Clinical Ethics Committee Case 5:

Should we discharge our vulnerable patient to a family who seem unable to look after her?

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Biographical Information

Dr Ainsley Newson is Senior Lecturer in Biomedical Ethics in the Centre for Ethics in Medicine at the University of Bristol. She has a PhD in Medical Ethics from the University of Melbourne in Australia. She also has Bachelors in Science (majoring in human genetics) and Law (majoring in health law and intellectual property). Her current research interests include clinical and reproductive decision-making in genetics; and she has published on these issues in a range of academic journals and books. Ainsley sits on a range of committees including the BMJ Ethics Committee and the European Clinical Ethics Network and she has recently joined the Editorial Committee of Clinical Ethics. She has been a member of a Clinical Ethics Committee for 5 years; first at St Mary’s Hospital in London and since 2006 at the Royal United Hospital in Bath. She is experienced in public engagement on issues in bioethics and regularly contributes to media debates.

Introduction

This is the fifth of a series of cases provided and discussed by UK clinical ethics committees. This series developed from the Virtual Ethics Committee, which discussed a case in each issue of the first two volumes of the journal. We invited all of the clinical ethics committees registered with the Clinical Ethics Network to volunteer to both submit a case and then discuss a case allocated according to the experience of the committee from the resulting pool (i.e. committees do not discuss their own cases). The committees were given some guidance on how to generate a case, including the advice that unless consent from all parties to a case could be obtained, we would prefer fictional cases based on the combined experience of the committee, or on an issue that they thought needed to be more widely discussed. The editorial committee took this decision in order to safeguard patient confidentiality. To the same end, we decided that the committee referring a case would not be identified (as this would provide a geographical indicator of identity), but we would name the committee discussing the case. A member of the editorial committee attends the discussion of the case and writes the summary to be published in Clinical Ethics, once the discussing committee and the journal editors have approved it. All committees and all of our readers individually, are invited to respond to the summary of the discussion once printed.
Following the journal’s usual review process, we welcome short articles or letters expanding upon points raised by the discussing committee or sharing similar experiences. We are also interested in publishing examples of good practice or guidelines on difficult areas that have been generated by clinical ethics committees during the course of their work.

We have had a terrific response to the invitation to participate in this series from clinical ethics committees based all over the UK, and look forward to some lively case discussion. **Future report series (starting with volume 5) will examine the contributions of Clinical Ethics Committees to organisational policy-making.** Committees which would like to participate should contact the new Case Studies editor: Ainsley Newson (ainsley.newson@bristol.ac.uk).

Central and North West London (CNWL) Foundation NHS Trust Clinical Ethics Committee agreed to discuss the case presented here. The Committee has been in operation since January 2004. CNWL is a mental health trust and cases referred are in relation to dilemmas around patients’ mental health problems. The Committee comprises 10 members: a lay chair, lawyer, ethicist, faith representative and a number of clinicians who represent different disciplines (such as, nursing, medical, social work, occupational therapy and psychology/family therapy) and different geographical parts of the Trust. The committee meets monthly for a two-hour meeting. Referring clinicians are present at the meeting and a guidance note is written up soon after the meeting. Topics covered have included treating physical illness under compulsion, disclosing information to families when patients lack capacity, sexually transmitted diseases in patients with learning disability, requests for palliative care in patients with anorexia and determining best interests.

**Referral to the Clinical Ethics Committee: A 55 year-old woman with Alzheimer’s Disease**

**Case description**

Mrs. A is 55 years old and suffers from Alzheimer’s Disease. She has had to take early retirement from her job at the checkout in a local supermarket on ill health grounds. She normally lives with her 56 year old husband and two adult children but she was recently admitted to the assessment ward of the psychiatric hospital following concerns on the part of her mental health social worker that she was not receiving adequate help and care at home from her family. Mrs A had been found wandering away from her house in the early hours of the morning by the police and had appeared unkempt and frightened. When she had been returned home, after her name and address had been found in her coat pocket, the family had been unaware of her absence and seemed unconcerned. The social worker had suggested a period of further assessment and respite to the family, which they were keen to take up, during which further discussions could take place to ascertain what further help could be offered.

