some other young people with cancer, where they will learn about photo and video techniques used to make a “self-portrait” and to receive assistance to plan and create their own “self-portrait”. During this workshop a small documentary film crew will film the interactions between your child and other young people and the work they do with the artist. They may be asked some questions, asked to explain what they are doing, or be asked to participate in a short interview about their experience of the workshop.

The images and voice recordings the documentary film team collect will be used to create a short documentary film and an online educational resource for family, friends, support workers, health care professionals and the wide community.

Are there any benefits for my child participating in the workshop?

There are no known benefits for your child in participating in this study but we hope that the results from this study will help healthcare workers to understand what it is like for adolescents who have cancer to experience growing up at the same time. We also hope to use this information to make some suggestions about how caring for adolescents with cancer might be improved. Your child may also enjoy the process of creating a “self-portrait”, which they will be allowed to keep, and they may enjoy meeting other young people and sharing experiences.

Are there any side-effects and risk associated with this study?

Sometimes talking about personal things can be distressing. The researchers conducting the workshop are experienced in conducting research and creating art projects with young people. They are experienced identifying when a child or adolescent is becoming upset and will check with your child if it is OK to continue participating, if they'd like a break or to talk about something else. If your child does become upset, the researchers will negotiate who your child would like to support them and reassure them that it is common to become upset when talking about personal things and that it does not necessarily mean that something is wrong with them.

Having their image in a film means that other people will be able to recognize them. At a later date, your child may regret how they are identified in the film and it is important that you discuss this possibility with your child before consenting to their participation.
Other information
Agreeing for your child to participate in a filmed workshop means you are agreeing to include your child’s image or voice, “self portrait” and any other objects they bring to the workshop in a documentary film and educational resources.

If you have any questions about the conduct of this study, please do not hesitate to discuss them with A/Prof Ian Kerridge or any of the other investigators named at the top of this form.

This project has been approved by The Children’s Hospital at Westmead Ethics Committee. If you have any concerns about the conduct of this study, please do not hesitate to contact Eleanor Thackray, Secretary of the Ethics Committee (02 9845 3017).

This Information Sheet is for you to keep. We will also give you a copy of the signed consent form.
CONSENT TO PARTICIPATE IN RESEARCH

Name of Researcher:

1. I understand that the researcher will conduct this study in a manner conforming to ethical & scientific principles set out by the National Health & Medical Research Council of Australia & the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.

2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks & inconveniences which may occur to my child during the study have been explained to me by ____________________________ ("the researcher") & I, being over the age of 16 acknowledge that I understand the general purposes, methods, demands & possible risks & inconveniences which may occur during the study.

3. I acknowledge that I have been given time to consider the information & to seek other advice.

4. I acknowledge that refusal to take part in this study will not adversely affect & child in any way.

5. I acknowledge that my child is volunteering to take part in this study & my child may withdraw at any time.

6. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.

7. I acknowledge that I have received a copy of this form & the Participant Information Sheet, which I have signed.

8. I acknowledge any regulatory authorities may have access to & to monitor the research in which I am agreeing for my child to participate. However, I understand my child’s identity will not be disclosed to anyone else or in publications or presentations.

9. I understand my child’s identity may be disclosed if they choose to participate in a filmed workshop.

Before signing, please read ‘IMPORTANT NOTE’ following.

IMPORTANT NOTE: This consent should only be signed as follows: Where a participant is over the age of 16 years, then by the participant personally.

Name of participant __________________________________________________ Date of Birth ____________________________

Address of participant __________________________________________________

Signature of participant ____________________________________________ Date: ____________________________

Signature of researcher ____________________________________________ Date: ____________________________

Signature of witness ____________________________________________ Date: ____________________________
PARTICIPANT INFORMATION SHEET
Adolescents with Cancer 14 – 17 years old

Growing Up with Cancer

Investigators:

Associate Professor Ian Kerridge, Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital, (02) 9845 7073 and Director, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3405

Dr Christopher Jordens, Lecturer and Research Fellow, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3406

Clinical Professor David Bennett, Head, NSW Centre for Adolescent Health. Children’s Hospital at Westmead. (02) 9845 2512

Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen, (02) 8296 6313

Mr Kris Smith, Associate Lecturer in Photomedia, University of Newcastle, (02) 4921 7230

Dr Julie Mooney-Somers, Senior Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3412

Mr Peter Lewis, PhD Candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3433

We would like you to consider participating in a research study to be conducted in the oncology departments of the Children’s Hospital at Westmead and Westmead Hospital and The University of Sydney.

What is the study about?

This study is about how young people with cancer experience growing up through adolescence to young adulthood. Adolescence can be a difficult time for some people and we’d like to find out more about whether having cancer makes it even harder. For others, adolescence is not a particularly difficult time, and we’d also like to hear from these people about growing up with cancer. Adolescence is a time when young people are growing up and learning about who they really are. We’d like to find out if having cancer has any influence on the process of growing up for you. We also think that interaction with family and friends is a very important way for you to learn about who you really are, so we’re interested in talking about how you let them know what you think and feel.

We plan to find all this out by talking to you about what it has been like to have cancer and also to invite you to join in some creative activities, such as taking photographs, drawing, painting, creative writing, or whatever your creative preference is.
**Who can participate in the study?**

We’d like to invite anyone between 14 and 24 years old who is being treated for cancer at the Children’s Hospital at Westmead or Westmead Hospital to talk to us.

**What will the study involve?**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

This whole study will be conducted over a total of three years, but you will only be required to participate for a very short period during that time. You will be invited to participate in a number of activities. You can just complete a survey about how you feel or you can complete a survey as well as talk with us and create a “self-portrait”. However, not everybody who is interested will have the opportunity to talk with us and create a “self-portrait”. You don’t have to decide before you do the survey.

**Part 1: Survey**

The online (computer based) survey tells us about how having cancer makes you feel about your cancer, your overall health and how you perceive yourself. This survey will take about 45 minutes to complete. The survey will be anonymous, which means we won’t know who has completed it.

**Part 2: First Conversation**

You will be invited to participate in one conversation lasting about 45 minutes with one of our researchers to discuss your experience of adolescence and young adulthood while having a diagnosis of cancer.

The conversation can be arranged at a time and in a place that is convenient for you. The conversation will be recorded on a digital recorder so the researchers can remember what you talked about.

**Part 3: “Self-Portrait”**

At the end of the first conversation you will receive information about the “self-portrait” and have an opportunity to ask questions.

You will be invited to participate in a creative process to provide a “self-portrait” about the impact that cancer has had on your experience of growing up. You will be invited to attend a workshop(s) in Sydney with one of our research team, the artist Kris Smith, and some other young people with cancer, where you will learn about photo and video techniques used to make a “self-portrait” and to receive assistance to plan and create your own “self-portrait”.

**Part 4: Second Conversation**

After you’ve created a “self-portrait” you will be asked to a second conversation to discuss your “self-portrait”. The second conversation will be conducted at a time and in a venue that you choose and it will be recorded so we can remember what you said and compare your experience with the experience of others. The second conversation is likely to be longer than the first. We will also ask you to repeat the survey so that we can see if anything has changed.

**Part 5: Exhibition of “Self-Portraits”**

We plan to display these “self-portraits” in public galleries as works of art. Viewers of the exhibition will have the opportunity to learn about your experiences of adolescence and cancer.
The purpose of this is to celebrate your creativity and your generous contribution to our research. You do not have to agree to exhibiting your “self-portrait”, like the other parts of the research project, this is voluntary. The “self-portrait” you create will belong to you.

