

UK CLINICAL ETHICS NETWORK NEWSLETTER

Issue 11, Spring 2004



Welcome to the Spring Edition of the UK Clinical Ethics Network Newsletter

This issue of the Newsletter considers the draft Mental Incapacity Bill and the effect it is likely to have on treatment of those lacking capacity. Consultation on mental incapacity and proposals to change the law commenced over a decade ago. On 24th February the Government responded to recommendations made by the Joint Committee that had considered the Bill.

On page 2 there is a summary of some of the key provisions of the Bill. A worked through case study on page 5 identifies key ethical issues that can arise in treatment of those lacking capacity and the implications that the Bill, if enacted, would have on their treatment.

The Network would be very pleased to receive your views on the potential impact of the Bill on the type of referrals made to Clinical Ethics Committees.

On page 9 there is an account of the Education and Training Project for which Ethox Centre has received funding. If your CEC would like to add its views on the type of education and training that would be considered useful for members of CECs, or take part in the pilot workshops, the Network would be delighted to hear from you.

The next Ethox workshops will take place in Oxford on 5th and 6th of April and a booking form is enclosed.

The Annual General Meeting of the Network will be held in London on 6th May followed by the Annual Conference on 7th May. Details are included on page 7 and we look forward to seeing as many of you as possible there.

We are currently working on a new ethical issues page for the web site on Resource Allocation, which will go online in the second half of March.

As with the previous Newsletter, this issue is being sent by email to those who requested it (if you would prefer to receive the Newsletter via email then please contact us). The Newsletter will also be available online.

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MENTAL INCAPACITY BILL 2003

In June 2003 the Lord Chancellor's Department published the draft Mental Incapacity Bill. This is a culmination of much consultation - in 1989 the Law Commission started a six year consultation process on mental incapacity and produced its report '*Mental Incapacity*' (No. 231 1995).

The aim of the Bill is to "help those who may lack capacity make their own decisions where they can and enable sound decisions to be made for them when they cannot" (the Government's response to the Scrutiny Committee's Report on the Draft Mental Incapacity Bill, February 2004, paragraph 3).

Due to changes suggested in the consultation process the Bill will be revised and it is anticipated that it will be introduced later in the parliamentary session. It may be renamed the Mental Capacity Bill. Even if the Bill is enacted it will not become law until Codes of Practice are in place. It will only be relevant to England, Wales and Northern Ireland. The Adults with Incapacity (Scotland) Act 2000 applies in Scotland. <http://www.scotland-legislation.hms.gov.uk/legislation/scotland/acts2000/20000004.htm>

The Bill applies to those persons aged 16 years and older who lack capacity and to decisions in all spheres of life; housing, finance health care etc. However, this article will consider its application to issues of healthcare and will therefore refer to 'the patient'.

Below we identify some key areas of the Bill and potential issues of concern that could arise before a clinical ethics committee. The clauses referred to below may change when the Bill is amended.

Presumption against lack of capacity

Clause 3(1): a person must be assumed to have capacity unless it is established that he lacks capacity.

This reflects the existing common law position.

Persons who lack capacity

Clause 1: a person lacks capacity if at the material time he is unable to make a decision for himself in relation to the matter to be decided.

*This is a functional test - capacity is assessed at the time the decision is to be made and in relation to **that** decision.*

Clause 2 expands on this further.

A person is unable to make a decision for himself if he is unable to:

- understand the information relevant to the decision
- retain that information
- use the information as part of the process of making the decision.

This is similar to the current position at common law (Re C (adult: refusal of medical treatment) 1994) although the requirement that the person 'believes' the information is omitted in the Bill.

In addition the Bill provides that someone would be considered unable to make a decision if he is unable to communicate the decision by any means.

Autonomy

Clause 2(2): a person is not taken to be unable to make a decision, and therefore lack capacity, merely because he makes an unwise decision

Codes of Practice will be issued that will give guidance where a person with apparent capacity makes repeatedly unwise decisions that put him/ her at risk.

Clause 2(3): a person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success.

This might include using specific communication strategies, providing information in more accessible form or treating an underlying mental disorder to enable a person to regain capacity (Recommendation 12 of the Joint Committee).