During the assessment in hospital, Mrs A continually asked to go home and made attempts to leave the ward on a couple of occasions but was easily persuaded to stay. A consultant psychiatrist felt that she lacked capacity to make an informed decision to go home as she was unable to retain information for a period sufficient to “weigh it in the balance”. She believed she had small children at home, whom she needed to look after and to bring home from school. She was disorientated in time and place and, although she had immediate recall for three words, she could not remember them after a few minutes. She was unable to copy a diagram correctly or write a sentence. She needed help with washing and dressing and often became incontinent of urine if not reminded to go to the toilet at regular intervals.

An assessment of her social circumstances took place at Mrs. A’s home with her social worker and the occupational therapist. The house was poorly furnished and dirty. There were several hazards with
regard to steps and stairs. A great many empty beer and whisky bottles were lying around in the living room and kitchen. A financial assessment revealed that Mrs. A’s Disability Living Allowance (DLA) and other benefits, such as Mr. A’s carer’s allowance were making up a good proportion of the family’s income.

Her husband visited Mrs. A in hospital about twice a week. He was seen to speak to her rather roughly and she became very quiet and uncommunicative during his visits. Her son once visited while under the influence of alcohol and Mrs. A appeared wary and frightened of him. A neighbour also visited on occasions and revealed to nursing staff that the family was well known in the area for frequent violent disagreements which predated the onset of Mrs. A’s illness.

At a case conference three weeks after admission, Mrs. A’s family attended along with the consultant psychiatrist, the social worker, the occupational therapist and nursing staff. The family said they were keen to look after Mrs. A at home and declined the offer of home carers to help with her personal hygiene etc but were keen to have day care at a local day centre twice a week and to access respite care in a residential home every two months or so. Mr A felt that he could continue working in a nearby factory and that Mrs A could be left alone for periods in the daytime. Their daughter attended a local college and their son was unemployed but was not usually or reliably around.

It was thought by the professionals present that discharging Mrs. A with this level of care would not be safe. The family were adamant that if they wished to take Mrs. A home, then they had every right to do so and that they could not be prevented from discharging her. Despite her lack of capacity to make a decision about her future care, Mrs A was able to express an opinion and it was ascertained that she wished to go home. However, she thought she still lived in her childhood home and she did not appreciate the limitations on her ability to care for herself.

Key questions underpinning the referral to the Clinical Ethics Committee
Our team has approached the CEC to discuss the case, with the following questions in mind:

1. Is it ethical to discharge Mrs. A to the care of her family, in the knowledge that, in the opinion of the professionals concerned, she will get less than adequate care?
2. What is “adequate care”? Should members of the care team judge the domestic situation based on their own standards or the standards normal for this family?
3. Are we depriving Mrs. A of her liberty illegally?
4. What solution is in Mrs. A’s “best interests”?

Response from CNWL Foundation NHS Trust Clinical Ethics Committee
Thank you for your referral, which we considered at our meeting on 24th September 2008.1 We thought this case was ethically and legally complex, not least because of the multiple stakeholders and the range of options for legal intervention. You proposed four questions and we structured our discussion around these.

We began by discussing a few aspects of the case on which we would have sought further factual clarification. First, we would have liked to know whether you had any specific proposals for Mrs A’s plan of care and what you would consider as optimum care for Mrs A’s level of need. We have made some

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1 Editor’s note: This case was considered before the amendments introduced by the Mental Health Act 2007 came into force, including the deprivation of liberty amendments to the Mental Capacity Act 2005. These amendments are described in more detail in an accompanying commentary.
assumptions about what options are practicable within your care environment. Second, we would have sought more information on your concerns about continuing neglect and possible abuse of Mrs A in her family home. Has there yet been a frank discussion with the family, to share concerns and seek reassurance? We have assumed no such discussion has yet taken place.

