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The Mental Capacity Bill

Bill 120 of 2003-04

This paper discusses the provisions of the *Mental Capacity Bill* which is due to be considered on second reading in the House of Commons on 11 October 2004. Explanatory Notes to the Bill have also been published [Bill 120-EN].

The purpose of the Bill is to provide a statutory framework to protect those lacking capacity, and also carers and professionals.

The *Mental Capacity Bill* represents the culmination of a long process of policy development and consultation, proposing reform of the law governing decision-making on behalf of persons who lack capacity. A draft *Mental Incapacity Bill* was published in June 2003 which was scrutinised by the Joint Committee on the Draft Mental Incapacity Bill.

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Summary of main points

The *Mental Capacity Bill* was published on 18 June 2004 and represents the culmination of a long process of policy development and consultation, proposing reform of the law governing decision-making on behalf of persons who lack capacity. A draft *Mental Incapacity Bill* was published in June 2003 which was scrutinised by the Joint Committee on the Draft Mental Incapacity Bill. The Committee made nearly 100 recommendations designed to improve and clarify the Bill. The Government published its response in February 2004. A draft Code of Practice was published on 9 September 2004. This includes further detail (including scenarios) and guidance about how the Bill's provisions might operate in practice.

The purpose of the Bill is to provide a statutory framework to protect those lacking capacity, and also carers and professionals. It is based on several key principles:

- An adult is to be assumed to have capacity unless it is proved otherwise
- There is to be no blanket label of incapacity - an assessment of a person's capacity must be made in relation to individual decisions
- Everyone is to be encouraged to participate as fully as possible in decision-making
- A person should have the right to make eccentric or unwise decisions
- All decisions made on behalf of people without capacity must be in their best interests
- All decisions made for another person should involve as few restrictions on their basic rights and freedoms as possible.

Key elements in the Bill include:

- A defence for people who provide care or treatment for someone who lacks capacity
- A new form of power of attorney which would enable the person appointed to make decisions not only in relation to financial matters, as at present, but also in relation to health and welfare matters
- A new system of court appointed deputies to replace and extend the present regime of receivership in the Court of Protection
- A new Court of Protection with extended powers
- A new public body, the Public Guardian, which would have powers related to attorneys and deputies
- A new Independent Consultee who would act for a person lacking capacity who has no one to speak for them
- Individuals would be able to make advance decisions to refuse treatment in the future.
- A new criminal offence of ill treatment or neglect of a person who lacks capacity
- Research would be permitted on incapacitated people, subject to prescribed restrictions
- A statutory clarification that the Bill would not introduce euthanasia (although some argue that the Bill would allow a form of euthanasia)

The Bill extends to England and Wales. Similar legislation has already been passed in Scotland in the form of the *Adults with Incapacity (Scotland) Act 2000*.

CONTENTS

I	Introduction and background	7
	A. Mental incapacity	7
	B. Numbers likely to be affected by mental incapacity	8
	C. The consultation process	8
II	The Bill	11
	A. General principles	12
	B. Decision-making	13
	C. Lasting powers of attorney	19
	D. The Court of Protection and the appointment of deputies	27
	E. Advance decisions to refuse treatment	34
	F. Scope of the Bill: The debate about euthanasia	41
	G. Research	47
	H. Independent consultee service	50
	I. Codes of practice	53
	J. International Protection of Adults	55
	K. Miscellaneous	56
III	The draft Code of Practice	58
IV	Comment on the draft Bill and the Bill	60
	A. The Law Society	60
	B. Making Decisions Alliance	61
	C. Mind	63

D.	Citizens Advice	64
E.	The Royal College of Psychiatrists	64
F.	The Royal College of Physicians	65
G.	The Catholic Bishops' Conference of England and Wales	67
H.	The Society for the Protection of Unborn Children (SPUC)	68
I.	The Linacre Centre	69
J.	The Pro-life Party	71

I Introduction and background

A. Mental incapacity

At present there is no comprehensive statutory framework governing decision-making for people who lack capacity. There can be uncertainty about who can take decisions and in which situations. It is not possible for a person to plan ahead and appoint someone to have authority to take all decisions for him should he lose mental capacity at some stage in the future, because only decisions on financial and property matters can be delegated in this way.

The term “mental incapacity” may have a different meaning in different circumstances. A person who lacks mental capacity may also be referred to as a patient. The *Mental Health Act 1983* defines “a patient” as a person who is incapable, by reason of mental disorder, of managing and administering his property and affairs.¹ However, even the test for “a patient” may be open to differing interpretations when it is used in different legal situations.²

It may therefore be difficult to decide whether a person does have capacity when a decision has to be made. There may also be uncertainty about who can make decisions and also about what act carers can perform. Families and friends have no legal right to be involved in making decisions on health and welfare matters on behalf of someone who lacks mental capacity.

The results of an NOP poll conducted for the Making Decisions Alliance³ in October 2002 revealed the extent of the widespread public misconception in this area:

92% of people thought that a partner would have the legal right to be consulted about decisions on their behalf if they could not make decisions themselves due to a severe head injury from an accident. Yet in reality, there is no mental capacity legislation in England or Wales. This means that thousands of people who are unable to make decisions themselves are open to exploitation; and that professionals are open to accusations of malpractice because the law is unclear about what they are allowed to do.⁴

There are, however, circumstances in which some decisions may be made on behalf of a person who has lost mental capacity, through the use of an Enduring Power of Attorney,

¹ Section 94

² See, for example, District Judge Gordon Ashton, “Benchmarks – diagnosing a patient – the prescribed Court of Appeal test for who is a patient”, *Law Society Gazette*, 20 March 2003, Vol 100 No 11, p35

³ The Making Decisions Alliance is an alliance of a wide range of organisations and groups working with people who may, for a range of different reasons, have difficulty in making or communicating decisions.

⁴ Making Decisions Alliance Press Release, *Who has the right to decide for us if we can't decide for ourselves?*, 19 February 2003.

an order of the Court of Protection, the appointment of “an appointee” or the inherent jurisdiction of the High Court.⁵

B. Numbers likely to be affected by mental incapacity

The Government has estimated that mental incapacity will potentially affect a large number of people:

It is estimated that over 700,000 people in the UK currently suffer from dementia and this figure is likely to increase to about 840,000 by 2021. Around 145,000 adults in England have severe and profound learning disabilities and at least 1.2 million have a mild to moderate disability. In Wales over 12,000 people were registered as having a learning disability in 2001. At some point in their lives approximately 1 per cent of the UK population will suffer from schizophrenia, 1 per cent will be subject to manic depression and 5 per cent will have serious or clinical depression. About one adult in seven in the UK cares for another adult - nearly 6 million carers in all. Many of these people care for adults who lack capacity who may need decisions made for them.⁶

C. The consultation process

1. The Law Commission report, *Mental Incapacity*

In 1989 the Law Commission commenced a study into the adequacy of the law and other procedures for decision-making on behalf of persons without capacity. Following consultation, it issued its final report, *Mental Incapacity*, and draft bill in March 1995.⁷ The report contains the following recommendation:

1.2 The Commission recommends that there should be a single comprehensive piece of legislation to make new provision for people who lack mental capacity. This should provide a coherent statutory scheme to which recourse can be had when any decision (whether personal, medical or financial) needs to be made for a person aged 16 or over who lacks capacity.

A summary of the Law Commission’s recommendations is available online.⁸

⁵ Each of these methods is explained in more detail, in context, in later sections of this paper.

⁶ Department for Constitutional Affairs press release 304/04, *Minister heralds shift in attitude towards millions who lack mental capacity*, 18 June 2004

⁷ Law Commission Report No 231, <http://www.lawcom.gov.uk/549.htm>

⁸ <http://www.lawcom.gov.uk/549.htm>

2. The Green Paper, *Who Decides?*

The Law Commission report and the Report of the House of Lords Medical Ethics Committee in 1994⁹ formed the basis of a Green Paper, *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults*,¹⁰ published in 1997.

The Government acknowledged the clear need for reform of the law relating to the decision-making process for those who are unable to make decisions for themselves. It accepted many of the Law Commission's recommendations and sought views on how they might be implemented. Over 4000 responses were received from a wide range of respondents.

3. *Making Decisions*

In October 1999, the Government published a white paper, *Making Decisions*,¹¹ which set out, in the light of the responses to the consultation paper, the Government's proposals:

to reform the law in order to improve and clarify the decision-making process for those who are unable to make decisions for themselves, or who cannot communicate their decisions.¹²

Making Decisions formed the basis of the draft *Mental Incapacity Bill*.

4. *Making Decisions: Helping people who have difficulty deciding for themselves*

In April 2002, the Lord Chancellor's Department published a further consultation paper, *Making Decisions: Helping people who have difficulty deciding for themselves*,¹³ in which it sought views on a series of guidance leaflets. The guidance leaflets were produced in May 2003 and provide guidance respectively for legal practitioners, social care professionals, healthcare professionals, family and friends, people who wish to prepare for possible future incapacity and people with learning difficulties, and are available online.¹⁴

The information in these booklets relates to the current law in England and Wales only.

A summary of the responses to the consultation is available online.¹⁵

⁹ House of Lords Select Committee on Medical Ethics Report, 1994, HL 21 1993-94

¹⁰ Cm 3803, *Who decides? Making Decisions on Behalf of Mentally Incapacitated Adults*, <http://www.lcd.gov.uk/menincap/>

¹¹ Cm 4465, *Making Decisions*, <http://www.lcd.gov.uk/family/mdecisions/indexfr.htm>

¹² *Ibid* p1

¹³ <http://www.lcd.gov.uk/consult/family/decision.htm>

¹⁴ <http://www.lcd.gov.uk/family/mi/index.htm>

¹⁵ <http://www.lcd.gov.uk/consult/family/decisionresp.htm>

5. The Mental Incapacity Consultative Forum

The Mental Incapacity Consultative Forum was set up in 2002. The Department for Constitutional Affairs website includes the following information:

Rosie Winterton MP, the Minister responsible for this area of policy work at that time, set up a Consultative Forum comprised of members from various voluntary organisations as well as professionals in the fields of health, law and social care. She was clear that working with people who have daily practical experience of working with and caring for people with impaired mental incapacity would enable us to make changes that met their specific needs. The first forum meeting was held in June 2002. During these meetings members have the opportunity to speak personally to the Minister of the problems and difficulties that they have encountered.¹⁶

6. The draft Bill and consideration by the Joint Committee

The Government published the draft *Mental Incapacity Bill* on 27 June 2003.¹⁷ Announcing publication, Lord Filkin, then Parliamentary Under-Secretary at the Department for Constitutional Affairs, said:

This draft legislation is an important step in taking forward discussion about how society can best meet the needs and protect the rights of the growing number of people who have limited mental capacity. Our aim is to better protect all adults who have suffered impaired capacity from a young age, those who lose capacity perhaps through an injury or illness, those who have periods of incapacity and those who suffer from dementia in later life. We also want carers and professionals to be clearer about their legal position. I am pleased that this Bill is being published as a draft and then looked at by a committee of both Houses of Parliament: this Bill covers important and sensitive issues and these need to be properly discussed. This is a good way to do that. I also want to be confident that our proposals would work well in practice, because that's what really matters.¹⁸

The draft Bill was scrutinised by the Joint Committee on the Draft Mental Incapacity Bill, which reported to both houses on 17 November 2003.¹⁹ It generally endorsed the principles and general direction of the draft Bill, but expressed the view that a great deal of work remained to be done to 'get the Bill right' and made nearly 100 recommendations. One of these recommendations was that the Bill's title should be changed to the *Mental Capacity Bill* for the following reason:

¹⁶ <http://www.dca.gov.uk/menincap/intro.htm>

¹⁷ Cm 5859 – I & II, <http://www.dca.gov.uk/menincap/meninc.pdf>

¹⁸ Department for Constitutional Affairs press release 304/04, *Minister heralds shift in attitude towards millions who lack mental capacity*, 18 June 2004

¹⁹ Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>

We think this reflects more accurately what the Bill is about and removes some of the more pejorative undertones regrettably associated with incapacity. We hope that change will symbolise the changes in public attitudes and understanding which are long overdue and which this Bill should help to bring about.²⁰

The Joint Committee expressed regret that the draft Bill had been presented for scrutiny without the accompanying assessments of the resource implications and also expressed surprise and disappointment that the Treasury had waived the requirement for a full resource impact assessment of costs and benefits to accompany the draft Bill.²¹

The Government's response to the Joint Committee's Report was published on 24 February 2004.²² The Government welcomed the Report, and agreed with the suggested change of name.