Persons lacking capacity

Clause 4: all decisions made for someone who lacks capacity must be taken in the person's best interests. There is a checklist of issues (set out in clause 4 (2)) that must be worked through by all decision-makers when considering what is in the person's best interests.

The Bill builds on case law but offers more precise guidance.

Regard must be had to the following:

- whether the patient is likely to have capacity to make the decision in the future

If so, can the decision be put off until that time?

- the need to permit, encourage and improve the patients ability to participate in the decision

The patient should be included in every decision made on his behalf

- the past and present wishes and feelings of the person who lacks capacity

Consider the patient's life and any statements made before loss of capacity

- if practicable and appropriate, the decision-maker should consult with others to gain views on the past and present wishes and feelings of the patient and the type of considerations that would be relevant.

i.e. someone named by the patient as someone to be consulted, anyone who has a caring role or is interested in the welfare of the patient.

- the decision taken should be the least restrictive one possible

Potential difficulties may arise where there is a conflict between the views of the healthcare professionals treating a patient lacking capacity and the view of best interests expressed by a person engaged in the care of the patient. Which view prevails? There should be no difficulty if the patient has made an advance directive (see below) but frequently this will not be the case.

Advance decisions to refuse treatment

Clause 23: an advance decision is one made by a person with capacity after he / she has reached 18. The advance decision would provide that where, at a later time when the patient lacks capacity and in the circumstances specified, a specified treatment is proposed to be carried out or continued, that treatment may not be carried out.

- The advance decision can be expressed in broad terms

- There is no requirement that the advance directive be written down.

The Joint Committee recommended that advance directives should be made in writing and be independently witnessed. The Government is considering this recommendation.

- The advance directive can be withdrawn at any time when the patient has capacity to do so
- The advance decision must be applicable and valid

It would be invalid if anything has been done that is inconsistent with it. For an example see the issues raised in the case discussed below.

It is useful to consider a case recently decided on this matter. This would be persuasive when interpreting the provisions of the Bill, if enacted.

HE v A Hospital NHS Trust [2003] EWHC 1017, 7th May 2003

The patient aged 24, was born and brought up as a Muslim. Her parents separated when she was a child and after this both she and her mother became Jehovah's Witnesses. The patient had a congenital heart problem which required further surgery as an adult. In February 2001 she signed an advance directive refusing blood and primary blood components. It also stipulated that the advance directive could only be expressly revoked in writing.

In November 2002 surgery was planned without the use of blood products. In April 2003 she was very seriously ill and was taken to hospital in an ambulance. She told her brother that she didn't want to die. She had septic shock secondary to bacterial endocarditis and required debridement or partial amputation. Such surgery was impossible without significant blood loss. The patient was sedated and remained unconscious. The patient's condition deteriorated and the prognosis was that she would die without a blood transfusion. The mother informed the hospital of the advance directive. The patient's father applied to the court to permit treatment including a transfusion.

The court granted a declaration that treatment with blood products was lawful.

Some issues the court considered:

- An advance directive is revocable even if it states that it is irrevocable or revocable only in writing.
- A written advance directive can be revoked orally.
- It is a question of fact whether the advance directive had been revoked or ceases to be operative. The patient's statement that she 'did not want to die' was not necessarily weighty but particularly relevant was the rejection of faith upon which the advance directive was based (she was betrothed to be married to a Muslim, on condition that she would revert to being a Muslim, she had not attended Jehovah's Witness meetings since January 2003 as she promised her fiancé she would not do so.)
- The burden of proof is on those who seek to establish the existence and continuing validity of an advance directive.
- If there is doubt about the continuing validity and applicability of the advance directive any doubt falls to be resolved in favour of the preservation of life.
- The more extreme the gravity of the issue the stronger and more cogent must be the evidence of validity.

Munby J. stated (paragraph 37) that:

"An advance directive is, after all, nothing more or less than the embodiment of the patient's autonomy and right of self-determination". However, given the decision above, it could be argued that in a grave life-threatening situation any doubt falls to be resolved in favour of best interests and therefore respect for autonomy is trumped by beneficence.