We also discussed Mrs A’s capacity to make decisions about her care. Given that capacity is decision-specific, Mrs A may be able to be involved in some decisions about her care. If she does have capacity, Mrs A has a right to make an unwise decision which may conflict with her clinical team’s assessment of what lies in her best interests. That said, we have assumed that a formal capacity assessment has shown that Mrs A has impairment in the functioning of the mind or brain, and lacks capacity with respect to a decision about whether and how she should be discharged.

Question 1. Is it ethical to discharge Mrs. A to the care of her family, in the knowledge that, in the opinion of the professionals concerned, she will get less than adequate care?

There is, in our view, an underlying ethical theme to this question, which recurred throughout our discussion. Rather than asking whether it is ethical to discharge Mrs A, we should first ask whether it is ethical to interfere with her private and family life. What is being proposed here is the intervention of a public body in Mrs A’s home and family life and the relationships she formed and choices she made when she had capacity. This life had involved distinctive personal feelings, goals, habits and experiences. Given the presumption of familial privacy in our society and the existence of a private sphere for individual action (free from public restraint), the onus is on the care provider to justify becoming involved to potentially go against Mrs A’s stated requests to go home. Generally we operate a strong presumption not to split up families unless there is no alternative. Any interference must be lawful, necessary and proportionate to the risks and for a permitted purpose, such as her health.

The consensus which emerged is that the standard of care Mrs A should ideally receive is but one of a complex array of considerations that should be borne in mind when deciding whether and how she should be discharged. While placing Mrs A in permanent institutional care will be safer for her, these factors are not the only ones to consider. How Mrs A might cope with inpatient care is also important; would she recognise anyone caring for her? Might she feel alone and frightened? Might the new environment be safer, but not necessarily better? Rather than asking whether it is ethical to discharge Mrs A to less than adequate care, we would ask whether it is possible to discharge her and to ensure she does get ‘adequate’ care. It may be better for Mrs A to be placed in a non-ideal but adequate environment, if that environment is made as safe as possible and is one that she will feel familiar in.

A counter-argument to this position is, however, that we do not seem to have any real way of determining what Mrs A wants at this point in time. We could adopt a substituted judgement approach to ask what Mrs A would have wanted, were she competent. In doing this we would have to draw on any available prior knowledge of Mrs A’s wishes about living arrangements when she was well, for example by asking her GP, others involved in her care, her friends and family.

The above consensus also relies on the caveat that the current attitude and behaviour of Mrs A’s family would likely have to change. We would see this challenge as working with the family to determine why they are resistant to receiving care in their home and to encourage them to see that services have to be involved. The family will need to be made aware that there really is no alternative if they wish their mother to return home. For example her home would have to be made safe and her family would have to agree to allow regular contact with the care team. However we also recognise that there is a
significant probability that this family commitment may not be sustainable in the longer term. If the family accept it, their role as carers would need to be supported.

In summary, we would encourage you to adopt the least restrictive option that is most congruent with the family, provided safeguards are in place to reassure you of Mrs A’s safety, and that these safeguards are acceptable to all parties. Mrs A’s relationship with her family is far from ideal but is nonetheless close, and her wishes should be respected insofar as they can be ascertained.

Question 2. What is “adequate care”? Should members of the care team judge the domestic situation based on their own standards or the standards normal for this family?

Our answer to this question is somewhat mixed. We would say that ‘adequate care’ at the very least should avoid neglect or ill treatment – this is part of your professional duty to Mrs A. Above this threshold, care should be delivered mindful of an individual’s right to determine his or her lifestyle. For an incapacitated patient such as Mrs A who cannot provide us with a reliable view of what she would choose, there is an onus on care providers to consider previous values, as we have suggested above. This information may provide you with a sense of the value Mrs A would place on her care together with other factors such as financial and dependency issues and will assist you in defining the threshold of adequacy for her care.