Particular recommendations made by the Joint Committee, and the Government's response, are discussed, in context, in the following sections of this paper.

II The Bill

The *Mental Capacity Bill* was published on 18 June 2004 and the Government stated that it had accepted 88 of the 99 recommendations made by the Joint Committee and used them to improve the Bill. David Lammy, Parliamentary Under-Secretary of State for Constitutional Affairs said:

The Bill is based on clearly defined principles. Its starting point is that everyone has the right to make their own decisions, and must be assumed to have capacity to do so unless it is proved otherwise. No one should be labelled as incapable—each decision should be considered individually and everyone should be helped to make or contribute to making decisions about their lives. The Bill sets out clear guidelines for, and limits on, other people's role in decision making.

(...)

The Bill offers better protection both for people who lack capacity and for carers and professionals. For the first time it offers statutory guidance to help assess what constitutes someone's best interests. All decisions must be made in the best interests of the incapacitated person, with adequate weight given to what they themselves would have wanted—their wishes, feelings, values and beliefs—while ensuring that the decision is the least restrictive of their basic rights and freedoms.²³

²⁰ *Ibid* p7

²¹ *Ibid* para 340

²² Cm 6121, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm#part2>

²³ HC Deb 18 June 2004 c67-70WS

This part of the paper sets out the main areas covered by the Bill and includes reference to the Report of the Joint Committee on the Draft Mental Incapacity Bill and to the Government's response to that Report.

Further information and details about the clauses in the Bill are given in the Government's Explanatory Notes published with the Bill.²⁴ The Explanatory Notes also include a summary of the Regulatory Impact Assessment which is available online²⁵ and in the House of Commons Library.

A. General principles

The main aim of the Bill is to promote the interests of people who lack capacity by establishing a statutory framework for the decision-making process. **Clause 1** sets out the principles on which the Bill is based. This follows a recommendation by the Joint Committee on the draft Mental Incapacity Bill that a statement of principles should be incorporated into the Bill. This emphasises the underlying ethos of the Bill, which is not only to protect a person who lacks capacity, but also to enable them to participate in decision-making.

Clause 1 provides as follows:

- (1) The following principles apply for the purposes of this Act
- (2) A person must be assumed to have capacity unless it is established that he lacks capacity.
- (3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- (4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- (5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- (6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

In a recent statement to the House, David Lammy, said:

The overriding aim of the Bill is to improve the lives of vulnerable adults, their carers, families and professionals. It provides a statutory framework for decision

²⁴ Bill 120-EN, <http://www.publications.parliament.uk/pa/cm200304/cmbills/120/en/04120x--.htm>

²⁵ <http://www.dca.gov.uk/risk/mcbria.pdf>

making for people who lack capacity, making clear who can take decisions, in which situations and how they should go about this.²⁶

B. Decision-making

The Bill's provisions on decision making are broadly based on the Law Commission's 1995 Report, *Mental Incapacity*.²⁷

1. Capacity

a. Background

The Law Commission Report recommended that there should be a statutory definition of capacity, and suggested:

A person should be regarded as unable to make a decision if at the material time he or she is:

- unable by reason of mental disability to make a decision on the matter in question
- unable to communicate a decision on that matter because he or she is unconscious.²⁸

The Report defined mental disability as a disorder of the brain or mind, which may be permanent or temporary, and results in a disturbance of mental function. An example of a temporary disorder might be someone who has suffered a head injury but is expected to recover. Those with permanent mental disability include individuals suffering from a wide range of conditions including learning disabilities of varying severity, dementia and those who are unconscious following head injury or strokes.

b. The Bill

Clause 2 of the Bill is broadly based on the Law Commission proposals. In addition, the clause states that the Bill's provision on the treatment of people lacking capacity will not extend to anyone under 16 years of age.

The level of capacity needed to make a decision would be dependent on the nature of the decision being taken. A person may have the capacity to decide on straightforward everyday matters but lack capacity to make complex decisions, for example on medical treatment or financial issues. If there is any doubt over whether someone lacks capacity, this should be decided on a balance of probability.

²⁶ HC Deb 18 June 2004 c68WS

²⁷ The report will be referred to as the Law Commission Report throughout this Research Paper.

²⁸ Law Commission Report 231, March 1995

2. Inability to make decisions

a. Background

The courts have adopted a functional approach to the assessment of legal capacity, which is specific to each decision. This involves assessing the ability of a person to understand the proposed course of action. The principles were established in common law and are taken from the ruling in the case *Re C*.²⁹

The case *Re C* required the court to determine whether a paranoid schizophrenic patient, who was detained in Broadmoor, was competent to refuse consent for the amputation of his gangrenous leg. The Court was asked to determine whether or not he had the capacity to refuse the proposed operation. The judge held that C was competent to refuse to consent to treatment, and set out a three-stage test to assess a patient's capacity to make a decision. The courts will assess a person's ability to:

- Comprehend and retain the information
- Believe the information
- Weigh up the information, balancing risks and needs, to make a decision

The Law Commission Report recommended adopting a test for decision-making capacity broadly based on the *Re C* judgment. The Report recommended that an inability to make a decision should mean an inability to understand or retain relevant information, including the consequences of deciding one way or the other. In addition, they noted that those considered unable to make a decision would include patients who were unable to communicate that decision.

The draft Bill set out a functional test of capacity which incorporated both the common law approach and the Law Commission recommendations. This was endorsed by the Joint Committee Report.

b. The Bill

Clause 3 of the Bill details how a person's ability to make a decision would be assessed and is broadly the same as the provisions in the draft *Mental Incapacity Bill*.

The person making a decision should be able to:

- Understand and retain the relevant information.
- Use or weigh the information to reach a decision.
- Communicate the decision

²⁹ *Re C* [1994] 1 All ER 819

The clause provides further details on issues that might need to be considered in relation to the making of a particular decision. It states that the person need only retain the information for a short period, provided this is a sufficient time in which to make the decision. It also emphasizes that the information must include details of the reasonably foreseen consequences of that decision. This could be important in some decisions, such as those relating to medical treatment.

However, decisions which are complex or that could have serious consequences may require a formal assessment of capacity from a consultant psychiatrist or psychologist. The draft Code of Practice provides further details of situations where it is envisaged that a professional opinion should be sought as a matter of good practice.³⁰

3. Best interests

a. Background

The concept of acting in a person's best interests is one of the underlying principles of the Bill. Lord Filkin said:

The Mental Capacity Bill heralds a cultural shift in the way we treat people who lack capacity. Vulnerable people will no longer be labelled 'mentally incapable' and their views forgotten about. Instead they will be placed at the heart of decision making, empowered to make as many decisions for themselves as possible. And where they can't, their best interests will be paramount. Carers and professionals will be clearer about their legal position.³¹

The principle of best interests is based on a common law ruling in the case *Re F*.³² The House of Lords decided that doctors could sterilise a mentally incompetent woman as it was in her best interests. Best interests were defined by Lord Brandon:

The operation or other treatment will be in the patient's best interests, if but only if, it is carried out in order either to save their lives, or to ensure improvement or prevent deterioration in their physical or mental health.³³

Following *Re F* the courts have given a wider interpretation to the concept of best interests and this may now be taken to include both direct and indirect benefit to the patient.³⁴

³⁰ *Mental Incapacity Bill: Draft Code of Practice*, <http://www.dca.gov.uk/menincap/mcbdraftcode.pdf>. See section III of this Research Paper

³¹ Department for Constitutional Affairs press release 304/04, *Minister heralds shift in attitude towards millions who lack mental capacity*, 18 June 2004

³² *Re F* [1990] 2 AC 1 (HL)

³³ *Re F* [1990] 2 AC 1 (HL) at 55

³⁴ *Re Y* [1996] 2 FLR 787

The Law Commission Report recommended that a “best interests” criterion should be used as a basis for making a decision for a patient who lacks capacity. The best interests of a person would be established using a checklist of factors. It would stress the importance of:

- The ascertainable past and present wishes and feeling of the person concerned.
- The need to consult with any close family or friends of the person concerned, who may be able to provide more information on best interests.

The draft *Mental Incapacity Bill* set out a statutory requirement that all decisions made for someone who lacks capacity should be made in their best interests, and also listed factors that must be taken into account. These were based on the Law Commission proposals.

The Joint Committee recommended that it should be made clear that a list of best interest factors could not cover all situations, and proposed that any other relevant factors should be taken into account. They also sought reassurance that the person’s own values should be a central consideration.

b. The Bill

Clause 4 of the *Mental Capacity Bill* sets out the steps that would be taken to assess the best interests of a person found to lack capacity. These are essentially the same as the factors listed in the draft Bill. The major points are:

- The need to consider whether the lack of capacity is temporary or permanent.
- The importance of involving the person in the decision-making process.
- The need to ascertain past wishes and preferences. This concept is especially important for people with dementia to allow decisions to be made consistent with their previous wishes.
- The acknowledgment that family members or close friends will often have important information or views as to what would be in the persons best interests.

However, in response to the Joint Committee Report there are some additional provisions included in the Bill:

- **Clause 4(5)(b)** would require that the values of the person lacking capacity must be considered. A person may often be able to express a preference, even when not able to make the decision. This would also allow a seemingly irrational decision to be made by a person if this could be justified, by their religious values for example.

- Best interests could include any circumstances that appear to be relevant, not just those specified.
- This clause also states that the person determining best interests need only consider factors as ‘far as is reasonably ascertainable’. This would provide protection to those who genuinely believe they are acting in someone’s best interests, and can provide reasons to support the decision made. In cases where there was uncertainty or disagreement about a person’s best interests, the court who have the ultimate responsibility for the decision.

Any decision made under a lasting power of attorney should also be made on the principle of best interests.