General Authority

This seeks to create a statutory form of the common law defence of necessity. Concerns have been raised that it may allow too much interference in the lives of people who lack capacity. It will be renamed and redrafted.

Reading:

The Draft Mental Incapacity Bill

www.lcd.gov.uk/menincap/meninc.pdf

Overview of Bill

www.dca.gov.uk/menincap/overview.htm

Joint Committee Report on the Draft Mental Incapacity Bill

http://www.parliament.uk/parliamentary_committees/jcmib.cfm

The Government's responses to the Scrutiny Committee's Report on the draft Mental Incapacity Bill (February 2004)

www.dca.gov.uk/pubs/reports/mental-incapacity.htm

Mental Incapacity Bill (draft), Review, Bulletin of Medical Ethics, October 2003, page 22



CASE STUDY

A female patient aged 76 with cognitive impairment was admitted to hospital with pneumonia. Her capacity has been assessed by a psychiatrist who determined that she lacked capacity to decide her own treatment. She had lived at home, with the assistance of two carers. At hospital it was proposed to treat her with intravenous antibiotics but she refused all treatment, removed her oxygen mask and insisted that she wanted to go home.

The clinician in charge of her care sought the view of the hospital clinical ethics committee regarding the ethical issues raised - was it ethical to treat her without her cooperation?

Ethical Issues:

The patient has clearly expressed her wishes. However if she is cared for in accordance with her wishes she is likely to come to permanent harm.

There is a difficulty in balancing respect for her **autonomy** against acting beneficently towards her. If she had capacity then in law she could refuse treatment even if that would result in her death (Re B (Consent to treatment: capacity) 2002). However the fact that she lacks capacity in law does not mean that her wishes should not be accorded respect. Autonomy is an ethical rather than a legal concept. There is a continuum of autonomy rather than it being an all or nothing concept and she has exercised her autonomy by refusing

treatment. How far her autonomy should be respected where it would result in harm to her is a difficult assessment.

The principle of **beneficence** requires that she is treated in a way that will help or benefit her. The legal term for this is acting in the patient's best interests and this is reflected both in case law and in statute, including the draft Mental Incapacity Bill.

In deciding what course of action to pursue that will be in her best interests it is important to look at the medical and non medical interests. Antibiotics and intravenous fluids will probably prolong her life but with such treatment will her stated aim of returning home be achievable? It may not be in her best interests to treat her against her will if the medical benefits to be achieved are minimal.

In addition in order to treat her with intravenous fluids and antibiotics it may be necessary to sedate her. This may result in her developing respiratory failure and therefore cancel out any benefit from treatment. In this respect it could be said that acting against her wishes by using sedation would harm her and thus be contrary to the principle of non-maleficence.

What course of action would produce the best likely outcome and can the needs of the patient be accommodated by any less intrusive means? Issues to consider:

- Assess whether the patient's desire to return home is a persistent one or is it likely to have arisen through fear and uncertainty?
- Has she been informed of the proposed course of treatment and the different options in a way that is understandable to her?
- Given that she has been informed as far as possible and that she still expresses a desire not to receive treatment in hospital is there any way that her desire to return home is achievable?
- Consider the likely prognosis with and without treatment, and make a decision about what would be in her overall best interests.

Issues that are highlighted to be considered under the draft Mental Incapacity Bill

Clause 3(1) states that a person must be assumed to have capacity unless it is established that he /she lacks capacity.

The test for capacity is a functional one i.e. individuals will be regarded as 'lacking capacity' for certain decisions at the time that the decision is to be made.

The patient has been assessed by a psychiatrist as lacking capacity.

A person should not be considered as lacking capacity unless all practicable steps have been taken to help the patient make a decision himself. The patient should be provided with information about the reasonably foreseeable consequences of deciding one way or another or failing to make a decision (clause 2 (5))

Has the patient been provided with information in a way that will help her to make the decision?

As the patient has been assessed as lacking capacity she can be treated in her best interests. The checklist of issues (set out in clause 4 (2)) must be worked through by all decision-makers.

- Is her capacity likely to return in the future?

If her cognitive impairment is reduced because of her pneumonia then this may be the case.