That said, it is important to recognise that ‘adequate’ care does not mean the best possible medical care. We do need to protect Mrs A from harm as much as possible but even in respite care this would not be infallible. There will be risks to her safety in any environment unless Mrs A was locked in to a ward. This infringement on her liberty would not seem to justify the reduction in risk that would result. Therefore the definition of adequate care needs to be defined so that it is in proportion to ensuring quality of life for Mrs A and her family.

Our answer to the second part of this question is “neither”. We cannot impute our own standards on to what is “normal” for this family, yet neither can we simply accept what may be a dangerous situation for Mrs A. There are some fairly straightforward steps that could be taken to ameliorate some of these risks and you could work with the family to put these into place. If the family is not able to be persuaded that these measures are necessary then legal recourse might have to be instigated and Mrs A would not be able to return home. Mrs A’s family needs to understand that Alzheimer’s is a progressive disease and that her condition will continue to deteriorate. At present she has care needs that were not being met in her home.

In summary, we feel that at the very least you should be certain to do no harm and that optimally you need to work with the family to reach agreement about an appropriate standard of care for Mrs A, all things considered.

Question 3. Are we depriving Mrs. A of her liberty illegally?

This question brings to mind the decision of the European Court of Human Rights in the Bournewood case, in which an incapacitated but compliant patient who was informally detained in hospital was deemed to have been illegally deprived of his liberty. Were Mrs A to be informally detained, she too would have no access to the protections and safeguards offered by the Mental Health Act 1983. We note

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that this area of the law will soon change, but we have considered the case under law as it stands in September 2008.³

As a Clinical Ethics Committee, we are not a legal body and so cannot make an absolute determination as to the legality of keeping Mrs A as an inpatient. But leaving that to one side, if Mrs A was being confined in a restricted space for a not negligible length of time and has not consented to the confinement then she may be being deprived of her liberty illegally. As Mrs A is incapable of providing consent, the only issue in her case is whether she is being so confined. As her care team is exercising continuous care and control over her movements, it would appear that she is not free to leave.

If we had a strong desire to keep Mrs A in hospital, we could detain her under the Mental Health Act. Admitting Mrs A under section 3 of the Mental Health Act would, however, open up the possibility of a tribunal hearing to provide a second opinion as to the legality of her detention as well as making social care arrangements. A supervised community treatment order (once the changes to the Mental Health Act are in force) could also be an option, although this will only take care of her mental health needs and not her physical care. Presently our duty is to ensure Mrs A’s safety and quality of life as much as possible. Until we can establish her safety at home it would be irresponsible to discharge her to her family’s care.

Question 4. What solution is in Mrs. A’s “best interests”? We raised the concept of Mrs A’s “best interests” relatively early in our discussion and returned to it several times, to both hone our definition and to apply it to the case.

We initially discussed three concepts of “best interests”:⁴

1. Promoting fulfilment of Mrs A’s desires: This approach posits that it is good to satisfy a person’s desires. Any decision should therefore take account of what Mrs A would have wanted, had she had capacity. This is arguable either way, as Mrs A’s previous circumstances may not have been ideal. She also appears withdrawn whenever her husband visits. This could suggest that given an explicit choice, she would have chosen to leave the family home. But it is just as likely that she would choose to remain with her family, given that she has remained with them previously despite apparent problems. However Mrs A’s previously held values were formed when she was well and not when she was dependent, incapacitated and vulnerable. She may now be, in effect, a different ‘person’ than she used to be and her prior values may not validly inform a current choice.

2. Taking a mental state perspective: Under hedonism, for example, happiness is an intrinsic good. We would examine Mrs A’s current state of mind to try to determine how happy she is with her current circumstances to determine what to do. Mrs A’s current attachment with her family is arguable. She states she wants to go home but her idea of home is not the reality she will return to. This may suggest that discharging Mrs A may not promote her happiness. Alternatively, we could place Mrs A in care and then assess her demeanour a short time afterwards. If she appears unhappy she could return to her family, with the safeguards discussed above in place.