Part 6: Documentary Film
Throughout the whole research process we will be collecting film and voice recordings to be used in various ways including for educational purposes or for a documentary film (for which we are seeking funding). We will ask your permission to contact you at a later date about using your image or voice in the film if we get the money to make it. Agreeing to be contacted later does not mean you agree to be in the film. We will provide separate information about the film and ask you to sign a separate consent form if we get funding.

Are there any benefits for participating in the study?
There are no known benefits for you participating in this study but we hope that the results from this study will help us to understand what it is like for adolescents who have cancer to be in the process of growing up at the same time. We hope to use that information to recommend better ways for the health care system to look after adolescents with cancer. You may also enjoy the process of creating your “self-portrait” which you will be able to keep, and you may enjoy meeting other young people and sharing experiences.

Are there any side-effects and risk associated with this study?
Sometimes talking about personal things can be upsetting. The researcher conducting the conversation has helped look after young people in the hospital for a long time and has also had conversations with them for other research projects. You don’t have to share anything about yourself that you don’t want to, especially if you are worried that sharing will make you upset. If you do become upset when you didn’t expect to, you can stop the conversation and take your time to recover. If you feel like continuing the conversation when you feel better, then we can, but if you don’t want to talk anymore, that’s OK. It’s completely up to you. Also, if you get upset and you’d like a family member or friend to be with you, then that’s OK too. Getting upset is a normal response to some situations and often gets better quickly, but if you’re worried about not feeling better or being too upset, we can arrange for you to talk to a counsellor if you think that would help. Some people who participate in research projects where there participation is known to others, as would be the case if you choose to create a “self-portrait”, regret participating later in life. Please consider this possibility carefully when deciding whether or not to participate.

Other information
Whatever you share with us will be strictly confidential unless you tell us that we can share it with others. We will tell other people what you said, for example, when we present our findings to other health care workers or when we send written reports to professional journals talking about our research. But there will be no way for other people to know that you spoke with us or that it was you who told us what we report. Creating a “self portrait” will mean that people will know who you are. Please consider this when you are deciding whether or not to participate in the creative activities. You can just agree to talk without agreeing to make a “self portrait” or agreeing to be contacted about the film, but you don’t have to agree to anything if you don’t want to. We will
always ask if it is ok to show your “self portrait” or include your image or voice in an exhibition, documentary film, educational resources or in any research reports.

We’ll ask if we can record our conversation with you on a little tape recorder that will sit just next to us while we talk. The recordings will be typed out (transcribed) by a professional typist who understands the need to keep the information secret. We get the tapes typed out because it's easier to manage all the information they contain. Everything we keep, the tapes and the transcripts, will be kept in a locked filing cabinet at the Centre for Values, Ethics and Law in Medicine at the University of Sydney. We will return your “self portrait” to you at the end of the project.

Participation in this project is voluntary and if you decide not to take part or decide to withdraw at any time. This will not otherwise affect your care at the Hospital.

This project has been approved by The Children's Hospital at Westmead Ethics Committee. If you have any concerns about the conduct of this study, please do not hesitate to contact Eleanor Thackray, Secretary of the Ethics Committee (02 9845 3017).

This Information Sheet is for you to keep. We will also give you a copy of the signed consent form.
Title: Growing up with cancer

Investigators:
Associate Professor Ian Kerridge, Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital, (02) 9845 7073 and Director, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3405

Dr Christopher Jordens, Lecturer and Research Fellow, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3406

Clinical Professor David Bennett, Head, NSW Centre for Adolescent Health. Children’s Hospital at Westmead. (02) 9845 2512

Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen, (02) 8296 6313

Mr Kris Smith, Associate Lecturer in Photomedia, University of Newcastle, (02) 4921 7230

Dr Julie Mooney-Somers, Senior Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3412

Mr Peter Lewis, PhD Candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3433

I have read and understand the Information Sheet, and give my consent for to participate in this research study, which has been explained to me by ________________________________________

1. I understand that I am free to withdraw from the study at any time and this decision will not otherwise affect my child’s treatment at the Hospital.

2. I understand my child’s identity will be disclosed by displaying his/her “self portrait”.

3. I agree to be contacted at a later date about possible participation in a documentary film subject to funding. □Yes □No

NAME OF CHILD: _________________________________________________ (Please print)

NAME OF PARENT OR GUARDIAN: ____________________________________ (Please print)

SIGNATURE OF PARENT OR GUARDIAN: ____________________________ Date: _______

NAME OF WITNESS: _______________________________________________ (Please print)

SIGNATURE OF WITNESS: __________________________________________ Date: _______

NAME OF INTERPRETER: _________________________________________ (Please print)

SIGNATURE OF INTERPRETER: ____________________________________ Date: _______
PARTICIPANT INFORMATION SHEET
Adolescents with Cancer 14 – 17 years old

Growing Up with Cancer – Filming in self portrait workshops

Investigators:

Associate Professor Ian Kerridge, Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital, (02) 9845 7073 and Director, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3405

Dr Christopher Jordens, Lecturer and Research Fellow, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3406

Clinical Professor David Bennett, Head, NSW Centre for Adolescent Health. Children’s Hospital at Westmead. (02) 9845 2512

Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen, (02) 8296 6313

Mr Kris Smith, Associate Lecturer in Photomedia, University of Newcastle, (02) 4921 7230

Dr Julie Mooney-Somers, Senior Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3412

Mr Peter Lewis, PhD Candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3433

We would like you to consider participating in a self portrait workshop where you will learn photo and video techniques used to make a “self-portrait” and receive assistance to plan and create your own “self portrait” about the impact of cancer on your experience of growing up. You will be filmed at this workshop by a documentary film team.

What is the study about?

This study is about how young people with cancer experience growing up through adolescence to young adulthood. Adolescence can be a difficult time for some people and we’d like to find out more about whether having cancer makes it even harder. For others, adolescence is not a particularly difficult time, and we’d also like to hear from these people about growing up with cancer. Adolescence is a time when young people are growing up and learning about who they really are. We’d like to find out if having cancer has any influence on the process of growing up for you. We also think that interaction with family and friends is a very important way for you to learn about who you really are, so we’re interested in talking about how you let them know what you think and feel.
We plan to find all this out by talking to you about what it has been like to have cancer and also to invite you to join in some creative activities, such as taking photographs, drawing, painting, creative writing, or whatever your creative preference is.

**Who can participate in the workshop?**

We'd like to invite anyone who is between 14 and 24 years old, who is being treated for cancer at the Children’s Hospital at Westmead or Westmead Hospital and who has indicated that they would be interested in creating a “self portrait” to participate in a filmed workshop.

**What will happen in the filmed workshop?**

If you agree to participate in this workshop, you will be asked to sign the Participant Consent Form and the Model Release Form.

You will attend a workshop in Sydney with one of our research team, the artist Kris Smith, and some other young people with cancer, where you will learn about photo and video techniques used to make a “self-portrait” and to receive assistance to plan and create your own “self-portrait”. During this workshop a small documentary film crew will film the interactions between you and other young people and the work you do with the artist. They may ask you some questions, ask you to explain what you are doing, or ask to interview you about your experience of the workshop.

The images and voice recordings they collect will be used to create a short documentary film and an online educational resource for family, friends, support workers, health care professionals and the wide community.

**Are there any benefits for participating in the workshop?**

This study aims to further medical knowledge and may improve future treatment of young people with cancer however, it may not directly benefit you. Rather than being upset, some people actually welcome the chance to discuss their experience of cancer with someone keen to listen. You may also enjoy the creative process of making a “self-portrait” which you will be allowed to keep and you may enjoy meeting other young people and sharing experiences.