4. Acts in connection with treatment and limitations

Clause 5 is a new clause in the Bill which would provide a statutory defence for an action that is done in connection with an incapacitated person, who is unable to consent. The action must be a reasonable thing to do in the situation and must be in the person’s best interests. Without this provision any action that involved touching the incapacitated person, including everyday activities such as helping someone dress, could be unlawful.³⁵

a. Background

The common law principle of necessity is used as a defence to an action that might otherwise be unlawful. The test is whether there was reasonable necessity for performing the act in the circumstances existing at the time.³⁶

The principle of necessity has been extended to permit actions performed in connection with the care or treatment for a person who lacks capacity, most usually relating to medical treatment. The House of Lords first used the principle of necessity to justify medical treatment in the case *Re F*. Lord Goff stated:

There is however a third group of cases which is also properly described as founded upon the principle of necessity and which is more pertinent to the resolution of the problem in the present case. These cases are concerned with action taken as a matter of necessity to assist another person without his consent.³⁷

³⁵ The tort of battery is the touching of someone without their consent, even if the person involved is not harmed.

³⁶ Osborn’s Concise Law Dictionary

³⁷ *Re F* [HL] [1989] 2 FLR 376 at p437

He explained the basic requirements in order for cases of necessity to fall within the principle:

not only must there be a necessity to act when it is not practicable to communicate with the assisted person but also the action taken must be such as a reasonable person would in all the circumstances take, acting in the best interests of the patient.³⁸

b. The draft Bill and Joint Committee Report

The draft Bill adopted recommendations from the Law Commission Report, which proposed that the common law principle of necessity should be given a statutory basis, known as a general authority to act.

Certain requirements were set out including:

- The action must be in the best interests of the person who lacks capacity
- The person acting under the general authority must reasonably believe the patient lacks capacity and it is reasonable to perform the act in question.
- The use of force or restriction of liberty would be permissible only if the person believes it is necessary to avoid significant harm to the patient.
- Life-sustaining treatment could be given in cases where there is a dispute, whilst awaiting a court decision.

The Joint Committee Report expressed concern over the clauses in the draft Bill relating to the general authority. It was concerned that the term “general authority” could be misinterpreted as conferring general powers to intervene and act, when it was actually intended only to provide a defence to an action done in someone’s best interests but without consent. The Committee recommended that:

Clauses 6 and 7 be redrafted to clarify the legislative intent of the general authority, in order to counter what appear to be widespread misunderstandings of the concept and its purpose. It might also be helpful for the Department to consider an alternative to the term ‘general authority’ which would avoid its misleading connotations and clarify that it is intended to convey permission to act in the incapacitated person’s best interests in circumstances currently covered by the Common Law.³⁹

³⁸ *Re F* [HL] [1989] 2 FLR 376 at p437

³⁹ Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, para 111, <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>

c. *The Bill*

The Bill addresses the points raised by the Joint Committee and includes several major changes:

- The term “general authority” is no longer used.
- **Clause 5** would offer statutory protection to acts performed under the principle of necessity. Such acts or treatments are referred to as a “section 5 act”
- Section 5 acts would still allow liability for negligence.
- A valid advance directive would take precedence over the rules in this clause.

Clause 6 sets out limitations on section 5 acts. These include the following:

- Restraint would only be allowed when reasonably thought to be necessary to prevent harm to the person lacking capacity, and would have to be proportionate to the seriousness of the harm.
- A valid decision of an attorney or deputy would take precedence over any action that could be taken under clause 5.

Clause 8 would provide that a person acting under clause 5 would be entitled to use or pledge the money of the person lacking capacity or to be reimbursed from it for expenditure related to that person’s care or treatment. However, this would not entitle a carer to gain access to funds held by a third party (eg a bank) for which formal steps would need to be taken (eg registering an LPA or obtaining a court order).

C. Lasting powers of attorney

1. Current position and background

A power of attorney is a deed by which a person (the donor) confers power on another (the attorney, sometimes called the donee) to act on behalf of the donor. An ordinary power of attorney automatically comes to an end as soon as the donor becomes mentally incapable. Until the *Enduring Powers of Attorney Act 1985* there was no mechanism for a person to select an attorney who would have power to manage his property and financial affairs even if the donor should become mentally incapable.

An Enduring Power of Attorney (EPA) enables a donor to appoint an attorney either to act with immediate effect in relation to the donor’s property and financial affairs and to continue to act after the donor has become mentally incapable; or to act as attorney only after the donor has lost mental capacity. EPAs cannot authorise an attorney to make decisions on health and welfare matters.

The attorney has a duty to register the EPA with the Public Guardianship Office as soon as the donor has become, or is becoming, mentally incapable of managing his own affairs. The duty arises when the attorney has reason to believe that the donor is becoming mentally incapable and therefore this is a decision for the attorney to make. It is not necessary for the attorney to provide medical evidence (unless the EPA requires it). Notice of the application to register the EPA must be given to the donor and to specified relatives who can object to the registration on various grounds. If the donor becomes mentally incapable, the power will become irrevocable without confirmation by the Court.

However, the *Enduring Powers of Attorney Act 1985* does not provide for any penalties for non-registration and concerns have been raised about the scope for abuse.⁴⁰ EPAs which should have been registered with the Court of Protection because the donor has become mentally incapable may not be registered. Furthermore, the very existence of the EPA may not be known and so it may not be available when it is needed. The Court of Protection and the Public Guardianship Office only have powers to investigate the possible misuse of an EPA if it is registered or if it is clear that it should be registered.

According to the Government White Paper, *Making Decisions*,⁴¹ the following concerns were raised in the consultation process:

The Drafting or Creation of the power:

- powers were used prior to the donor becoming incapacitated
- family members did not know about the existence of the EPA – some felt that it would be a safeguard if other people had to be alerted that the power had been created
- donors of EPAs were already without capacity by the time they signed their EPA.

The registration process:

- notification of others in the statutory list is inadequate, since the donor and relative may not see, or care anything for, one another
- there is no adequate system to compel the attorney to register the EPA when the donor becomes incapable.

⁴⁰ See, for example, Tom Dumont, “The Misuse of Enduring Powers of Attorney”, *TACT the Association of Corporate Trustees*, Issue 15, April 2001

⁴¹ Cm 4465, *Making Decisions*, <http://www.lcd.gov.uk/family/mdecisions/indexfr.htm>

The powers of the attorney:

- the court will not usually know about unregistered powers which are being exercised, where instances of financial abuse might occur.

The lack of a regional office:

- there is a lack of access for members of the public to speak to someone about EPAs.⁴²

Tom Dumont, a barrister, has commented on some of the problems:

15% of EPAs may be abused. About 10,000 EPAs are registered every year. A similar amount are probably being operated without registration. A calculated guess suggests that there may be anywhere between 100,000 – 250,000 EPAs being used at any given time. There could therefore be between 10,000 and 37,500 EPAs being abused over any given period. All of those EPAs will be used to operate a bank or building society account. All a bank has to do is divide that figure by its market share to realise that there is a significant risk that an account provided by it to an elderly customer is being abused.⁴³

Following concerns raised about possible financial abuse of EPAs, a working group was set up by the then Lord Chancellor's Department in October 2002 to review existing procedures, forms and guidance.

2. The draft *Mental Incapacity Bill*

The draft Bill proposed a new form of Power of Attorney, to be called a Lasting Power of Attorney (LPA), to replace the EPA. Like an EPA, an LPA would operate when the donor had lost mental capacity but there would be significant differences in the way in which an LPA would operate. In particular, individuals would be able to delegate decision-making on health care and personal welfare in addition to financial matters to a chosen attorney, and registration of the LPA would be compulsory before it could be used.

3. The Report of the Joint Committee

The Joint Committee commented on evidence which revealed dissatisfaction with the present system of EPAs:

We were very concerned by evidence presented to the Committee indicating that financial abuse occurs in approximately 10-15% of cases involving EPAs.

⁴² *Ibid* p14

⁴³ Tom Dumont, "The Misuse of Enduring Powers of Attorney", *TACT the Association of Corporate Trustees*, Issue 15, April 2001

Further evidence estimated that abuse was as high as 20%. A precise figure for the amount of financial abuse is, however, difficult to calculate as it is unclear exactly how many EPAs are in existence since they must only be registered at the point at which the donor is, or is becoming, mentally incapable of managing his own affairs. Some concern was expressed that unregistered EPAs were being used to take advantage of donors who were beginning to lose capacity or were continuing to be used even after the donor had lost capacity. Denzil Lush, the Master of the Court of Protection stated in his submission:

“I don’t believe that, when it published its report on Mental Incapacity in 1995, the Law Commission was fully aware of the extent of financial exploitation, particularly affecting the elderly mentally infirm. Certainly, the more important surveys on abuse have post-dated that report. But, even if it was aware, it failed to address the problem by providing adequate, private law safeguards.”⁴⁴

The Joint Committee reported that LPAs were generally seen as an improvement over EPAs but that evidence had revealed a recurring theme that clarification of the extent of the powers and further safeguards were required.⁴⁵

The Joint Committee made various recommendations concerning LPAs including the following:

- Codes of Practice should make clear that those acting under an LPA must appreciate the concept of capacity/incapacity and be fully aware of the responsibilities placed on them when carrying out or assisting decision-making on behalf of any person who is considered incapable.⁴⁶
- The Bill should clarify whether an attorney would be able to make any personal welfare decisions when a donor retains capacity.⁴⁷
- A warning about the potential for conflict be given to donors.⁴⁸
- Attorneys should be under an express duty of care.⁴⁹
- Guidance should be provided to assist financial institutions to deal with the operational realities of LPAs.⁵⁰

⁴⁴ Para 138 (with footnotes omitted), Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>

⁴⁵ *Ibid* para 141

⁴⁶ *Ibid* para 77

⁴⁷ *Ibid* para 144

⁴⁸ *Ibid* para 150

⁴⁹ *Ibid* para 154

⁵⁰ *Ibid*

- There should be two witnesses to certify the capacity of the donor where there are no persons named to receive notification of the registration of an LPA. This would act as a further precaution against the potential for duress.⁵¹
- The Committee approved of the proposed system requiring registration of LPAs before use on the basis that this would assist in the monitoring of LPAs and detecting possible abuse. However it recommended that attorneys should be placed under an obligation to notify both the donor and the Public Guardian that the donor is, or is becoming incapacitated, thereby putting this information on the public record and opening it up to challenge.⁵²

4. Government response

Some of the Government's responses to recommendations made by the Joint Committee are reflected in those parts of the Bill which are discussed in the next section of this paper. The Government also agreed to include further matters in Codes of Practice. The draft Code of Practice was published on 9 September 2004 and is discussed in Section III of this Research Paper.⁵³ Specific Government responses include the following:

- The Government agreed that donors should be given more information about the potential for conflict of interest. In the draft Code of Practice, it is stated that the Office of the Public Guardian will produce detailed guidance, in due course, on explaining the procedures involved in making an LPA and important issues to consider when making an LPA.⁵⁴
- The Government acknowledged the need for the Codes of Practice to give guidance:
 - to all who have to consider and assess capacity: this would not only provide information on what must be done, but also provide guidance, and signposts to further more detailed guidance where necessary, on what constitutes good practice when acting for or making decisions on behalf of others.
 - on the standards of conduct expected from formal decision-makers under the Bill.