3. Objective best interests: Under this theory, certain things are good or bad for a person regardless of one’s subjective attitude towards them. Applying this approach to Mrs A, we would ask what Mrs A needs now and how she should live. Mrs A needs to be protected from harm, but she also will

³ Editor’s note: The Mental Capacity Act 2005 has been amended by the Mental Health Act 2007 to introduce new “deprivation of liberty” provisions, which will come into force in April 2009.
⁴ Philosophical discussions of “best interests” are often framed in terms of “well being”. The three theoretical approaches to well-being discussed here are adapted from: Hope T, Savulescu J, Hendrick J. (2008) Medical Ethics and Law: The Core Curriculum, 2nd Ed. London: Elsevier, p34-36.
require resources to help her to cope with her debilitating illness. Fragments of familiarity, even if her perception of them is inaccurate, could provide her with some quality of life. Placing her in a facility where she recognises no-one and has an entirely new routine to adapt to may cause harm.

Whichever concept of best interests is chosen, the consensus we reached is that Mrs A’s best interests must be construed more broadly than simply her best medical interests. Sometimes the best outcome for a patient isn’t necessarily the best medical outcome. Therefore Mrs A could remain as part of her family, if you feel comfortable that this is what she would have wanted, all things considered, as long as you feel reassured that the safeguards in place will protect her from abuse and neglect. Her medical care at home may be less than she would receive as an inpatient, but so long as it is adequate without any sign of neglect then the additional pleasure that she may receive from being around her family may mean it is better for her to be at home.

A brief final point about financial matters. You have hinted that there may be a financial motivation behind the family’s desire to take Mrs A home. This could be looked into in a little more depth, including having the social worker work with the family to establish that Mrs A’s allowance is being spent on her care, or at the least is being spent on measures that will promote and maintain her quality of care and relationships with her family.

Concluding remarks
This case forces us to consider the assumptions, values and mechanisms involved in providing care to patients who are perhaps no longer the same person they once were. Our committee’s view is that we must see patients not just as clinical problems to solve but as individuals (competent or not) who exist within a wider fabric of interests and connections. The case of Mrs A raises the question of whether we should always choose what may be the most appropriate clinical option for patients, if this may necessitate a compromise of the patient’s broader social interests.

Practically speaking, if you can arrange that Mrs A return to her family home (with appropriate safeguards in place and the family on board) then she can live in a familiar environment and receive regular monitoring for neglect and her general mood via the visits to the day care facility. This solution, in our view, would be justifiable on a trial basis in order to accommodate the expressed wishes of Mrs A and her family. Assessing Mrs A at her regular day care would avoid the perceived intrusion of her family’s home, although checks for its safety would still be regularly required. An alternative to this course of action, should agreement with the family not be possible, is recourse to legal safeguards such as guardianship or other options available under the revised legislation in this area.

Members of CNWL Foundation NHS Trust Clinical Ethics Committee who contributed to this case:
Anselm Eldergill, Professor of Mental Health Law and Independent Chair
Dr Graham Behr, Consultant Psychiatrist
Dr Jo Emmanuel, Consultant Psychiatrist
Jon Ruddock, Acting Service Manager
Carolyn Johnston, Advisor in Medical Law and Ethics, Kings College London
Matthew Malherbe, Clinical Audit Specialist
Ibrahim Jubber, student and external observer
**Acknowledgement:** AN acknowledges the help of Dr Heather Draper, previous Case Studies section editor, who initiated this report series.

**In box**

**Deprivation of liberty under the Mental Capacity Act 2005 (MCA 2005) – due to come into force in April 2009**

*When is deprivation of liberty lawful?*

Under section 4A of the MCA 2005, as amended by the Mental Health Act 2007 (MHA 2007), it is lawful to deprive a person of their liberty in a hospital or care home only if

(i) a standard or urgent authorisation under is in force under Schedule A1 MCA 2005 or
(ii) it is a consequence of giving effect to an order of the Court of Protection on a personal welfare matter, in accordance with the provisions of the MCA 2005.

Deprivation of liberty is also permitted while a court decision is being sought on a relevant issue if three conditions are satisfied (see s 4B).