- There is a need to permit, encourage and improve the patient's ability to participate in the decision.

The patient should be included in the discussions and matters should be explained to her in a manner that she can understand.

- Take into account the past and present wishes and feelings of the patient and the facts she would consider if able to do so.

The wishes of the patient have been clearly expressed. Consider if this view is a persistent one.

- If practicable and appropriate, consult with others to gain views on the past and present wishes and feelings of the patient and the type of considerations that would be relevant.

Attempt to make contact with and take into account the views of the carers. Are there any family members who can add anything?

- Achieve the purpose of the decision in as least a restrictive way as possible.

The purpose of the treatment decision is to treat the patient's pneumonia and if possible to make her well enough to return home. Is it possible for her to receive treatment /care at home or in an environment that will cause her less distress and which she may be happy with?

- Find out whether the patient has made an advance directive and if so is it valid and applicable?

The process outlined above would currently be considered good practice in the care of incapacitated patients. The Bill highlights and clarifies these issues of good practice.



ROYAL COLLEGE OF PHYSICIANS WORKING PARTY ON CLINICAL ETHICS COMMITTEES

The Royal College of Physicians has established a Working Party on Clinical Ethics Committees to review the role of CECs and to make recommendations on their future development. The Working Party wishes to obtain as many views as possible and would welcome any comments or information from members of the Network. They are working to a tight deadline and hope to publish the report in June 2004. If you wish to contribute to the evidence being collected by the Working Party, please write to:

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Royal College of Physicians
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London NW1 4LE



UK CLINICAL ETHICS NETWORK AGM AND ANNUAL CONFERENCE

The next Annual General Meeting and Annual Conference of the UK Clinical Ethics Network are currently being organised. This year both events are being hosted by the St Mary's Clinical Ethics Committee. The Annual General Meeting will be held on Thursday 6th May at the Function Room, Education Centre, St Mary's Hospital, London. The Annual Conference will be held the following day, Friday 7th May at The Mostyn Hotel, near Marble Arch in London.

Annual General Meeting

The AGM is open to all members of the UK Clinical Ethics Network. There will be an overview of the relationship between the Ethox Centre and the Network, a report on the options available to the Network for developing a constitution, a discussion on the options available to the Network for securing future funding, and a report on the progress of the web site. The agenda and registration form for the event are enclosed with this newsletter.

Following the success of last year, we will again be organising an evening meal for anyone who wishes to join us. The meal will be at The Montcalm Hotel, which is only a short distance from the venues for both the AGM and Conference. We are expecting to meet at 8.00pm – 8.30pm at an approximate cost of £30.00 - £40.00 per head. If you would like to join us, please indicate on the AGM registration form so we can have an idea of numbers.

Annual Conference

This year's Annual Conference has a European influence, with speakers from Germany and The Netherlands attending. There will be comparisons between the experiences of the UK and Germany in developing Clinical Ethics Networks, and a comparison between the British and Dutch experiences of end of life decision-making. The afternoon session will revolve around group work on case studies. Different methods of ethical analysis will first be discussed, and then each group will look at a case and consider it from one of the different ethical viewpoints.

The conference is open to anyone who has an interest in medical ethics, and is not restricted to members of the Network. Registration is progressing well and we expect a good attendance. Further details of the conference, as well as the flier and registration form are available on the Network website at www.ethics-network.org.uk/Course/conference.htm

If you would like the conference details to be sent to you then please contact:

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ETHICS SUPPORT PROJECT

A grant has been awarded by the Department of Health to assess the education and training needs of members of clinical ethics committees and to develop a range of suitable and effective training programmes for them. The grant runs from April 2003 until March 2005.

The first stage of the project was to assess the educational and training needs of members of CECs to enable them to function effectively.

The needs assessment included interviews with chairs of new and established CECs and those involved with ethics education. In addition informal discussions were held with members of CECs through the Network.

Many thanks to those who were involved in the needs assessment.

Conclusions from the assessment

All of those interviewed recognised the need for members of CECs to have some ethics education, but identified the lack of availability of relevant training, the cost and limited time available for training as being constraints.