The draft Code of Practice proposes guidance on decisions relating to capacity⁵⁵ and also guidance for attorneys, including on their duties and responsibilities and their expected standard of conduct.⁵⁶

⁵¹ *Ibid* para 159

⁵² *Ibid* para 157

⁵³ *Mental Incapacity Bill: Draft Code of Practice*, <http://www.dca.gov.uk/menincap/mcbdraftcode.pdf>

⁵⁴ *Ibid*, Chapter 6, p54

⁵⁵ *Ibid*, Chapter 3

⁵⁶ *Ibid*, Chapter 6

- The Government did not consider that it was necessary to impose an express duty of care on attorneys because, under established law, an attorney is an agent for the donor and this triggers a range of common law duties under the law of agency, including a duty to act with due care and skill. In addition, the attorney would have a duty to act in the donor's best interests. Furthermore, an agent may also be liable for acting negligently and the Government stated that the Bill would not affect anyone's obligations in the law of negligence. The draft Code of Practice includes an explanation of the range of common law duties which apply to agents, and the new statutory duty to act in the donor's best interests.⁵⁷
- The Government considered that there could be difficulties if attorneys were obliged to give notice at a notional point of incapacity because this would conflict with the functional approach to capacity. That is, it could mean a reliance on a blanket label of incapacity as a means of avoiding the complexities of assessing capacity in relation to the particular decision at the particular time.
- The Government agreed that there should be additional safeguards for the registration of an LPA where there are no named persons for notification of registration.⁵⁸

5. The Bill

A new form of power of attorney, the Lasting Power of Attorney (LPA), would replace the Enduring Power of Attorney. Like an EPA, an LPA would operate (or continue to operate) when the donor had lost mental capacity. Significant features of an LPA include the following:

- Individuals would be able to delegate decision-making on health care and personal welfare in addition to financial matters to a chosen attorney (**Clause 9**).
- There would be a compulsory registration system. All LPAs would have to be registered with the Public Guardian before the attorney could use them, even if the donor retains capacity. (**Clause 9(2)**)
- An attorney would be obliged to act in the donor's best interests. (**Clause 9(4)**)
- Where the LPA authorises the attorney to make decisions about a donor's personal welfare:
 - The attorney would only have power to make decisions if the donor lacks, (or the attorney reasonably believes that he lacks) capacity

⁵⁷ *Ibid* Chapters 4 and 6

⁵⁸ Cm 6121, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm#part2>

- The authority would be subject to any advance decision to refuse treatment, unless the LPA is granted later and gives power to the attorney to give or refuse consent to the treatment to which the advance decision relates
- The attorney would be able to give or refuse consent to health care treatment being given or continued (**Clause 11(6)**).

The original provision in the draft Bill has been amended to take into account a recommendation for clarity made by the Joint Committee.

- Powers relating to the donor's property and financial affairs could be exercised at once if the donor wishes (**Clause 11**).
- An attorney would only have power to give or refuse consent to the carrying out or continuation of life sustaining treatment if this is expressly stated in the LPA. The donor could also impose other conditions and restrictions in the LPA (**Clause 11(7)**).
- An attorney with authority to make decisions about the donor's property and affairs would have a limited power to make gifts of the donor's property (**Clause 12**).
- A donor would only be able to create an LPA if at the time:
 - He has reached the age of 18 and
 - He has capacity to execute the document (**Clause 9(2)**)

Clause 10 sets out who could be appointed as attorney(s). Two or more attorneys could be appointed and they could be appointed to act jointly or to act jointly and severally. Although an LPA would not be able to authorise the attorney to appoint a successor or substitute, it could itself appoint a replacement attorney if the original attorney became unable to act for a reason specified in **Clause 13(6)**.

An LPA would not authorise an attorney to perform an act that is intended to restrain the donor unless specified conditions set out in **Clause 11** are met.

Clause 13 sets out the situations in which an LPA would be revoked. This includes the lack of capacity of the attorney. However, it is not entirely clear whether a temporary lack of capacity on the part of the attorney would be sufficient to revoke the LPA.

Clause 14 provides protection, in specified circumstances, to the attorney and others if no power has in fact been created or the power has been revoked.

Schedule 1 sets out detailed provisions about making instruments, registration, cancellation of registration, and records of alterations in registered powers.

As with an EPA, the LPA would have to be in a prescribed form, but an LPA would also have to be registered in order to confer authority to act.

The LPA would have to include the following statements:

- by the donor that he intends the power to confer authority to make decisions on his behalf when he no longer has capacity
- by the donor naming individuals he would want to be notified of any application to register the power or that there are no such individuals. (This takes the place of the requirement to notify a fixed list of relatives of an application to register an EPA)
- by the donor and the attorney(s) that they have read (or have had read to them) any prescribed information;
- by the attorney that he understands the principle of best interests.

There would also have to be a certificate signed by a person of a prescribed description that in his opinion, when the donor executes the document:

- the donor understands the purpose of the instrument and the scope of the authority conferred under it
- that no fraud or undue pressure is being used to induce the donor to create and LPA and
- there is nothing else which would prevent an LPA from being created by the instrument (**Schedule 1 paragraph 2(1)(e)**).

This provision has been extended from that contained in the draft Bill (previously the certificate was only to have been as to the capacity of the donor). Regulations may set out a prescribed form for the certificate and that it must include prescribed information.

This requirement seems designed to ensure that (among other things) a person making an LPA has the requisite mental capacity at the time. This would address an area of concern raised in the consultation process.

In *Who Decides?* the issue of how documents should be executed was specifically considered:

6.39. The Law Commission's provisional proposal that a donor's capacity to execute should be subject to a certificate from a doctor and solicitor was regarded as overly intrusive by respondents to their consultation.

6.40. Although the Law Commission revised its view, and rejected a requirement for certification, the Government considers that a system for certification by a solicitor and a medical practitioner might help prevent unnecessary abuse of these powers.⁵⁹

⁵⁹ Cm 3803, *Who decides? Making Decisions on Behalf of Mentally Incapacitated Adults*, <http://www.lcd.gov.uk/menincap/>

It is not entirely clear how the person signing the certificate would ascertain the matters he is required to certify, what investigations would be necessary and whether there would be any penalty for incorrect certification. It is also not clear at present who the “prescribed description” will cover. This may include a person (not a close relative or someone who might benefit financially) who has known the donor well for a certain time. It is understood that further consultation will be conducted with interested groups before policy is finalised in this area.⁶⁰ Decisions in this area may have practical implications for the way in which the scheme will work in practice.

Regulations may also provide that, where the LPA includes a statement that there are no persons whom the donor wishes to be notified of any application to register the LPA, a certificate must be given by two persons of a prescribed description. This is a new provision which was not in the draft Bill and is a response to a recommendation made by the Joint Committee.⁶¹

The Public Guardian would not be able to register the LPA without the direction of the court if there is a deputy appointed by the court for the donor and the powers conferred on the deputy would conflict with the attorney’s powers if the LPA were registered.

The *Enduring Powers Of Attorney Act 1985* would be repealed and so no new EPA could be created (**Clause 62**). Existing EPAs would continue to have legal effect and be governed by the legal rules and procedures in force when they were made (**Clause 62 (3)** and **Schedule 4**).

D. The Court of Protection and the appointment of deputies

1. The current position and background

At present there is no single court with jurisdiction over decision-making for those lacking capacity.

a. The jurisdiction of the Court of Protection and receivership

If a person who lacks capacity does not have an EPA, and has property or other assets which need to be dealt with, it is necessary to make an application to the Court of Protection. The Court has jurisdiction under Part VII of the *Mental Health Act 1983* to manage the property and affairs of patients,⁶² and the Public Guardianship Office (PGO) administers the Court’s judicial decisions. The Court needs to be provided with medical evidence that the person is incapable, by reason of mental disorder, of managing and administering his property and affairs, and also requires details of the person’s assets.

⁶⁰ Information from official at Department of Constitutional Affairs in telephone conversation 8 July 2004

⁶¹ **Schedule 1 paragraph 2(2)(b)**

⁶² Anyone found on medical criteria to be incapable by reason of mental disorder of managing and administering his property and affairs

The Court of Protection may make a short order⁶³ where the assets are of limited value⁶⁴ and there is no property to be sold. Otherwise, the Court may appoint a receiver to manage the client's property and affairs. The receiver is often a family member or friend or may be a professional adviser. If no-one is able and willing to act as receiver, the Court can appoint a receiver from an approved panel.

The receiver cannot be authorised to make decisions on health matters.

Further details about receivership are available on the website of the Public Guardianship Office.⁶⁵

A scheme to pilot regional Court of Protection hearings commenced in Preston on 1 October 2001 and ran for a six month period until March 2002. It was hoped that holding hearings locally would benefit parties by reducing the time, cost and anxiety involved in attending court. According to the Department for Constitutional Affairs, the scheme proved successful, hearings continue to take place at Preston, and the Department is now looking at setting up a second regional hearing centre.⁶⁶ Other Court of Protection hearings are held in London.

b. Appointment of an "appointee"

If a person who becomes mentally incapable receives only social security benefits and pensions, the Department for Work and Pensions can designate an appointee to take over the person's claim for benefits, receive the payments and spend the money on the person's needs.⁶⁷

c. The inherent jurisdiction of the High Court

The Court of Protection has no power to agree to medical treatment on behalf of a patient. However, the High Court has jurisdiction to make a declaration as to the legality of a particular operation.

d. The Official Solicitor

The Official Solicitor represents persons under legal disability (including people who, because of mental disorder, cannot manage their own affairs), in civil court proceedings, when no other suitable person or agency is able and willing to act. The purpose of his

⁶³ This confers a limited authority as specified in the order

⁶⁴ Currently the limit is £16,000

⁶⁵ <http://www.guardianship.gov.uk/theservice/externalreceivers.htm>

⁶⁶ <http://www.lcd.gov.uk/menincap/intro.htm>

⁶⁷ For more details, see Benefits Agency leaflet GL21, *A helping hand for benefits?*, April 2004, http://www.dwp.gov.uk/publications/dwp/2004/gl21_apr.pdf

representation is to prevent a possible denial of justice, and/or to safeguard the welfare, property or status of the person under disability.⁶⁸

The Official Solicitor represents mentally disordered adults in various types of proceedings including those concerning where a person under disability is to live and with whom he or she is to have contact, and medical treatment applications concerning, for example, sterilisation, abortion, emergency caesareans and end-of-life decisions such as the withdrawal of nutrition and hydration from a patient in Persistent Vegetative State.⁶⁹

2. The draft Bill

The draft Bill proposed that a new court of record, still to be called the Court of Protection, but with an extended jurisdiction, would replace the existing Court of Protection. This new Court of Protection would have power to make single orders (orders relating to a single issue) in relation to a person lacking capacity, where there is no need for on-going decision making powers. The Court would also have power to appoint deputies, with continuing powers, to act on behalf of incapacitated persons. Deputies would take the place of receivers but would have an enhanced role because they would be able to take decisions on some health and welfare matters in addition to financial and property matters.