**Are there any side-effects and risk associated with this workshop?**

While there are no physical risks associated with participating in this study, people can become emotionally upset when discussing things that are very personal or painful. This may happen unexpectedly for you. Being upset by such things is a normal response. The researchers running the workshop will give you the chance to recover if you do become upset. You may then choose to continue the workshop or you may choose not to, depending on how you feel at the time. Your choice either way will be respected. The researcher will help you contact a support person if you would like and/or refer you to a counsellor for help.

Having your image in a film means that other people will be able to recognize you. Some people who participate in research projects where their participation is known to others regret participating later in life. Please consider this possibility carefully when deciding whether or not to participate.
Other information

Agreeing to participate in a filmed workshop means you are agreeing to include your image or voice, “self portrait” and any other objects you bring to the workshop in a documentary film and educational resources.

Participation in this project is voluntary and you can decide not to take part or decide to withdraw at any time. This will not otherwise affect your care at the Hospital.

This project has been approved by The Children’s Hospital at Westmead Ethics Committee. If you have any concerns about the conduct of this study, please do not hesitate to contact Eleanor Thackray, Secretary of the Ethics Committee (02 9845 3017).

This Information Sheet is for you to keep. We will also give you a copy of the signed consent form.
Title: Growing up with cancer

Investigators:
Associate Professor Ian Kerridge, Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital, (02) 9845 7073 and Director, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3405

Dr Christopher Jordens, Lecturer and Research Fellow, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3406

Clinical Professor David Bennett, Head, NSW Centre for Adolescent Health. Children’s Hospital at Westmead. (02) 9845 2512

Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen, (02) 8296 6313

Mr Kris Smith, Associate Lecturer in Photomedia, University of Newcastle, (02) 4921 7230

Dr Julie Mooney-Somers, Senior Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3412

Mr Peter Lewis, PhD Candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3433

I have read and understand the Information Sheet, and give my consent for to participate in this research study, which has been explained to me by ________________________________

1. I understand that I am free to withdraw from the study at any time and this decision will not otherwise affect my child’s treatment at the Hospital.
2. I understand my child’s identity will be disclosed by displaying his/her “self portrait”.

NAME OF CHILD: _________________________________________________ (Please print)

NAME OF PARENT OR GUARDIAN: ___________________________________ (Please print)

SIGNATURE OF PARENT OR GUARDIAN: ____________________________ Date: _______

NAME OF WITNESS: ______________________________________________ (Please print)

SIGNATURE OF WITNESS: ____________________________ Date: _______

NAME OF INTERPRETER: _________________________________________ (Please print)

SIGNATURE OF INTERPRETER: ____________________________________ Date: _______
Study Title: Growing Up With Cancer

Chief Investigator:
A/Prof. I. Kerridge, Director, The Centre for Values Ethics and the Law in Medicine, The University of Sydney, (02) 9036 3405
Department of Haematology and Oncology, Westmead Hospital

Invitation
You are invited to participate in a research study into the experience of transition from adolescence to young adulthood for people with cancer.

The study is being conducted by:
Associate Professor Ian Kerridge, Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital, (02) 9845 7073 and Director, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3405

Dr Christopher Jordens, Lecturer and Research Fellow, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3406

Clinical Professor David Bennett, Head, NSW Centre for Adolescent Health. Children’s Hospital at Westmead. (02) 9845 2512

Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen, (02) 8296 6313

Mr Kris Smith, Associate Lecturer in Photomedia, University of Newcastle, (02) 4921 7230

Dr Julie Mooney-Somers, Senior Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3412

Mr Peter Lewis, PhD Candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3433

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?
This study is about how young people with cancer experience growing up through adolescence to young adulthood. Adolescence can be a difficult time for some people and we’d like to find out more about whether having cancer makes it even harder. For others, adolescence is not a particularly difficult time, and we’d also like to hear from these people about growing up with cancer. Adolescence is a time when young people are growing up and finding out who they are. We’d like to find out what your experience has been throughout your journey to adulthood in light of having cancer.

We plan to find all this out by talking to you about what it has been like to have cancer and also to
find out how having cancer influences the choices you make about participating in your own health care.

**Who will be invited to enter the study?**
You are invited to participate in this study because you are a young person between the ages of 18 and 29 years with or who has had a diagnosis of cancer.

**Do you have a choice?**
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

**What will happen on the study?**
If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

This whole study will be conducted over a total of three years, but you will only be required to participate for a very short period during that time. You can just complete a survey about how you feel or you can complete a survey as well as talk with us and create a “self-portrait”. However, not everybody who is interested will have the opportunity to talk with us and create a “self-portrait”. You don’t have to decide before you do the survey.

**Part 1: Survey**
The online (computer based) survey tells us about how having cancer makes you feel about your cancer, your overall health and how you perceive yourself. This survey will take about 45 minutes to complete. The survey will be anonymous, which means we won’t know who has completed it.

**Part 2: First Conversation**
You will be invited to participate in one conversation lasting about 45 minutes with one of our researchers to discuss your experience of adolescence and young adulthood while having a diagnosis of cancer.

The conversation can be arranged at a time and in a place that is convenient for you. The conversation will be recorded on a digital recorder so the researchers can remember what you talked about.

**Part 3: “Self-Portrait”**
At the end of the first conversation you will receive information about the “self-portrait” and have an opportunity to ask questions.

You will be invited to participate in a creative process to provide a “self-portrait” about the impact that cancer has had on your experience of growing up. You will be invited to attend a workshop(s) in Sydney with one of our research team, the artist Kris Smith, and some other young people with cancer, where you will learn about photo and video techniques used to make a “self-portrait” and to receive assistance to plan and create your own “self-portrait”.
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Young People with Cancer 18 -29 years old

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Part 4: Second Conversation
After you’ve created a “self-portrait” you will be asked to a second conversation to discuss your “self-portrait”. The second conversation will be conducted at a time and in a venue that you choose and it will be recorded so we can remember what you said and compare your experience with the experience of others. The second conversation is likely to be longer than the first. We will also ask you to repeat the survey so that we can see if anything has changed.

Part 5: Exhibition of “Self-Portraits”
We plan to display these “self-portraits” in public galleries as works of art. Viewers of the exhibition will have the opportunity to learn about your experiences of adolescence and cancer. The purpose of this is to celebrate your creativity and your generous contribution to our research. You do not have to agree to exhibiting your “self-portrait”, like the other parts of the research project, this is voluntary. The “self-portrait” you create will belong to you.

Part 6: Documentary Film
Throughout the whole research process we will be collecting film and voice recordings to be used in various ways including for educational purposes or for a documentary film (for which we are seeking funding). We will ask your permission to contact you at a later date about using your image or voice in the film if we get the money to make it. Agreeing to be contacted later does not mean you agree to be in the film. We will provide separate information about the film and ask you to sign a separate consent form if we get funding.

Are there any risks?
While there are no physical risks associated with participating in this study, people can become emotionally upset when discussing things that are very personal or painful. This may happen unexpectedly for you. Being upset by such things is a normal response. The person you are talking with will give you the chance to recover if you do become upset. You may then choose to continue the conversation or you may choose not to depending on how you feel at the time. Your choice either way will be respected. The researcher will help you contact a support person if you would like and/or refer you to a counselor for help. Having your “self-portrait” publicly displayed or choosing to have your image in a film means that other people will be able to recognise you.