*If ineligible to be deprived of liberty*

If a person is ineligible to be deprived of her liberty under the MCA 2005, the court cannot include in a welfare order provision which authorises her to be so deprived, (s 16A).

**Aim of Schedule A1 MCA 2005**

This Schedule sets out detailed procedures and requirements relating to standard and urgent authorisations of deprivation of liberty in hospitals or care homes, and applies to publicly or privately funded care or treatment. The aim of the authorisation procedure is to ensure the lawfulness of the deprivation of liberty - it is not concerned with providing care or treatment to people who lack the capacity to consent. The MCA 2005 primarily deals with the latter situation.

**Standard authorisation to detain and deprive a person of their liberty**

Before a standard authorisation can be given to detain a person as a resident in a hospital or care home and deprive them of their liberty, there are six requirements which must be met. The person must be

(a) over 18 – (age requirement)
(b) suffering from a mental disorder within the meaning of the MHA 1983 – (mental health requirement)
(c) lack capacity to decide whether or not they should be a resident in the hospital or care home – (mental capacity requirement).
(d) The deprivation of liberty authorised must be
   (i) in the best interests of the person
   (ii) necessary in order to prevent harm to her, and
   (iii) a proportionate response to the likelihood of suffering harm and the seriousness of that harm – (best interests requirement)
(e) A person is ineligible to be detained and deprived of their liberty if
   (i) they are detained in hospital under the main powers of detention in the MHA 1983.
(ii) they are on leave of absence from detention or subject to guardianship, supervised community treatment or conditional discharge and, in connection with that, are subject to a measure which would be inconsistent with the authorisation if granted.

(iii) they are on leave of absence from detention, or subject to supervised community treatment or conditional discharge and if the authorisation was given it would be for deprivation of liberty in a hospital for the purposes of treatment for mental disorder. So authorisation cannot be used as an alternative to the recall procedures in the MHA 1983.

(iv) the authorisation would be for deprivation of liberty in a hospital for the purposes of treatment for mental disorder, the person would otherwise meet the criteria for detention under Part 2 of the MHA 1983 and the person objects to being detained in the hospital or to some or all of the treatment, (the eligibility requirement).

(f) There are refusals if

(i) the authorisation sought is for the purposes of treatment or care covered by a valid and applicable advance decision by the person, or

(ii) it would conflict with a valid decision by an attorney or deputy on their behalf or a relevant decision of the Court of Protection, (no refusal requirement).

Who requests?
The managing authority of a hospital or care home must request authorisation from the supervisory body if a person meets or is likely to meet all of the qualifying requirements is or is likely to be detained as a resident in that hospital or care home in circumstances which amount to deprivation of their liberty. The managing authority of a hospital or care home must keep written records of requests for authorisation made and the reasons for them.

There are also provisions for a third party to seek to initiate the standard authorisation process.

Who is the request made to?
The supervisory body is

(i) for a care home – the local authority where the person is ordinarily resident or where the care home is situated

(ii) for a hospital – the PCT which commissions care or Welsh Ministers if the care is commissioned by them.

Urgent authorisation to detain and deprive a person of their liberty
Urgent authorisations may be given by the managing authority of a care home or hospital to provide a lawful basis for the deprivation of liberty where it is urgently required, the six qualifying requirements (above) appear to be met, and whilst a standard authorisation is being obtained. An urgent authorisation can only last a maximum of 7 days unless it is extended to 14 days by the supervisory body in exceptional circumstances. An urgent authorisation must be in writing and the managing authority must keep a written record of their reasons for giving it.

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5 The managing authority is the PCT, Strategic Health Authority, LHB, Special Health Authority, NHS trust or NHSFT re: an NHS hospital; the person registered under the Care Standards Act 2000 re: an independent hospital; or the person registered re: that home under Part 2 of the Care Standards Act 2000 re: a care home.
N.B. Guidance on identifying deprivation of liberty will be produced as a MCA Code of Practice.

*For further information - see [http://www.dh.gov.uk](http://www.dh.gov.uk).*

Sara Fovargue