3. The Report of the Joint Committee

The Joint Committee's recommendations included the following:

- That further guidance should be provided to assist the Court of Protection in deciding when a single order is more appropriate than the appointment of a deputy,⁷⁰ and to assist in the appointment of the most appropriate individual to act as deputy.⁷¹
- That further guidance should be drawn up for deputies as to their expected standard of conduct.⁷²
- That sufficient legal aid should be made available to ensure that the Court of Protection is sufficiently accessible for those with limited assets.⁷³
- That deputies should not be able to consent to the withdrawal or refusal of life-sustaining treatment and that unless an individual has indicated his wishes through an

⁶⁸ <http://www.offsol.demon.co.uk/>

⁶⁹ Cm 3803, *Who decides? Making Decisions on Behalf of Mentally Incapacitated Adults*, p114, <http://www.lcd.gov.uk/menincap/>

⁷⁰ Para 164, Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>

⁷¹ *Ibid* para 181

⁷² *Ibid* para 180

⁷³ *Ibid* para 173

LPA or advance decision, decisions relating to the carrying out or continuation of life-sustaining treatment should be referred to the Court of Protection for determination.⁷⁴

- That the Bill should clarify which decisions should be made by a Court appointed deputy and not under the general authority, and that guidance should be given about when it would be appropriate to apply to the Court of Protection for the appointment of a deputy.⁷⁵ (The term “general authority” was used in the draft bill in relation to the proposed statutory defence for carers, now contained in Clause 5 of the Bill, but following concerns expressed by the Joint Committee, this term is no longer used.⁷⁶)
- That the Court should have power to remove an attorney appointed by an LPA who is acting incompetently or failing to comply with the Code of Practice as to the expected standard of conduct.⁷⁷

4. Government response

Some of the Government’s responses to recommendations made by the Joint Committee are reflected in those parts of the Bill which are discussed in the next section of this paper. Other matters are included in the draft Code of Practice, which is discussed in Section III of this Research Paper.⁷⁸ Specific Government responses include the following:

- The Government agreed that guidance should be given:
 - to assist the Court in deciding when a single order is more appropriate than the appointment of a deputy
 - as to the standard of conduct expected of deputies

The draft Code of Practice gives examples of the types of cases where an application for a single order might be appropriate (for example, where formal authority is needed to deal with significant one-off financial decisions for a person lacking capacity to manage financial affairs, but there is no need for on-going financial powers) and also explains the duties and responsibilities of deputies.⁷⁹

- The Government acknowledged the need for public funding for legal help and advice to be made available to enable those with limited assets to have access to the Court of Protection. It confirmed that Legal Representation would continue to be available, if

⁷⁴ *Ibid* paras 183-4

⁷⁵ *Ibid* para 187

⁷⁶ See section II B 4 of this Research Paper

⁷⁷ *Ibid* para 254

⁷⁸ *Mental Incapacity Bill: Draft Code of Practice*, <http://www.dca.gov.uk/menincap/mcbdraftcode.pdf>

⁷⁹ *Ibid* Chapter 7

necessary, for serious health or welfare issues. This is also set out in the draft Code of Practice.⁸⁰

- The Government did not agree that a Court appointed deputy should be denied authority, in all circumstances, to refuse consent to the provision or continuance of life-sustaining treatment on behalf of a person who lacks capacity. It pointed out that:
 - deputies would be given powers that are as limited in scope and duration as possible.
 - the power would only be given expressly and in exceptional circumstances
 - doctors would be able to challenge a deputy's decision to refuse life-sustaining treatment in Court, while providing life-sustaining treatment in the meantime.

- The Government pointed to a possible misunderstanding of the relationship between the general authority (this term is not now used in the Bill) and LPAs and deputies. The Government acknowledged this to be a complex area and stated that it would try to make the Bill itself as clear as possible and provide the necessary explanation in the Codes of Practice or elsewhere.⁸¹ The general authority and LPAs/deputies would deal with different situations and might co-exist:
 - Attorneys and deputies would be agents of the person who lacks capacity and would have authority to bind the person who lacks capacity through their decisions (for example, by signing documents).
 - The general authority was primarily a defence against liability for someone who might do something which could otherwise be considered unlawful whilst caring for the person lacking capacity (for example, helping the person to wash).⁸²

5. The Bill

a. *Court Appointed Deputies*

The Court of Protection would have power to make decisions itself or to appoint a deputy to make decisions on behalf of persons who lack capacity (**Clause 16**). However a decision of the Court would be regarded as preferable to the appointment of a deputy, and if a deputy is appointed, his powers should be as limited in scope and duration as possible (**Clause 16(4)**). **Clause 19(6)** provides that a deputy would be treated as an “agent” of the person who lacks capacity and this means that the deputy would be bound by the fiduciary duties imposed on agents and would have to act with due care and skill.

⁸⁰ *Ibid* Chapter 10

⁸¹ This is now covered in Chapter 5 of the draft Code of Practice

⁸² Cm 6121, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm#part2>

Deputies would take the place of receivers but would have an enhanced role because they would be able to take decisions on some health and welfare matters, in addition to financial and property matters (**Clauses 16 and 17 and Schedule 2**). In particular, the Bill provides a facility for the Court to appoint a deputy to give or refuse consent to the carrying out or continuation of a treatment by a person providing health care for the person (**Clause 17(1)(d)**). However, the deputy would not have power to direct that a different person should take over responsibility for healthcare (**Clause 20**). New provisions have been added to **Clause 20** to address concerns raised by the Joint Committee. A deputy would not be able to refuse consent to the carrying out or continuation of life sustaining treatment in relation to the person lacking capacity unless the court, which must be satisfied that there are exceptional circumstances, has expressly conferred authority to that effect. Certain specified matters must always be dealt with by the Court rather than by a deputy and other more general restrictions on deputies have also been added to the clause.

The Government's Explanatory Notes include the following comment on the appointment of deputies:

In welfare (including healthcare) matters a deputy is never required in order for care or treatment to be given to a person because clause 5 provides sufficient scope for carers and professionals to act. Nevertheless, a deputy may be helpful particularly in cases of dispute. For matters concerning property and affairs, a deputy may be needed in order to provide the authority to deal with contractual matters and where there is an on-going need for such decisions to be taken.⁸³

The Court would be obliged to follow the general principles of the Bill, particularly the best interests principle (**Clause 16(3)**). Deputies would have a similar duty (**Clause 20(7)**).

The Court would have power to revoke the appointment of a deputy or to vary the powers conferred on him if he is not acting in the best interests of the person without capacity or is, or is proposing to, act improperly (**Clause 16(8)**). This is a new provision which was not in the draft Bill. It ensures that the Court would have similar powers in relation to deputies as it would have in relation to attorneys (see **Clause 22(3)**).

A deputy would not have power to act on behalf of a person whom he knows or has reasonable grounds for believing, has recovered capacity in relation to the matter in question (**Clause 20(1)**).

⁸³ Bill 120-EN para 60 <http://www.publications.parliament.uk/pa/cm200304/cmbills/120/en/04120x-a.htm>

b. *Court of Protection*

The existing Court of Protection (which is actually an office of the Supreme Court) would be replaced by a new superior court of record, still to be called the Court of Protection. Whereas the existing court sits in London,⁸⁴ the new court would be able to sit anywhere in England and Wales (**Clause 43**). The new court would have an extended jurisdiction because it would be able to make decisions not only about financial matters, but also about personal welfare and health matters (currently dealt with under the inherent jurisdiction of the High Court). The court's jurisdiction would include power to:

- Make a declaration as to a person's capacity (**Clause 15**)
- Rule on the lawfulness of anything done or yet to be done in relation to a mentally incapable person (**Clause 15**)
- Make single orders in relation to an incapacitated person (instead of appointing a deputy) (**Clause 16**)
- Remove attorneys who have acted improperly (**Clause 21**)
- Direct that a Lasting Power of Attorney (LPA) should not be registered in certain circumstances (**Clause 22**)
- Resolve disputes about LPAs (**Clause 23**)
- Give directions about the operation of LPAs (**Clause 23**)

Clauses 44 to 54 include further detailed provisions about the Court of Protection, including for example, such matters as the judges of the Court, general powers, practice and procedure, and the power of the Court to call for reports.

Certain categories of people would be given the right to apply to Court without permission (**Clause 48**). Others would need to seek permission.

c. *The Public Guardian*

A new public official, the Public Guardian would be the registering authority for LPAs and Deputies. He or she would supervise deputies and would provide information to help the Court in its decisions. The Public Guardian would also have further powers including being able to direct a Court of Protection visitor⁸⁵ to visit donors and/or attorneys and deputies and the power to deal with complaints about the way in which an attorney or a deputy is exercising his powers. The Public Guardian would also be authorised to examine and take copies of any health record or local authority record compiled in connection with a social services function, and would have power to interview in private the person lacking capacity (**Clause 56**). These are similar rights to those enjoyed by the Public Guardian when reporting to the Court of Protection.

⁸⁴ A scheme to pilot regional hearings has been conducted recently.

⁸⁵ As defined in Clause 57

In the context of protecting vulnerable people from abuse, the Government has stated that the Public Guardian would have a role working with Councils and other agencies.⁸⁶

E. Advance decisions to refuse treatment

1. Background

Under common law a competent adult has the absolute right to refuse consent to any medical treatment or procedure, whether the reasons are rational or irrational and even if the result of the refusal is serious harm or death.⁸⁷ Advance statements, also referred to as advance directives or living wills, provide a mechanism by which a competent individual can express how they wish to be treated if they subsequently become incompetent. The scope of an advance statement can range from a general expression of a patient's values and beliefs to a clear statement refusing specified medical treatments. It may be in writing or expressed orally. In common law it has been held that although a patient may refuse treatment they do not have the right to demand a particular treatment, nor will a doctor be required to provide medical treatment that he does not believe to be in the patient's best interests.⁸⁸ However, in the recent ruling in *R v Burke*, Mummy J stated that a valid and relevant advance directive which requested the provision of artificial hydration and nutrition would be determinative, provided it accorded the patient some benefit.⁸⁹ Lord Donaldson commented in a letter to *The Times*:

And what has happened to the well-known distinction between “board” and “treatment”, artificial nourishment and hydration surely being in the latter category? Are we now to see the courts ordering treatment, whereas hitherto their intervention has been confined to authorising or forbidding treatment which doctors wished to provide?⁹⁰

An advance request for treatment would not be provided with statutory protection under the *Mental Capacity Bill*, so such demands could only be settled under case law.