Are there any benefits?
This study aims to further medical knowledge and may improve future treatment of young people with cancer however, it may not directly benefit you. Rather than being upset, some people actually welcome the chance to discuss their experience of cancer with someone keen to listen. You may also enjoy the creative process of making a “self-portrait” which you will be allowed to keep and you may enjoy meeting other young people and sharing experiences.

Confidentiality / Privacy
Of the people treating you, only those named above will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results that will be held securely at The University of Sydney. We will seek your explicit permission to display your “self-portrait” or include your image or voice in an exhibition, documentary film, educational resources or in research dissemination (such as conferences presentations or peer reviewed journal articles).
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Young People with Cancer 18 -29 years old

Study Title: Growing Up With Cancer

Will taking part in this study cost me anything, and will I be paid?
Participation in this study will not cost you anything financially however full participation in the study is likely to be time consuming. No payment will be offered for your participation.

What happens with the results?
If you give us your permission by signing the consent document, we plan to discuss/publish the results at conferences and other professional forums, in peer reviewed journals or with the Sydney West Area Health Service Ethics Committee and Australian Research Council for monitoring purposes and to display your “self portrait” in a public gallery. Results of the study will be provided to you, if you wish.

Complaints
If you have any concerns about the conduct of the study, or your rights as a study participant, you may contact: Ms Jillian Gwynne Lewis, Westmead Hospital Patient Representative, (Contact details: Telephone No 9845 7014 Email address: jillian.lewis@swahs.health.nsw.gov.au). You should quote SSA reference number 09/WMEAD/62.

Contact details
When you have read this information, the researcher will discuss it with you and any queries you may have. If you would like to know more at any stage please do not hesitate to contact him on 9036 3405. If you have any problems while on the study, please contact Dr Ian Kerridge. Working hours telephone 9036 3405 After hours telephone 9036 3405.

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form. This information sheet is for you to keep.
CONSENT TO PARTICIPATE IN RESEARCH

Name of Researcher: [insert name here]

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.

2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by ____________________________ ("the researcher") and I, being over the age of 18 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.

3. I acknowledge that I have been given time to consider the information and to seek other advice.

4. I acknowledge that refusal to take part in this study will not affect the usual treatment of my condition.

5. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.

6. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.

7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.

8. I acknowledge that any regulatory authorities may have access to my medical records to monitor the research in which I am agreeing to participate.

9. I understand my identity will be disclosed if I choose to display my “self portrait” in an exhibition.

10. I agree to be contacted at a later date about possible use of audio and visual material collected during the research project in an exhibition, documentary film, educational resources or research dissemination.

Before signing, please read ‘IMPORTANT NOTE’ following.

IMPORTANT NOTE:
This consent should only be signed as follows:
1. Where a participant is over the age of 18 years, then by the participant personally.

Name of participant _________________________________ Date of Birth __________________
Address of participant ______________________________________________________________

Signature of participant ______________________________ Date: ______________________

Signature of researcher ______________________________ Date: ______________________

Signature of witness ______________________________ Date: ______________________
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Young People with Cancer 18-29 years old

Study Title: Growing Up With Cancer– Filming in self portrait workshops

Chief Investigator:
A/Prof I. Kerridge, Director, The Centre for Values Ethics and the Law in Medicine, The University of Sydney, (02) 9036 3405
Department of Haematology and Oncology

Invitation
You are invited to participate in a self portrait workshop where you will learn photo and video techniques used to make a “self-portrait” and receive assistance to plan and create your own “self portrait” about the impact of cancer on your experience of growing up. You will be filmed at this workshop by a documentary film team.

The study is being conducted by:
Associate Professor Ian Kerridge, Staff Haematologist/BMT Physician, Haematology Department, Westmead Hospital, (02) 9845 7073 and Director, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3405
Dr Christopher Jordens, Lecturer and Research Fellow, Centre for Values Ethics and the Law in Medicine, University of Sydney, (02) 9036 3406
Clinical Professor David Bennett, Head, NSW Centre for Adolescent Health. Children’s Hospital at Westmead. (02) 9845 2512
Dr Pandora Patterson, National Research and Evaluation Manager, CanTeen, (02) 8296 6313
Mr Kris Smith, Associate Lecturer in Photomedia, University of Newcastle, (02) 4921 7230
Dr Julie Mooney-Somers, Senior Researcher, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3412
Mr Peter Lewis, PhD Candidate, Centre for Values, Ethics and the Law in Medicine, University of Sydney, (02) 9036 3433

The Participant Information Form you received at the beginning of the research study explains why the research is being done and what it will involve. This additional form explains why we are filming the workshop and what participating in it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Young People with Cancer 18-29 years old

Study Title: Growing Up With Cancer– Filming in self portrait workshops

What is the purpose of filming the workshop?
This study is about how young people with cancer experience growing up through adolescence to young adulthood. Adolescence can be a difficult time for some people and we’d like to find out more about whether having cancer makes it even harder. For others, adolescence is not a particularly difficult time, and we’d also like to hear from these people about growing up with cancer. Adolescence is a time when young people are growing up and finding out who they are. We’d like to find out what your experience has been throughout your journey to adulthood in light of having cancer.

We plan to find all this out by talking to you about what it has been like to have cancer and also to find out how having cancer influences the choices you make about participating in your own health care.

Who will be invited to enter the workshop?
You are invited to participate in this study because you are a young person between the ages of 18 and 29 years with or who has had a diagnosis of cancer, and you have indicated that you would be interested in creating a “self portrait”.

Do you have a choice?
Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

What will happen in the filmed workshop?
If you agree to participate in this workshop, you will be asked to sign the Participant Consent Form and the Model Release Form.

You will attend a workshop in Sydney with one of our research team, the artist Kris Smith, and some other young people with cancer, where you will learn about photo and video techniques used to make a “self-portrait” and to receive assistance to plan and create your own “self-portrait”. During this workshop a small documentary film crew will film the interactions between you and other young people and the work you do with the artist. They may ask you some questions, ask you to explain what you are doing, or ask to interview you about your experience of the workshop.

The images and voice recordings they collect will be used to create a short documentary film and an online educational resource for family, friends, support workers, health care professionals and the wide community.

Are there any risks?
While there are no physical risks associated with participating in this study, people can become emotionally upset when discussing things that are very personal or painful. This may happen unexpectedly for you. Being upset by such things is a normal response. The researchers running the workshop will give you the chance to recover if you do become upset. You may then choose to continue the workshop or you may choose not to, depending on how you feel at the time. Your choice either way will be respected. The researcher will help you contact a support person if you
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Young People with Cancer 18-29 years old

Study Title: Growing Up With Cancer – Filming in self portrait workshops

would like and/or refer you to a counselor for help. Having your image in a film means that other people will be able to recognise you.

Are there any benefits? 
This study aims to further medical knowledge and may improve future treatment of young people with cancer however, it may not directly benefit you. Rather than being upset, some people actually welcome the chance to discuss their experience of cancer with someone keen to listen. You may also enjoy the creative process of making a “self-portrait” which you will be allowed to keep and you may enjoy meeting other young people and sharing experiences.

Confidentiality / Privacy
Agreeing to participate in a filmed workshop means you are agreeing to include your image or voice, “self portrait” and any other objects you bring to the workshop in a documentary film and educational resources.

Will taking part in this workshop cost me anything, and will I be paid?
Participation in this workshop will not cost you anything financially. No payment will be offered for your participation.

What happens with the results?
If you give us your permission by signing the consent document and release form, the documentary film and online educational resources will be made available to young people with cancer and their family and friends, health care professionals and potentially to the wider community.