As new members join established CECs the range of knowledge and experience of ethics can vary, so it was thought that a workshop introducing basic ethical thinking for new CEC members and workshops on specialist topics would address these different needs.

In addition interviewees thought it would be useful for members of CECs to learn together to form cohesion within the Committee. How the Committee works together and the process of deliberation and decision-making are considered important.

Proposals

Drawing on the findings of the educational needs assessment, three key areas have been identified for developing models of education and training for members of CECs:

- Individual workshops that can be hosted centrally, or by an individual ethics committee. The subject of the workshops would include a basic introduction to ethics and topic specific workshops such as 'end of life', resource issues, capacity to consent/refuse treatment and genetics.
- A range of resource packs on ethical issues that members of CECs can use for self-education. The packs will include handouts, recommended reading, key articles and a CD ROM of visual materials.
- Seminars for individual committees on developing processes of decision-making and working as a committee in ethical decision-making. These seminars could be facilitated by a member of Ethox initially, or by an expert facilitator identified by the Clinical Ethics Network.

Workshops

It is proposed to run three workshops in 2004. They will be aimed at members of clinical ethics committees. The first will be held on Monday 10th May at Ethox and will cover Ethics and Genetics. The cost is £50 (flier enclosed).

A workshop will be held on mental incapacity and consent/ refusal of treatment in late September and in November the workshop topic will be Ethics and Resources.

With the feedback we receive from these workshops we will hope to run more workshops on other topics in 2005.

We will prepare resource packs on these topics for use by CECs in self education.

If you have any comments or views on the style or content of the workshops we should be very pleased to hear from you.



ENQUIRIES TO THE NETWORK

Ethical Decision Making Within Multi-Disciplinary Teams

The Network has been approached by Julie Woodley, University of Bristol, who is carrying out research for her PhD into the ethical decision making processes employed by members of multidisciplinary teams. Below she explains the nature of her investigations.

“As part of my PhD studies I am presently undertaking research into ethical decision making within multi-professional teams. Whilst many studies have been conducted into the ethical concepts of individual professions, the healthcare team ethic has been largely ignored until recently.

It is one of the aims of this research to investigate this team decision making process in order to inform the production of a computer- based system which would hopefully prove useful in exploring healthcare dilemmas.

I have carried out an extensive literature review into ethical decision making models but would like to analyse how multi-professional teams actually make case based decisions within the real life situation.

I would therefore like to enlist assistance from clinical ethics committee members.”

For further details please contact Julie Woodley (Senior Lecturer),
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Telephone: 0117 3288528
Email: Julie.Tonks@uwe.ac.uk

Pro Forma documentation for referrals to Clinical Ethics Committees

The Network has been contacted by a Clinical Ethics Forum asking whether use of pro formas, to be completed by individuals presenting clinical scenarios to an ethics committee / forum, are in general use.

The Network would be pleased to receive feedback from CECs on this matter, and if possible examples of pro formas that could be made available to other CECs.



ISSUES OF INTEREST

Presumed consent for organ donation

A survey by the British Medical Association (BMA) found that 62% of doctors would support a system of presumed consent for organ donation. Consent would not be presumed if the patient had registered an objection to organ donation, if the relatives made it clear that the patient had a serious objection, or if it would cause the family major distress.

100% of the Doctors surveyed thought that the current system of organ donation in the UK was insufficient for the UK's need for organs, while 73% thought that presumed consent would have a major impact on donor organ availability.

The BMA is supporting the move to promote a debate on a system of presumed consent. The BMA parliamentary briefing paper on Human Tissue and Organs – Presumed consent for Organ Donation can be found at:

www.bma.org.uk/ap.nsf/Content/Humantissueorganspresumed



Patient fights withdrawal of treatment guidelines

Leslie Burke, a 44 year-old man from Lancaster with the degenerative brain condition cerebellar ataxia, has sought a judicial review of the General Medical Council *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision Making* <http://www.gmc-uk.org>. The hearing was held on 26 February 2004.

Mr Burke's condition will eventually leave him confined to bed and unable to speak, but with an active mind. He is challenging the guidelines that allow artificial nutrition and hydration to be withdrawn if it is deemed too burdensome. The guidelines provide that doctors should seek court approval for withholding or withdrawing treatment where the patient is in PVS. There is no such requirement if the patient is comatose or otherwise unaware.