English case law recognises that a clear and informed advance refusal of medical treatment is, in principle, as valid as a contemporaneous refusal of treatment. This was laid down by Lord Donaldson in *Re T*, a case that involved the refusal of a blood transfusion by a Jehovah's Witness. He stated the circumstances under which an advance refusal would be legally binding:

⁸⁶ The Government response to the Scrutiny Committee's Report on the draft *Mental Incapacity Bill*, Cm 6121, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm>

⁸⁷ *Re T* [1993] Fam. 95; *Airedale NHS Trust v Bland* [1993] 1 All ER 821; *Re B* [2002] 1 FLR 1090

⁸⁸ *Re J* [1993] Fam 15; *Re C* [1998] Lloyd's Rep Med 1

⁸⁹ *R (Burke) v General Medical Council*, *Times Law Report*, 6 August 2004

⁹⁰ Letter page, *The Times*, 3 August 2004

An anticipatory choice which, if clearly established and applicable in the circumstances - two major "ifs" - would bind the practitioner.⁹¹

Lord Donaldson then described the need for the refusal to be applicable in that particular situation:

In all cases doctors will need to consider what is the true scope and basis of the refusal. Was it intended to apply in the circumstances which have arisen? Was it based upon assumptions which in the event have not been realised? A refusal is only effective within its true scope and is vitiated if it is based upon false assumptions.⁹²

This principle was confirmed by the House of Lords in *Airedale NHS Trust v Bland*.⁹³ Lord Keith stated that a patient's right to refuse treatment extended to anticipatory refusals provided the patient had anticipated the situation and issued clear instructions.

In 1995 the Law Commission Report, *Mental Incapacity*, recommended that there should be specific legislative provision for advance refusals of medical treatment.⁹⁴ The Report recommendations included:

1. An advance refusal should be defined as a refusal made by a person aged 18 or over with the necessary capacity of any medical, surgical or dental treatment or other procedure, and intended to have effect at any subsequent time when he or she may be without capacity to give or refuse consent;
2. In the absence of any indication to the contrary it shall be presumed that an advance refusal of treatment does not apply in circumstances where those having the care of the person concerned consider that the refusal (a) endangers that person's life or (b) if that person is a woman who is pregnant, the life of the foetus;
3. No person should incur liability (a) for withholding any treatment or procedure if there are reasonable grounds for believing that an advance refusal of treatment applies; or (b) for carrying out any treatment or procedure to which an advance refusal applies unless he or she knows or has reasonable grounds for believing that an advance refusal applies;
4. An advance refusal of treatment should not preclude the provision of "basic care", namely care to maintain bodily cleanliness and to alleviate severe pain, as well as the provision of direct oral nutrition and hydration;

⁹¹ *Re T* [1993] Fam. 95 at p103

⁹² *Re T* [1993] Fam. 95 at p116

⁹³ *Airedale NHS Trust v Bland*[1993] 1 All ER 821

⁹⁴ Law Commission Report No 231, <http://www.lawcom.gov.uk/549.htm>

5. An advance refusal should not preclude the taking of any action necessary to prevent the death of the maker or a serious deterioration in his or her condition pending a decision of the court on the validity or applicability of an advance refusal.⁹⁵

There have been two recent cases concerning the use of advance directives and anticipatory refusals of treatment.

The case *Re AK* concerned a 19 year old patient suffering from end stage motor neurone disease, who was dependent on a ventilator to breathe.⁹⁶ The patient requested that two weeks after he lost the ability to communicate by any means he would be disconnected from the ventilator. The judge ruled the advance decision was valid and stated:

To this extent an advance indication of the wishes of a patient of full capacity and sound mind is effective, but care must be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient.⁹⁷

The most recent case, *HE v NHS Trust A and AE*, involved the refusal of a blood transfusion by a Jehovah's Witness who was seriously ill. The patient had signed an advance directive refusing all blood products whilst she was a practising Jehovah's Witness. Since then, the patient had become betrothed to marry a Muslim on the condition she became a Muslim and had stopped attending Jehovah's Witness meetings. The Judge ruled that since the advance directive was founded entirely on the patient's faith as a Jehovah's Witness, her decision to abandon that faith and become a Muslim deprived the advance directive of any continuing validity and effect.

However, the ruling did confirm that a valid and applicable anticipatory refusal of treatment is legally binding. Mumby J stated:

A competent adult patient's anticipatory refusal of consent (a so-called 'advance directive' or 'living will') remains binding and effective notwithstanding that the patient has subsequently become and remains incompetent.⁹⁸

He added:

Where life is at stake the evidence must be scrutinised with special care. Clear and convincing proof is required. The continuing validity and applicability of the advance directive must be clearly established by convincing and inherently

⁹⁵ Law Commission Report No 231, <http://www.lawcom.gov.uk/549.htm>

⁹⁶ Motor neurone disease is a neurological condition which progressively worsens usually leading to death within several years

⁹⁷ *Re AK* [2001] 1 FLR 129

⁹⁸ *HE v NHS Trust A and AE*, [2003] 2 FLR 408 at p415

reliable evidence. If there is doubt, that doubt falls to be resolved in favour of the preservation of life⁹⁹.

2. Guidelines

The British Medical Association has published the *BMA Code of Practice 1995 on Advance Statements*.¹⁰⁰ The summary states:

1. The BMA strongly supports the principle of an advance statement. Through advance statements, patients have a legal right to decline specific treatment, including life-prolonging treatment.
2. Patients cannot use advance statements to insist on the provision of certain treatments but they may authorise or refuse treatments.
3. Drafting an advance statement is the patient's responsibility. It is recommended that this be done with medical advice and counselling as part of a continuing doctor-patient dialogue.
4. It is the responsibility of the patient to ensure that the existence of an advance statement is known to those who may be asked to comply with its provisions.
5. No person has a legal right to accept or decline treatment on behalf of another adult. Nevertheless, in addition to advance statements, the BMA recognises that the nomination of a health care proxy by the patient may be another helpful development in communicating the patient's views when the individual is no longer capable of expressing these
6. It is strongly recommended that patients review their advance statements at regular intervals and destroy rather than amend the advance statement if they feel dubious about any previously expressed choices.
7. The BMA urges its members to consider their own views and inform patients at the outset of any absolute objection the doctor has to the principle of an advance statement. Doctors with a conscientious objection to curtailing treatment are not obliged to comply with an advance statement but must be ready to step aside. They should ensure that at the time of drafting, the patient is aware of the situation and can make an informed choice

⁹⁹ *HE v NHS Trust A and AE*, [2003] 2 FLR 408 at p421

¹⁰⁰ *Advance Statements – British Medical Association*, May 1995, <http://www.bma.org.uk/ap.nsf/Content/advancestatements>. This is a separate publication from the BMA guidance on withholding and withdrawing medical treatment

8. The Association encourages doctors to raise the subject of an advance statement in a sensitive manner with patients who are anxious about the possible administration of unwanted treatments at a later stage.
9. Late discovery of an advance statement after life-prolonging treatment has been initiated is not sufficient grounds *for* ignoring it.
10. There is a significant ethical and legal difference between the concept of an advance statement and the issue of euthanasia. In supporting advance statements, the BMA confirms its commitment to the fundamental and legitimate right of patients to accept or reject treatment options. This is in contrast with euthanasia, where the primary purpose is to actively cause or hasten death. Euthanasia is illegal and the association's conclusions should not be seen as supporting it.¹⁰¹

3. The draft Bill

The Government's report, *Making Decisions*,¹⁰² did not include legislative proposals on advance decisions to refuse medical treatment. The draft *Mental Incapacity Bill* acknowledged the developments in case law related to advance directives, and sought to codify the common law position whilst providing additional safeguards.

The draft Bill outlined general provisions for advance refusals of treatment. These stressed the need for the advance decision to be:

- valid at the time when the decision needs to be made;
- applicable to the actual situation.

The other important principles expressed in the clauses were:

- The person making the advance decision must be over 18 years old and have capacity.
- The advance decision would need to specify the treatment refused.
- If there is any doubt about the existence or validity of an advance decision the court would determine the issue.

¹⁰¹ <http://www.bma.org.uk/ap.nsf/Content/advancestatements#Summaryofpoints>

¹⁰² Cm 4465, *Making Decisions*, <http://www.lcd.gov.uk/family/mdecisions/indexfr.htm>

4. The Report of the Joint Committee

The Joint Committee broadly agreed with the provisions relating to advance directives. They stated:

We recommend that the Bill should permit the making of advance decisions to refuse treatment. We recognise the genuine and deeply felt concerns of those who have moral objections to any decision that could end life, but that right is recognised in law for those who are capable of making such decisions and we think that it is right that the Bill should provide for those who wish to do so to have the legal means to have that decision respected should they become incapable. In doing so, the Bill should aim to set standards for good practice and ensure a means of challenge under circumstances where there were disagreements that could not be resolved.¹⁰³

The Committee also recommended that safeguards should be introduced including that the advance decision should be:

- recorded in writing
- valid and applicable
- updated regularly to take account of the progress in medical treatments
- easily revoked either orally or in writing

5. The Bill

Clauses 24 to 26 of the Bill, relating to advance decisions to refuse treatment, are broadly the same as those in the draft *Mental Incapacity Bill*. The intention of the Bill is to clarify the current common law position.

The Government's Explanatory Notes state that an advance decision as defined in these clauses is a special type of advance statement that represents an actual decision made to refuse treatment.¹⁰⁴ It must be made by a competent adult and specify the treatment being refused. The decision could be withdrawn or changed by the person at any time as long as they still have capacity.

A more general advance statement relating to values or non-specific broad treatment choices would not be covered by these clauses. However, such statements may still play

¹⁰³ Para 203, Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>

¹⁰⁴ Bill 120-EN para 77, <http://www.publications.parliament.uk/pa/cm200304/cmbills/120/en/04120x-a.htm>

an important role in the best interests checklist used for making decisions for a person who lacks capacity.¹⁰⁵

Clause 25 set out the requirements for an advance directive to be valid and applicable. The necessary conditions are:

- *Valid:* The advance decision should not have been overridden by a Lasting Power of Attorney, or withdrawn, or be inconsistent with current beliefs.
- *Applicable:* The advance decision would not be applicable if the person still has capacity, or the treatment is not specified, or unanticipated circumstances exist.
- An advance decision would not be applicable to life-sustaining treatment unless this has been clearly specified.

Clause 26 would address the legal effects of an advance decision:

- A valid advance decision would make it unlawful to administer the specified treatment.
- A person would not be liable for the consequences of withholding or stopping treatment if they reasonably believed a valid and applicable advance decision existed.
- A person would not be liable for continuing the treatment unless they were satisfied at the time a valid and applicable advance decision exists
- Where there is doubt about the existence or the validity or applicability of the advance decision a court would decide the issue. Life-sustaining treatment could be given whilst awaiting the decision

A doctor who has conscientious objections to following a patient's advance decision would not be pressurised into acting in a manner contrary to those beliefs, and could transfer the patient's care to another doctor. If they fail to do this and instead override a valid and applicable advance refusal they could be liable for an action in negligence.

The Lord Chancellor has produced a draft Code of Practice on advance decisions to refuse treatment that would add further guidance to the provisions in these clauses.¹⁰⁶

¹⁰⁵ Clause 4 of the Bill provides a checklist of factors to be used when assessing an incapacitated person's best interests. One of the factors to consider is "ascertaining past wishes".