Complaints
This study has been approved by the SWAHS Human Research Ethics Committee. If you have any concerns about the conduct of the study or about your rights as a study participant you may contact The Secretary, SWAHS Human Research Ethics Committee, phone 02 9845 8183 or e-mail researchoffice@swahs.health.nsw.gov.au.

Contact details
When you have read this information, the researcher will discuss it with you and any queries you may have. If you would like to know more at any stage please do not hesitate to contact him on 02 9036 3405. If you have any problems while on the study, please contact Dr Ian Kerridge Working hours telephone 02 9036 3405 After hours telephone 9036 3405.

Thank you for taking the time to consider this study. If you wish to take part in it, please sign the attached consent form. This information sheet is for you to keep.
PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Young People with Cancer 18-29 years old

Study Title: Growing Up With Cancer – Filming in self portrait workshops

CONSENT TO PARTICIPATE IN RESEARCH

Name of Researcher: [insert name here]

1. I understand that the researcher will conduct this workshop in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.

2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by ____________________________ (“the researcher”) and I, being over the age of 18 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.

3. I acknowledge that I have been given time to consider the information and to seek other advice.

4. I acknowledge that refusal to take part in this workshop will not affect the usual treatment of my condition.

5. I acknowledge that I am volunteering to take part in this workshop and I may withdraw at any time.

6. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.

7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.

8. I acknowledge that any regulatory authorities may have access to my medical records to monitor the research in which I am agreeing to participate.

9. I understand my identity may be disclosed if I choose to participate in a filmed workshop.

Before signing, please read ‘IMPORTANT NOTE’ following.

IMPORTANT NOTE:

This consent should only be signed as follows:

1. Where a participant is over the age of 18 years, then by the participant personally.

Name of participant _________________________________ Date of Birth __________________

Address of participant ______________________________________________________________

Signature of participant _______________________________ Date: ______________________

Signature of researcher _______________________________ Date: ______________________

Signature of witness ________________________________ Date: ______________________
Appendix 5: Participant’s Time Lines
Mrs. moved to Australia from Philippines.

Mrs. was transferred to Nursing Home, Singapore (SEA).
17 - Chemo
- Amputation
- Chemo

December - Diagnosis
October - Swollen ankle
10 - Started working

14 - Went to stoma stitching

12 - Started high school
11 - School completion
- Move to Sydney
- Swimming under age champion 12
- 2007 - Karate
- Diagnosed 20 Feb 2009
- Spent a month in hospital.
- October - Chemotherapy
- November - radio
Appendix 6: Full Conference Paper Published in eBook
HID9
Using Innovative Methods to help Young People reflect on the Meaning of Growing up with Cancer

Peter Lewis, Julie Mooney-Somers, Christopher Jordens, Kris Smith, and Ian Kerridge

Abstract
More adolescents and young adults are surviving cancer diagnosis and treatment than ever before. The experience of a life-threatening illness and onerous treatments may impact heavily on a young person’s developing sense of self by disrupting their efforts to achieve independence, maintain social relationships and realise life goals.
In order to explore this issue, we are inviting young people between the ages of 14 and 29 years to make sense of their experience using a combination of semi-structured interview and creative techniques for self expression (e.g. photography, painting, music). Recruits are first invited to participate in a semi-structured interview that is designed to elicit a spoken account of growing up with cancer. We then invite them to create a self-portrait in collaboration with a photo media artist who is a co-investigator on the project, the theme of which is the impact of cancer on their identity. In a follow-up interview, we invite each participant to reflect on topics raised in the first interview, on the content of the self-portrait, and on the creative process that generated it.
Combining traditional interviews with creative expression was intended to make participation in research more attractive to young people. Combining different modes of communication increases the potential for making meanings on topics such as identity, which young people may otherwise find conceptually challenging. In this paper we present early findings from the project and discuss how young people make sense of their illness experience in terms of their relationships with friends and peers.

Key Words: adolescents, young adults, identity, cancer, celebrity.

*****

1. Introduction
While deaths from cancer in the age group 12-24 years have decreased in number from 155 in 1995 (4.4/100,000) to 144 in 2004 (4.0/100,000) (after peaking at 4.7/100,000 in 1999), Thomas et al (2006) have found that decrease in the rate of death from cancer in this age group is lower than for other age groups in Australia. This relative decline in survival
rates in adolescents and young adults (young people) presents unique challenges to clinicians caring for young people with a cancer diagnosis.

The Growing Up with Cancer study aims to explore the impact of cancer on the transition of young people through adolescence and young adulthood. Many changes take place for young people during this time that affect all areas of their life – biological, psychological, and social. Young people in this age group are exploring aspects of identity such as sexuality, relationships, and independence, all of which may be disrupted by diagnosis and treatment for cancer. Our project uses a range of data collection techniques to study the experience of growing up with cancer from a number of different perspectives – young people with cancer aged 14 – 29 years, parents of young people with cancer, school students aged 13 – 18 years with little or no intimate knowledge of cancer, and health care professionals specialising in the care of young people with cancer.

This paper presents an introduction to the Growing Up with Cancer project and early findings from the young people with cancer aged 14 – 29 years group of participants. The paper will then focus on one aspect of the experience of growing up with cancer for young people identified by the research team from the interview data. The focus will be on the perspective of young people with cancer who re-enter familiar social situation post treatment to find that the behaviour of their friends, peers, or associates, is unexpected and at times troubling.

2. Background

Erikson (1968) locates identity formation within an eight stage developmental life cycle. Identity formation takes place at stage V, identity vs identity confusion. The pre-requisite for moving to stage VI, intimacy vs isolation, is resolution of the conflict over personal identity. In other words, to engage in meaningful, intimate relationships in young adulthood, it is first necessary to answer the question “Who am I?” Erikson conceived of this conflict over personal identity as characterised by the need to establish a sense of one’s current and future self and by a lack of commitment to a particular future identity. Adolescence is also characterised by a sense of instability in various aspects of a young person’s life. Adolescence is a time when past, present, and future come together to form a meaningful self-concept and a unified whole. “Who am I?” is not answered in isolation from the social context in which a young person is located. For this reason, discovering who we are involves “trying on” different personas, engaging in different social roles, and establishing an identity independent of one’s parents. Relationships with peers and friends are more important in adolescence than those with parents because of the new and different perspectives on one’s own identity that they provide. The question “who am
"I?" is answered not only through psychological processes but also through social processes (interaction with others).

Symbolic Interactionism provides an alternative focus to that of Erikson by privileging the location of identity development in the interpersonal space of social interaction. While Erikson acknowledges that social interaction plays a part in identity development, his priority is still what happens within a person’s mind. Symbolic interactionists would argue that the only access an observer has to what occurs in someone’s mind is provided by observations of the person’s words and actions in social situations. They do not reject the notion that people have minds (thoughts, feelings) that influence their behaviour, merely that all we can know about the nature of that mind is found in observing behaviour and engaging in direct interaction with the person.

This project draws on developmental and social-psychological conceptions of identity formation and maintenance to study the impact of cancer on the transition of young people through adolescence and young adulthood. It assumes that identity development is a central purpose of young people and that the social interactions that contribute to this development are of primary importance in understanding the impact of a cancer diagnosis and treatment on young people. Section 4 of the paper describes one finding from the interview data from the study and discusses its implications for young people’s identity and interactions using the concept of celebrity.

3. **Study Sample and Participants**

Participants were recruited through a written invitation mailed from the oncology or haematology department responsible for their care or mailed to members of CanTeen, a cancer support organisation for youth. Prospective participants expressed interest in participating by contacting the research team directly. Table 1 provides details of the participants recruited to the project so far.