It will be argued that that the guidelines are unlawful because they will allow doctors to withdraw treatment without knowing the patients wishes and without seeking court approval.

GMC Guidance states that:

Patients must be fully involved in all aspects of their care. Doctors must also seek patients' views on how they would like to be treated if their condition worsens.

Ruth Evans, Chairman of the GMC Standards Committee said, "This is an exceptionally difficult area of decision making, and one in which the law is still developing. For this reason, we welcome the forthcoming court case as an opportunity for further clarification of the law."

http://www.on-idle.com/gmc/vpo/apps/press_release_latest



MMR

The General Medical Council is carrying out an investigation into Dr. Andrew Wakefield, the doctor whose research raised fears of a link between measles, mumps and rubella (MMR) vaccine and autism. The Lancet has said it should not have published his research due to a "fatal conflict of interest".

Dr. Wakefield has hired a libel lawyer to demand an apology from The Lancet after claiming that the medical journal has cast doubt on his honesty.

In September 2003 the Legal Services Commission withdrew funding for the MMR litigation on the grounds that the litigation, which was seeking to establish a link between MMR and autism or bowel disease did not have any reasonable prospect of success. Recently the High Court said there was no legal reason to overturn the decision to deny the parents legal aid.

<http://www.legalservices.gov.uk>

<http://news.bbc.co.uk/1/hi/health>

<http://www.telegraph.co.uk/news/main.jhtml>



Medical Journal Code of Conduct

Following the fallout over the research published in the Lancet linking MMR to autism, medical journals may now have to adopt a code of conduct to ensure the accuracy of the research they publish.

The code is being drafted by Cope, the Committee on Publication Ethics, and includes guidance from the Press Complaints Commission and the World Association of Medical Editors. Cope has approximately 200 members, including the BMJ and the Lancet, which will adopt the code. Editors will have to ensure that the research they publish has no conflicts of interest, is accurate, and is not affected by marketing demands.

The draft code can be viewed at

<http://www.publicationethics.org.uk/cope2003/pages2003/editorcode1.phtml>



USEFUL WEBSITES

-  UK Clinical Ethics Network <http://www.ethics-network.org.uk>
-  Journal of Medical Ethics: <http://jme.bmjournals.com/>
-  British Medical Journal: <http://bmj.com/>
-  British Medical Association: <http://www.bma.org.uk>
-  General Medical Council: <http://www.gmc-uk.org/>



DATES FOR YOUR DIARY

-  **UK Clinical Ethics Network Annual General Meeting 2004**
Thursday 6th May
The AGM will be held at the Function Room, Education Centre, 2nd Floor Mint Wing, St Mary's Hospital, London. The meeting will begin at 2.30pm, and will be followed by a meal at a local restaurant. For an agenda and registration form contact Jane Goodall at admin@ethics-network.org.uk
-  **UK Clinical Ethics Network Annual Conference 2004**
Friday 7th May 2004
The Annual Conference will be hosted by the St Mary's Clinical Ethics Committee and will be held at the Mostyn Hotel, near Marble Arch, in London. Full details of the agenda, location, travel, accommodation and a registration form are available on the Network website or from Jane Goodall at admin@ethics-network.org.uk
-  **Ethics in Clinical Practice Workshops**
Monday 5th and Tuesday 6th April 2004
Monday 18th and Tuesday 19th October 2004
The dates of the Ethics in Clinical Practice workshops in 2004 have now been confirmed. They will be held at The Ethox Centre, Oxford. The agenda for the April workshop is available on the website or from Jane Goodall at admin@ethics-network.org.uk.
-  **Ethics and Genetics Workshop**
Monday 10th May 2004
The Ethics and Genetics workshop is open to members of clinical ethics committees, and is related to the Ethics Support Project (see page 9). The workshop will be held at The Ethox Centre, Oxford. The agenda is enclosed with this newsletter.
-  For details of other courses go to the Courses and Conferences page on the website. If you would like to advertise an event with us please contact Jane Goodall.



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