¹⁰⁶ *Mental Incapacity Bill: Draft Code of Practice*, <http://www.dca.gov.uk/menincap/mcbdraftcode.pdf>. See section III of this Research Paper

F. Scope of the Bill: The debate about euthanasia

Following the publication of the draft *Mental Incapacity Bill* concerns were expressed that allowing people to make advance refusals of life sustaining treatments, in particular the refusal of artificial nutrition and hydration, would legalise euthanasia by omission.¹⁰⁷

The Government refutes this and has stated that the Bill is not about euthanasia at all, that this is not a legal concept and that it will remain unlawful to take another person's life. The Government has also stated that the Bill is not about the legal position on withdrawal of artificial nutrition and hydration when someone is in a permanent vegetative state.¹⁰⁸

1. Background

a. Common law

In common law it is recognised that a competent patient can refuse any medical treatment, even at the risk of serious harm or death.¹⁰⁹ Similar principles in recent cases have applied to valid and applicable advance refusals of treatment, made by a person while competent to apply when they are incompetent.¹¹⁰ Life-sustaining medical treatments that can be refused include ventilation,¹¹¹ renal dialysis¹¹² and artificial nutrition and hydration (ANH).¹¹³

The common law is clear that the refusal of medical treatment by a competent adult that results in death is not suicide. In *Airedale NHS Trust v Bland*, Lord Goff clarified this issue:

I wish to add that in cases of this kind, there is no question of the patient having committed suicide, nor therefore of the doctor having aided or abetted him in doing so. It is simply that the patient has, as he is entitled to do so, declined to consent to treatment which might or would have the effect of prolonging his life, and the doctor in accordance with his duty, complied with the patient's wishes.¹¹⁴

A deliberate act performed by a doctor to bring about the death of a patient at a patient's request is murder under English law.¹¹⁵ (Although this may be referred to as mercy killing or euthanasia, in law the offence is murder). The law is also clear that a doctor who

¹⁰⁷ See section IV of this Research Paper for a selection of comments

¹⁰⁸ *Mental Incapacity Bill (now renamed Mental Capacity Bill) Factsheet*, April 2004, <http://www.dca.gov.uk/menincap/mcbfactsheet.htm>

¹⁰⁹ *Re B* [2002] 2 All ER 449

¹¹⁰ *Re T* [1993] Fam 95; *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 869

¹¹¹ *Re B* [2002] 2 All ER 449

¹¹² *Re JT* [1998] 1 FLR 48

¹¹³ *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 869

¹¹⁴ *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 869

¹¹⁵ Kennedy and Grubb, *Medical Law*, 3rd edition, 2000 at p1961

complies with a patient's contemporaneous or advance refusal of treatment is not committing euthanasia or mercy killing. Lord Goff stated that euthanasia is not lawful at common law and then differentiated this from a patient not continuing or receiving medical treatment, when it has been established there is not a duty to provide treatment, for example, if the treatment is considered futile. He stated:

The law draws a crucial distinction between cases in which doctors decide not to provide, or to continue to provide, for his patient treatment or care which could or might prolong his life and those which he decides, for example by administering a lethal drug, actively to bring his patient's life to an end.¹¹⁶

The classification of artificial hydration and nutrition as medical treatment was confirmed by the House of Lords in the case of *Airedale NHS Trust v Bland*.¹¹⁷ Treatments that are classed as artificial feeding include nasogastric feeding, feeding by percutaneous gastrostomy (through a tube that goes directly into the stomach) and total intravenous nutrition.

Doctors have a duty to provide basic care. Although there is no legal definition of basic care, the British Medical Association describes this as any treatment or procedure primarily designed to provide comfort or alleviate distress.¹¹⁸

b. Guidelines: Withholding and withdrawing medical treatment

The British Medical Association publishes guidelines for doctors on important ethical issues in medicine.¹¹⁹ These guidelines do not have any formal legal standing although they could be referred to in court as evidence to support a treatment decision:

The modern trend within the NHS is for clinical guidance, protocols and other formal statements of proper treatment and diagnoses. These may emanate from many 'official' sources, such as the Government or the Royal Colleges, and their incidence will be increased with the work of the National Institute of Clinical Excellence. As a consequence the courts will be presented with thought out and considered standards. Whilst such protocols and guidelines will not necessarily set the legal standard, they will be increasingly seen as providing very good evidence of the standard¹²⁰

The British Medical Association produced the guidelines *Withdrawing and withholding life-prolonging medical treatment*, (2nd edition, 2001). The BMA states that under some circumstances, in patients where death is imminent, the provision of artificial nutrition

¹¹⁶ *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 869

¹¹⁷ *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 869

¹¹⁸ *Medical Ethics Today*, The BMA's handbook of ethics and law, Second edition, p115

¹¹⁹ The British Medical Association is the professional association for doctors in the UK and provides advice and guidance on a wide range of medical issues. The guidance is not binding on doctors.

¹²⁰ Kennedy and Grubb, *Medical Law*, 3rd edition, 2000, p.453

and hydration may become intrusive, rather than providing a benefit to the patient. In such cases it would be acceptable to withdraw artificial nutrition and hydration.¹²¹ However, the guidelines also state that oral hydration and food should always be offered, but not forced upon patients.

In exceptional cases, such as the situation where an incapacitated patient is irreversibly brain damaged following a severe stroke, it may be thought that the burdens of artificial nutrition and hydration outweigh the benefits, and it would not be in the patient's best interests to receive treatment. In these situations the British Medical Association recommends that the senior doctor responsible for the patient's care should seek a second expert opinion, before making the decision to withdraw artificial nutrition and hydration. Lord Goff addressed the issue of best interests and withdrawal of treatment in *Airedale NHS Trust v Bland*.

This is because the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuation of this form of medical treatment or care.¹²²

The General Medical Council (GMC)¹²³ guidance is similar and recommends in cases where artificial nutrition and hydration is to be withdrawn from a patient where death is not imminent that:

As well as consulting the healthcare team and those close to the patient, ... [the doctor] must seek a second or expert opinion from a senior clinician (who might be from another discipline such as nursing) who has experience of the patient's condition and who is not already involved in patient care.¹²⁴

For patients who remain in a persistent vegetative state, artificial nutrition and hydration can only be withdrawn if a court declaration approves the decision.

The House of Lords' Medical Ethics Committee clearly stated:

The right to refuse medical treatment is far removed from the right to request assistance in dying.¹²⁵

¹²¹ *Medical Ethics Today*, The BMA's handbook of ethics and law, Second edition, p355

¹²² *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 869

¹²³ The General Medical Council (GMC) regulates the medical profession and was established under the *Medical Act 1858*. The GMC has statutory regulatory powers and governs the training of doctors and the practice of medicine. It keeps a medical register and has powers to suspend or strike off a doctor from the register. It issues ethical guidance on specific issues.

¹²⁴ GMC "Withholding and Withdrawing life prolonging medical treatment: good practice in decision making"

¹²⁵ House of Lord's Select Committee on Medical Ethics Report, 1994, HL 21

c. The ethics

There is no single accepted meaning for the word euthanasia, although the concept of deliberately caused death is common to all definitions in current usage. The meaning adopted often reflects a particular moral view, and includes a wide range of beliefs from those who believe that any shortening of life is wrong, to others who believe euthanasia should be legalised.

To avoid ambiguity euthanasia is frequently qualified with additional terms.¹²⁶ Descriptions of the terms used are provided below, but it should be realised that these terms are not necessarily accepted by everyone who participates in the euthanasia debate. The House of Lords Select Committee on Medical Ethics described the use of the terms active and passive euthanasia as unhelpful.¹²⁷

- *Passive euthanasia*: This refers to where death arises through withholding or withdrawing life-prolonging medical treatment.
- *Active euthanasia*: This refers to a deliberate act, such as a lethal injection, that results in the death of the patient.
- *Voluntary euthanasia*: Euthanasia at the request of the patient
- *Non-voluntary euthanasia*: Killing someone in their own interest who is unable to express a view either way due to for example unconsciousness
- *Involuntary euthanasia*: Killing someone in disregard of their own views.¹²⁸

The British Medical Association definition clearly confines the term euthanasia to the active killing of a patient at their request. The withdrawal of medical treatment from a patient is not considered by the BMA to be active euthanasia.¹²⁹ Although this probably reflects the most commonly understood meaning of euthanasia, it is not the only definition used.¹³⁰

Some argue that adopting a definition based solely on voluntary active euthanasia gives a "peculiarly narrow definition of euthanasia", and fails to reveal the extent of euthanasia.¹³¹

¹²⁶ Helga Kuhse *Euthanasia* in P Singer (ed) *A Companion to Ethics*, 1993 at p294-96

¹²⁷ House of Lord's Select Committee on Medical Ethics Report, 1994, HL 21

¹²⁸ See Helga Kuhse *Euthanasia* in P Singer (ed) *A Companion to Ethics*, 1993 at p294-96

¹²⁹ *Medical Ethics Today*, The BMA's handbook of ethics and law, Second edition, p389

¹³⁰ *Euthanasia, Volume II: National and European perspectives*, Ethical Eye, Council of Europe Publishing, January 2004, p9

¹³¹ John Keown, *Euthanasia, Ethics and Public Policy: An Argument Against Legalisation*, Cambridge University Press, 2003

Other definitions of euthanasia refer to any action or omission with the primary intent of bringing about a patient's death in order to end their suffering.¹³² This definition would classify withdrawal of medical treatment as a form of euthanasia.

The Linacre Centre¹³³ adopts this view and provided the following evidence to the House of Lords Select Committee on Medical Ethics:

3.1 It is certainly morally unacceptable to aim or intend to bring about someone's death for a reason or reasons incompatible with recognising the basic worth and dignity of that person as a human being, and incompatible, therefore, with justice. One's intent to bring about someone's death will be equally unacceptable whether it is achieved by:

- (a) a positive act, such as a lethal injection;
- (b) the omission of treatment decided upon precisely to hasten death;
- (c) the omission of care decided upon precisely to hasten death.¹³⁴

However, the moral disagreements between different sections of society on whether or not withdrawal of artificial feeding constitutes euthanasia are based on such different moral beliefs, it is unlikely that any consensus of opinion can be reached.

2. The Report of the Joint Committee and the Government's response

The Joint Committee's Report expressed a very clear view that the acceptance of advance decisions to refuse treatment does not constitute euthanasia.¹³⁵ However the Committee recognised the strongly held beliefs of those who hold it is morally wrong to make any medical decision that could end life.

The Committee recommended that such concerns should be specifically addressed in the Bill:

204. Many of the fears which have been raised with us about possible connections between the draft Bill and euthanasia appear to be misplaced. Nevertheless, in acknowledgment of the strength of feeling that clearly exists on this issue and in the hope that such misplaced fears do not detract attention from the many worthwhile aspects of the draft Bill, we recommend that additional assurance should be offered by the inclusion of a paragraph in the Statement of

¹³² *Euthanasia, Volume I: Ethical and human aspects*, Ethical Eye, Council of Europe Publishing, January 2004, p21

¹³³ The Linacre Centre states that it is the only Catholic centre for bioethics in the UK and Ireland. It states that its perspective is informed by Catholic moral teaching; however, in defending such teaching it seeks also to appeal to non-religious, philosophical reasoning to enable dialogue with those of no religious faith

¹³⁴ Submission by the Linacre Centre in June 1993 to the House of Lord's Select Committee on Medical Ethics, HL Paper 21, (1993-94)

¹³⁵ <http://pubs1.tso.parliament.uk/pa/jt200203/jtselect/jtdmi/189/189.pdf>

Principles we have recommended, or by an additional clause in the Bill, to make clear that nothing in the Bill permits euthanasia or alters the law relating to it.