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age at diagnosis (years)</th>
<th>Diagnosis*</th>
<th>Age at 1st interview (years)</th>
<th>Second interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>George</td>
<td>M</td>
<td>22</td>
<td>ALL</td>
<td>29</td>
<td>Yes</td>
</tr>
<tr>
<td>Andrew</td>
<td>M</td>
<td>16</td>
<td>ALL</td>
<td>21</td>
<td>No</td>
</tr>
<tr>
<td>Mick</td>
<td>M</td>
<td>14</td>
<td>ALL</td>
<td>29</td>
<td>No</td>
</tr>
<tr>
<td>Mahalya</td>
<td>F</td>
<td>13</td>
<td>AML</td>
<td>22</td>
<td>Yes</td>
</tr>
<tr>
<td>Kurt</td>
<td>M</td>
<td>11</td>
<td>ALL</td>
<td>17</td>
<td>No</td>
</tr>
<tr>
<td>Malcolm</td>
<td>M</td>
<td>15</td>
<td>Hodgkin’s Lymphoma</td>
<td>16</td>
<td>Yes</td>
</tr>
<tr>
<td>Alexis</td>
<td>F</td>
<td>14</td>
<td>ALL</td>
<td>16</td>
<td>No</td>
</tr>
</tbody>
</table>
4. Findings and Discussion

This section of the paper will focus on one aspect of identity development identified by the research team during interview data analysis. Most participants have reported attracting more attention from others including family, school friends, peers, and strangers after their diagnosis than they were used to. The increased attention is evaluated by the participants as both welcome and unwelcome. The experience of attracting more social attention will be discussed in terms of the concept of “celebrity”.

4a. Local Celebrity

Several participants attracted increased levels of attention when they returned to school after treatment.

*I remember there was a hype about me being sick for some reason. I became kind of like a super star for having cancer. ... when I was 13 ... I came back to school ... and then everyone followed me around. I mean like everyone, like lots of people followed me around. (Mahalya)*

This localised form of celebrity was commonly reported by participants who returned to school after treatment. While Mahalya says later in her interview that she liked the attention at the time, now that she is older and has left school, the attention she received troubles her.

*It’s not like there were any new friendships ... any new bridges were built, it just goes back to the way it used to. So what does that mean? Yeah, it makes you think that it was, you are just a novelty. Entertainment for people who have obviously very boring lives ... (Mahalya)*
Mahalya expresses ambivalence at being regarded by her peers as a novelty and she struggles to find meaning in this aspect of her cancer journey. Her choice of words such as “super star” reflects the conventional language of celebrity. She also refers to experiences common to celebrities, for example, being followed around, and being “consumed” as entertainment. In common with several other participants, Mahalya describes attracting attention from people who do not know her but who behave as though they do. This is an example of what some authors have called “illusions of intimacy”. Both male and female participants described similar experiences of returning to school after treatment.

I didn’t want to actually tell anyone at the school and my mum eventually … called them at the school and told my year co-ordinator and he explained it to people. He told everyone … in year nine at the time. (Rudi)

... at the school ... they had an assembly for me and (my friend) actually got up and done a presentation for them for me and ... all these people were getting up and talking that I never even hung around at school, saying that they missed me and they wished that I’d get better and they were really close to me … (Sharni)

Rudi and Sharni make explicit how their school peers found out about their cancer. No other participants make this process of disclosure explicit, but it is clear that when they return to school their cancer diagnosis and treatment is common knowledge. Few participants construct this common knowledge as a problem, and some find relief that they are not required to explain their extended absence from school. However, this does have implications for privacy and also suggests commonalities with the experience of celebrity. This impacts on the young people with cancer in three ways; 1) the privacy of the young person is compromised, 2) the young person becomes public property (because of the “illusion of intimacy”), and 3) the young person is deprived of the opportunity to interact with peers on the basis of a cancer identity constructed by him or herself.

For most participants, the consequences of becoming public property were not perceived negatively. However, for one participant, the consequences were negative, as Holly says below.

... there was one girl in particular in my year who just hated me for being sick. ... she took a joy in telling people that I enjoyed the attention. ... they thought that I was someone
that really was lapping up the attention and enjoying the spotlight that I got. (Holly)

Holly’s use of the word “spotlight” again echoes the language of celebrity. The negative attention she received was also the product of an illusion of intimacy. Holly provides an example of the negative attention given to celebrities when they are deemed to be unworthy of the attention they attract. Such celebrities become the subjects of “bad publicity”. The ongoing implication for Holly of her “bad publicity” is that she continues the process of mending damaged relationships with her peers even now.

The experiences of participants described above are recognisable in the type of celebrity known as “accidental celebrity” or “quasar”. A quasar celebrity is someone who attracts initial attention through no fault of their own and through a process over which they have no control. Mahalya, especially, protests that she did not do anything to deserve the attention she received. If the experiences of Rudi and Sharni are typical, a widespread knowledge of a peer’s diagnosis and treatment for cancer evokes a response in young people at school that, for the young person with cancer, may be experienced as pleasant or enjoyable in a superficial sense but which is unsatisfying in the longer term precisely because of its superficiality and ultimate meaninglessness. This has negative implications when considered in light of Erikson’s (1968) emphasis on peer interaction as a developmental necessity for adolescents. Mahalya describes a deep ambivalence over the meaning of the interactions she had with peers after returning to school. She lost control over her cancer identity and was behaved towards in a way consistent with how others saw her, not how she wanted to be seen and not how she sees herself. She queries her value (just a novelty) and her worth (was the attention warranted?).

4b. Media Celebrity

Media celebrity represents an escalation in attention from people with whom participants had daily contact, whether known personally or not, to attention attracted to the participant through appearance in the media. This section is not intended to imply a teleology of celebrity, where media celebrity is a goal to be attained. Rather, individuals may be thought of as occupying a space on a celebrity continuum, from local attention to community, national, or international attention. National and international attention may only be attracted through the participant’s appearance in mass media. Sharni became the subject of local media attention.

Then when (cancer support group) came around and we sold (merchandise) at the school, well everyone wanted to know me because the papers were there wanting to do
interviews on me because I was the one with cancer ... And like you find people that you didn’t even know that want to be your friend and it’s like “I don’t know you, sorry.”

(Sharni)

The experience described by Sharni here represents an escalation in the degree of attention. Her image became more publicly accessible through newspaper exposure and the level of attention from strangers also increased. Sharni’s experience introduces the idea of a public profile that is developed in the experience of Mahalya.

(One cancer support group) ... do stuff in the oncology ward so they funded my ... first solo exhibition and this painter that I really love came and opened it for me ...

(Mahalya)

At the time of her solo exhibition, cancer treatment was very recent for Mahalya. She was bald headed and very thin. Her exhibition meant the production of a catalogue (a copy of which Mahalya provided to the research team) and it was opened by a famous contemporary Australian artist. This activity promoted Mahalya to the celebrity status of “star” in Monaco’s (1978) three tier hierarchy. The “star” is someone who achieves prominence through the cultivation of a public persona in addition to and more important than their professional profile.

Alice provided an extreme example of cancer stardom. Alice described her progress towards stardom in a long story that commenced when her treating hospital invited her to a photographic studio for the creation of “glamour shots” of her for hospital promotional and fundraising purposes. She described herself as “cancer pin-up girl”. Pin-up is a term that has particular cultural and social meanings and is typified, according to Buszek (2006), by images of aggressive sexuality, imperious attitude, and frightening physique. The stereotypical image of cancer is also frightening. That the image of cancer is sexualised in some way may be deeply disconcerting. Pin-ups are for visual consumption, as an aid for masturbation, or as an ideal for emulation. Some pin-ups may represent characteristics to which others aspire, not just physically but socio-culturally. Alice’s star status was later affirmed when she became the subject of a television documentary. She now regularly speaks publicly of the issues facing young people with cancer in her advocacy role within an Australian state health service.

A position on a celebrity continuum has implications for a young person’s self-identity and relationships. At the most local end of the spectrum, a young person has the most control over their construction of an identity with or without cancer. However, their control is not absolute. Others
with whom they have daily contact may construct a cancer identity for them that they reject. This produces a tension because, if friends, peers, and distant acquaintances persistently behave towards the young person as though their own construction of the young person’s identity is true, then there is very little the individual can do to impose his or her own cancer identity on social situations. This can have a lasting impact as was revealed in the experience of Holly. It is also potentially intractable. Amongst familiars it may never be possible to reconstruct one’s own identity in a desirable way for oneself.

At the Media Celebrity end of the spectrum, there is very little control over who is informed about the diagnosis and treatment. Mahalya and Alice both feel a tension around this issue. On the one hand, both have been resistant to the construction of a cancer identity for themselves in the past. But they have benefited from accepting a cancer identity in some social situations. For example, Mahalya would not have had her artwork displayed publicly, or perhaps have had her identity as an artist affirmed, without accepting a cancer identity. Alice’s professional interest is in advocating for improved services and greater recognition of the difficulties experienced by young people with cancer. But her advocacy role only exists because of her appearance in a documentary film about her cancer and her appearance as “cancer pin-up girl”.

The maintenance of a position at the Media Celebrity end of the spectrum requires action and effort. Alice, therefore, continues to accept engagements to speak publicly about her cancer which continually reaffirms her cancer identity. Mahalya has not actively cultivated her public image and, therefore, finds herself an “anonymous” university student who is not readily recognisable to strangers. This illustrates that it is possible to shift positions towards either end of the spectrum. It also raises questions about the extent to which young people more generally are at liberty to construct their own identity and how young people with cancer work to resolve inherent tensions in being seen as someone they are not (or do not wish to be).

Notes

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Appendix 7: Full Conference Paper Published in eBook
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Abstract

According to qualitative research with adult cancer survivors, the experience of survival is characterised by (among other things) a diffuse sense of indebtedness. Survivors thus sometimes engage in activities that are designed to "give something back" to the communities or to the health care system that helped them survive. This paper examines whether expressions of indebtedness and/or actions undertaken to "repay" the debt are evident in young people’s accounts of survival.

The findings are based on semi-structured interviews conducted with 28 cancer survivors aged 16-30 years. Study participants spoke about becoming “a better person” because of their survival experience. Evidence proffered in support of this included intentions to be helpful or supportive, aspirations to do good works in the future, and descriptions of actual acts of charity, support for peers, and telling their story to help other young people with cancer. Participants also claimed that their personal experience gave them special insight and wisdom into problems experienced by their peers. Moreover, they often contrasted their own attempts to be a better person with a perceived lack of this desire, or associated actions, among their peers.

So while young cancer survivors did not refer explicitly to a sense of indebtedness in the interviews, they did express a desire to do good deeds for their local and broader community - a desire that they attributed to their cancer experience. We will argue that the ways participants described enacting “being a better person” in their daily lives and the ways they used this to differentiate themselves from their peers, contributed to the development of their cancer survivor identity. We will end our presentation by considering how the social, cultural and developmental contexts of these young cancer survivors’ lives may be implicated in the way they choose to undertake this ongoing identity work.

Keywords: adolescence, cancer survivorship, biography, narrative, qualitative methods

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Introduction

Adolescence, the period between the onset of puberty and the early 20’s, is an intensely turbulent time. During this period young people experience profound biological and social change: their body changes and grows, most become sexually active, they become independent from family, they complete schooling and transition into higher education or into the workforce and they achieve the legal status of “adult”. It is a period during which young people engage in activities to work out “who they are”, transform their personal identity, and establish independent and meaningful intimate relationships. A diagnosis of cancer and subsequent treatment may disrupt this process profoundly.

Young people with a cancer diagnosis are surviving in increasing numbers. The number of deaths from cancer in young people aged between 12-24 years in Australia decreased from 155 in 1995 (4.4/100,000) to 144 in 2004 (4.0/100,000). But while we know an enormous amount about the mortality and survival associated with a cancer diagnosis, much less is known about the long term social effects of cancer illness and treatment. In recent years a growing body of qualitative studies have explored the quality of survival following a cancer diagnosis (often called “survivorship”) including the physical and psychological impacts of cancer, and the experience of transitions from active treatment to follow up care, and from paediatric to adult oriented health care settings. This paper contributes to that body of literature.

The transition from cancer sufferer to cancer survivor is enormously complex and marked by anxiety and uncertainty. This transition has been referred to both in terms of identity paradox, and liminality, an uncertain state between recognisable social categories such as ‘ill’ and ‘healthy’. The impact on the lives or “narratives” of cancer survivors has been theorised as a ‘biographical disruption’, which has been understood in studies of young people with cancer as a restoration of biographical order, and a return to normal life. Slightly differently, Drew described cancer survival as a process that “requires and inspires the telling of a reflexive, transformative illness story” in which survivors make sense of their cancer experience. This “biographical revisioning” is a process in which taken-for-granted possible life trajectories and narrative pathways are regularly revisited and reconfigured as a way of making sense of cancer illness.

One of the ways in which cancer survivors make meaning of their cancer experience is through finding benefits in their illness. Benefits identified by older adult cancer survivors include an increase in their enjoyment and appreciation of life, a diminished concern for trivial matters, a revision of their life priorities, and alteration to their philosophy of life, while work with young people has identified being changed for the better. Young people may demonstrate that their lives have changed for the better by engaging in fund-raising activities for charity, acting as peer counsellors and planning professional careers in nursing or teaching.

One of the aims of the Growing up with Cancer project was to describe the impact of cancer illness and treatment on young peoples developing identity, relationships, agency, and autonomy. This paper aims to describe how cancer transformed participants’ identity into “being better people” and the implications this transformation has for their relationships with others both now and in the future.

Methods

The Growing up with Cancer study was a mixed method, qualitative research study of young people aged 16 - 30 years who had survived a diagnosis and treatment for cancer. Young people diagnosed with any type of cancer except skin cancer participated in multiple one-on-one interviews (conducted either face to face or by telephone), an online survey and the creation of a self-portrait that depicted aspects of participants’ cancer journey. This paper draws on interview data.

Interview data was professionally transcribed and members of the research team conducted a thematic analysis of the transcripts. Our analysis was guided by the theoretical perspective of symbolic interactionism which resulted in a focus on what participants said about their relationships and interactions with others including family members, friends, partners, peers, teachers, and acquaintances.

Findings

These findings are based on 47 semi-structured interviews conducted with 27 cancer survivors aged 16-30 years old at the time of their first interview and diagnosed with cancer between the ages of 10 and 22 years. Nineteen of 27 participants were school students at the time of their cancer diagnosis, five were university students, two were undertaking technical further education, and one was employed. Fifteen participants were women and twelve were men. Cancer diagnoses included acute lymphoblastic leukemia, acute myeloid leukemia, Ewing’s sarcoma, Osteosarcoma, Hodgkin’s lymphoma, and various testicular, ovarian, and brain tumours.

Participants spoke about a number of benefits that they had found in their cancer experience including enhanced relationships with parents, receiving gifts and attention from friends, and being shown leniency by school teachers. The benefit
we wish to focus on in this paper is that of ‘being a better person’ as a result of having cancer. We will describe participants’ reports of being transformed by cancer, of interacting with others in new ways because of this transformation, and of their long term plans to work for the benefit of others. Our concern here is not to determine whether participants really had become better people but to examine their claims in order to better understand their accounts of their survivorship.

Cancer as a transformative experience

Half the participants said that having cancer had made them better people than they were before their illness and treatment. They described cancer as a catalyst for changing their outlook on life and providing them wisdom and insight.

*It’s not until you’ve been through something like this that your outlook on life changes …* (George, 29)

*With my cancer I feel like it gave me a lot of wisdom. In terms of dealing with problems it gave me a lot of insight.* (Dilshara, 18)

As a result, participants reported being more compassionate, selfless, empathic, and charitable.

*Overall, generally I’m just a better person ... I’m more compassionate now as well
I’m more giving to charities than before like before I just used to walk past and try and look away ... I feel less selfish, I’m just less self absorbed ... I never really gave some people a chance but now I’m more compassionate so I actually take an interest in what they like* (Bill, 18)

Accounts of being a better person

Participants who talked about having been ‘transformed’ by cancer spoke of the specific ways in which they enacted this. Their descriptions included acts of charity, support for peers, and telling their story to help other young people with cancer. These were all activities that could be undertaken in the short term that required no formal training or lengthy preparation.

Five participants said that they regularly donated money to cancer charities and contrasted this to their lack of interest in donating money to charity before they had cancer. They offered this as evidence in their interview that they were now “better people”.

*I now do support different sorts of registered charities like Children with Cancer and Leukaemia Foundation where I wouldn’t have given two hoots ... before [cancer] * (George, 29)

Five participants gave examples of providing support to their friends individually, for example by counselling friends about their problems, and collectively, for example by advocating for a school year group in the student council. They drew an explicit link between their cancer experiences and (new) skills or insights that made them well positioned to offer support.

*Because I’ve had that experience [of surviving cancer] I’m able to relate to other people’s problems a lot better I’ve naturally fallen into the role of guidance counsellor. People notice that I have that wisdom and that grounding so they’ll naturally come to me for advice...* (Dilshara, 18)

Six participants reported that they shared their story of cancer survival with other people. They did this spontaneously as a response to a specific social situation. Sharni is a typical example of participants who offered their own cancer experience as a good model of how to deal with personal difficulties.

*I tell them [my cancer story] to make them realise if they are hurting or they do have people that are sick there is always a good side that can come from that life ... wanting to help other people realise that things can get better no matter how bad it gets ...* (Sharni, 21)

Participants also reported sharing their story with a wider audience in order to raise awareness of the effects of cancer on young people and to raise money for cancer charities.

*I’ve gone into schools to do presentations of CanTeen to raise awareness – and to schools that have someone who has been diagnosed with cancer, to help...* (Hendo, 18)
All of these participants implied that they were ‘duty bound’ to share the benefits of their cancer experience with others. This sense of duty was made explicit by one participant.

... when you look at why did I go through that ... I see it as a waste if I’m not going to share what I’ve learnt through that experience to help others and that’s one key thing if I’ve gone through it why not use my own experience to help others...

(Mick, 29)

Sixteen participants were active members of CanTeen, an Australian support group for young people living with cancer. CanTeen uses a model of peer support which gave participants the chance to voluntarily help other young people with cancer. Helping other young cancer survivors was also a dream for non-CanTeen members.

I’ve been wanting to help people who have gone through it [cancer]. Who are going through it. I’m not going to be a counsellor but I wouldn’t mind being a volunteer for say going to the hospital and just sitting there with the person who’s going through it to give their parents a break and have them talk to me and cry on me. I want to do that. (Erin, 24)

Accounts of planning to be a better person

Participants spoke about cancer survival giving them an awareness of the needs of others and the ability to help others in ways that they had not considered doing before. In addition to talking about being a better person through the ways young people related to people around them day to day, our participants also described longer term and more significant changes to their future selves. Five participants described how they intended to help other becoming “helping” professionals themselves so they could help others recover from life disrupting events. Disruptive events included but were not limited to cancer. Participants spoke of becoming nurses, doctors, social workers, and psychologists.

My biggest dream would probably be work in, as a psychologist, maybe a prison, working with prisoners, helping them get back on track ... (Talia, 17)

I want to work [as a nurse] in rural Australia, Alice Springs. I've wanted to go to Alice Springs for a long time. (Mahalya, 22)

Mahalya said that she wanted to work with Aboriginal people who live in rural Australia. Prisoners and Aboriginal people represent marginalised populations who are stigmatised in Australian society. This implies that participants had an affinity for marginalised groups. The implication of striving to become a ‘better person’ for these participants was considerable as admission to the professions named by participants would structure the years beyond the completion of treatment. They were to this degree ‘dreams for the future’.

Discussion

We would argue that the activities participants described as evidence of “being a better person” are part of a broader process of finding benefit in cancer survival. This is part of the larger project of making meaning of an illness experience described by so many in relation to chronic or life threatening illness.23 Our study demonstrates the particular ways in which young people who have faced a cancer diagnosis describe finding benefit. “Being a better person” is a special case of finding benefit in that it is oriented to the cancer experience benefiting other people now and in the future. Our participants’ imagined and in some cases were planning for, futures that included voluntary work and careers dedicated to “helping” others. These imagined futures constitute a young person’s planned biography and cancer affects the outcomes of these plans in a number of ways.

Biographical revision is a process of identity reconstruction undertaken in response to the experience of cancer.24 Young cancer survivors revise “who they are” in the present in light of their cancer experience. They subsequently imagine “who” they will become in the future in response to who they are now. This was evident in the accounts of our participants who spoke of being “better people” since their cancer experience than they were before. Their subsequent dreams for the future reflected their reconstructed identity as someone who is better (a moral claim) for having had cancer. They described not only being better people in the present but of planning to continue to be better people into the future. Young cancer survivors have a short biographical history and a long imagined future compared to older adult cancer survivors. Cancer illness and treatment narrows young people’s imagined futures in the short term. This is because the outcomes of disease and treatment are very uncertain. Cancer potentially results in ongoing physical, intellectual, and emotional constraints. Is it possible that what our participants described was a resistance to the potentially constraining effects of cancer and a reconstruction of their cancer experience as beneficial – one that provided additional opportunities to those they had before? Is the nature of biographical revision for young cancer survivors different to that of older cancer survivors in that it focuses on a lengthy future rather than a lengthy past?
How the identity work we have examined plays out in the longer term is something we can’t ascertain from our study. Our participants described dreams and intentions for the future – an imagining that they described as significantly different and morally better than their past imagined future – that may not eventuate. In this way young cancer survivors may be no different to other young people whose dreams become tempered, modified or simply abandoned. What we have shown, however, is that one of the responses of our study participants to their cancer experience was to accommodate cancer into the part of their reconstructed identity that deals with their long imagined future. For how long into the future will cancer continue to be a biographical touchstone for young cancer survivors?

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Appendix 8: Schedule of Interview Questions for Interview 1
Growing up with Cancer Semi-Structured Interview 1

Interview Schedule

1. Tell me about your life at the time of your diagnosis.
2. Can you pick five life events that stand out for you before you were diagnosed?
3. Which aspects of your life changed after diagnosis?
4. Can you pick five life events that are significant for you since your diagnosis?
5. Ask further questions in response to answers provided by participants.
Appendix 9: Coding Tree
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**Sense of self**

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