(...)

210. We believe that people, whether incapable or not, have the right to expect that they will be cared for to the highest standards. We recommend that the Codes of Practice should explicitly state that the duties and responsibilities placed on health professionals must apply equally to capable and incapacitated people. No assumption should be made that life has less value for the latter.¹³⁶

The Government's response acknowledged the Committee's advice relating to drafting but stated:

We are aware of precedents for clauses which state that nothing in the legislation affects other rules of law. We are not, however, fully persuaded that a clause stating that the Bill does not permit euthanasia (even if that were possible in drafting terms), would address the concerns of those who believe that the Bill does permit euthanasia. Some of the disagreements in this area are, of course, about the very definition of the word "euthanasia". We shall continue to take every opportunity to state what the Bill is about, and remain in contact with stakeholders who have concerns on this particular issue. We are also seeking to ensure that the Bill as it applies to end of life issues contains clear safeguards.¹³⁷

The Government also strongly agreed that the standards of care carried out by health professionals should apply equally to capable and incapacitated people.¹³⁸

3. The Bill

Clause 58 would be a declaratory provision which states:

For the avoidance of doubt, it is hereby declared that nothing in this Act is to be taken to affect the law relating to murder or manslaughter or the operation of section 2 of the Suicide Act 1961 (c. 60) (assisting suicide).

Although clause 58 would confirm that nothing in the Bill would change the law on unlawful killing or assisted suicide this is unlikely to resolve the ethical arguments surrounding the issue. In addition to the declaratory provision, the Bill would provide specific safeguards concerning the withdrawal or stopping of life-sustaining treatments. These include:

¹³⁶ Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, <http://www.publications.parliament.uk/pa/jt/dmi.htm>

¹³⁷ Cm 6121, The Government Response to the Scrutiny Committee's Report on the draft *Mental Incapacity Bill*, February 2004, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm>

¹³⁸ *Ibid*

- Advance decision: This will not apply to life-sustaining treatments unless the person has specified that it should.¹³⁹
- Lasting Powers of Attorney: Although an attorney could make healthcare decisions this would not extend to life-sustaining treatment unless expressly authorised.¹⁴⁰
- Section 5 acts: If there is any doubt over whether a life-sustaining treatment is in the best interests of a patient, the Bill would allow treatment to be given whilst a decision is sought from the court.¹⁴¹
- Independent consultees: NHS bodies would have a duty to seek the advice of an independent consultee when serious medical treatment is to be provided for a person who lacks capacity. Their role would be to make an independent assessment of best interests.¹⁴²

G. Research

Clauses 31 to 33 would make provision for medical research to be carried out on a person who lacks capacity within strictly defined limitations.

1. Current position and background

The basic principles governing research are derived from the *Declaration of Helsinki* (originally agreed in 1964; latest revisions in 2000). The fundamental principle is that whilst medical research is a public good, precedence must be given to the well being of the individual participating in the research. The Declaration also emphasises the need for informed consent from the research subject or from the legal representative of a person lacking capacity.

The Law Commission Report recognised that the participation of persons lacking capacity in research was unlawful unless it could be justified under the principle of necessity. Whilst this could be held to be true in therapeutic research, it would be highly unlikely to permit non-therapeutic research. It recommended that persons lacking capacity should only be allowed to participate in research projects when the following conditions are met:

- The research is into an incapacitating condition which the person concerned is affected by

¹³⁹ Clause 25(5)

¹⁴⁰ Clause 11(7) (a)

¹⁴¹ Clause 6(6) See section II B 4 of this Research Paper

¹⁴² Clause 35(5) See section II H of this Research Paper

- The risk to the person is negligible
- Approval has been given by an ethics committee, or appropriate authority
- Certain statutory procedures are complied with

More recently the *European Clinical Trials Directive* raised the issue of whether it was lawful for patients who lack capacity to be involved in medical research.¹⁴³ The Directive was introduced in May 2002 and implemented in the UK in May 2004. The Directive imposes restrictions on the participation of incapacitated adults in clinical trials by:

- requiring written consent from a legal representative of the patient
- only allowing participation in research that relates to the condition that the patient suffers from
- taking account of the expressed wishes of the patient.¹⁴⁴

2. Draft Bill and the Report of the Joint Committee

The draft *Mental Incapacity Bill* did not make any provisions for research. However, in the Explanatory Notes published with the draft Bill, the Government stated that the potential scope of the Bill was very wide and consequential amendments were still being considered.¹⁴⁵

The Joint Committee recommended that the Bill should set out the key principles governing research involving people who lack capacity. The view expressed was that properly regulated research involving people who lack capacity would be essential to provide new information and develop new treatments for incapacitating disorders. However, Baroness Knight of Collingtree dissented and proposed an amendment that “People judged to be incapable and unable to make decisions for themselves should not be used in medical research experimentation”. The amendment was not accepted.¹⁴⁶

The Joint Committee recommended that statutory provision should be made to ensure the ethical requirements were met. In addition, they recommended that strict protocols should be introduced to protect incapacitated adults from harm or exploitation.

We therefore recommend that the Bill should set out the key principles governing research, such as those enshrined by the World Medical Association. Those key principles should include the following:

¹⁴³ The European Union Directive 2001/20/EC

¹⁴⁴ Law Commission Report No 231, <http://www.lawcom.gov.uk/549.htm>

¹⁴⁵ Cm 5859 – I and II, p15

¹⁴⁶ Formal minutes 17 November 2003; Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, <http://www.publications.parliament.uk/pa/jt200203/jtselect/jtdmi/189/18926.htm>

- Research involving people who may be incapacitated must be reviewed by a properly established and independent ethics committee and can only proceed if ethical permission is granted.
- Where a person has the capacity to consent then his decision whether or not to partake in research must be respected.
- Considerable care should be taken to ensure that under these circumstances consent to participate was freely given and not a consequence of coercion.
- The inclusion of people in research, who lacked the capacity to consent, must only occur when such research has the potential for direct benefit to those with that particular problem and could not have been done through the involvement of those with capacity.
- Those undertaking research involving people lacking the capacity to consent must respect any indications that a person did not wish to participate (i.e. was dissenting).
- Any discomfort or risk involved in the research must be, at the most, minimal.¹⁴⁷

3. The Bill

The provisions contained in **clauses 30 to 33** of the Bill relating to research are derived from the principles contained in the Law Commission Report and from ethical codes of practice such as that of the Council of Europe *Convention on Human Rights and Biomedicine* (Article 17; Protection of persons not able to consent to research).¹⁴⁸

Clause 30 states that it would only be lawful for a person, who lacks capacity to consent, to be involved in research if the research project has received approval from the appropriate body (likely to be a regional ethics committee), and it is carried out in accordance with the other provisions in the Bill. The following types of research would be excluded from the Bill:

- Clinical trials: These are now covered by the *Medicines for Human Use (Clinical Trials) Regulations 2004*¹⁴⁹
- Anonymised medical data or tissue: Proposals to cover this are in the *Human Tissue Bill* currently before Parliament¹⁵⁰

Clause 31 details the requirements that must be satisfied before the appropriate body could approve a research project. The key points are:

¹⁴⁷ Para 289, Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>

¹⁴⁸ <http://www.oup.co.uk/pdf/bt/cassese/cases/part3/ch16/1121.pdf> on 28 June 2004

¹⁴⁹ SI 2004/1031

¹⁵⁰ *Human Tissue Bill* HL Bill 94 of 2003-04

- The research must be connected with the condition from which the person suffers
- The research must have the potential to directly benefit the person, or to provide knowledge about the condition suffered
- It must not be possible to carry out the research in other way; for example using adults who are able to consent
- The risks associated with the research must be negligible

Clause 32 sets out the need to identify a person who could be consulted about the involvement of the incapacitated person in a research project. The person consulted might be: a family member or close friend; an attorney or deputy; or a nominated person independent of the research project.

The clause also states that the wishes and feelings of the incapacitated person would have to form a central part of the decision-making. If it is thought that they would not want to participate in the research, they should not be recruited into the research project. The advice of the court could be sought to resolve difficult cases.

Clause 33 would provide further safeguards to protect incapacitated persons who participate in research. This would ensure that if the person indicates in any way that they wish to withdraw from the project, (this would include taking account of any provisions contained in an advance directive), this wish must be respected.

H. Independent consultee service

1. Background

Some people who lack capacity are in an especially vulnerable situation as they have no close family or friend who can participate in decision-making. This situation is most common for people suffering from dementia, and those who have been in long term residential care due to mental health problems or severe learning disabilities.

Welfare decisions must still be made in the incapacitated person's best interests. However it may be difficult to find someone who can support them in decision-making and assess whether the proposed course of action is actually in the person's best interests.

Attention was focused on the need to protect the rights of patients who lack capacity in the case *R v Bournewood Community and Mental Health NHS ex parte L*.¹⁵¹ The case concerned an incapacitated patient who was admitted to a mental health unit. The patient did not have capacity to consent to admission but appeared compliant so was not formally admitted under the *Mental Health Act 1983*. The Court of Appeal ruled that the patient had been unlawfully detained. The House of Lords overturned this decision in a majority

¹⁵¹ *R v Bournewood Community and Mental Health NHS ex parte L*. [1998] 3 All ER 289

ruling which stated that the common law principle of necessity permitted long term detention of an incapacitated patient, provided they were compliant.¹⁵² However, patients detained informally in this manner would not be protected by the statutory safeguards of *the Mental Health Act 1983*, so would be in a more vulnerable position. The decision is currently being challenged in the European Court of Human Rights.

2. Advocacy services

In its white paper, *Valuing people: A new strategy for learning disability for the 21st century*, the Government gave the following view of advocacy services:

Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices. Advocacy helps people put forward their views and can play an active part in planning and designing services which are responsive to their needs. This applies to people with severe and profound disabilities and to the less severely disabled.¹⁵³

The Joint Committee indicated that a number of witnesses strongly criticised the draft Bill for failing to provide a suitable alternative to the court, or assistance, such as independent advocacy, for people with capacity problems to be able to take up their concerns. Although a few witnesses expressed doubts about the usefulness of advocacy, many witnesses stressed the need for a right to advocacy services:

both to assist people with impaired capacity to make their own choices and have them respected, and also as an important safeguard to protect people from having control over their own lives taken away unnecessarily and in particular from the risk of abuse.¹⁵⁴

The Joint Committee itself acknowledged the essential role of advocacy services¹⁵⁵ and strongly recommended that further consideration be given to the provision of independent advocacy services and other means of enabling people lacking capacity to participate as fully as possible in any hearing affecting their rights and entitlements.¹⁵⁶

The Joint Committee stated that it would be inappropriate for them to recommend that resources be committed to provide a statutory right to advocacy for all people affected by

¹⁵² “*Consent by others*”, Ian Kennedy and Andrew Grubb, in *Medical Law: Text with Materials* (2000) 3rd ed.,: Oxford University Press

¹⁵³ Cm 5086, March 2001, http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities/LearningDisabilityPublications/fs/en?CONTENT_ID=4032080&chk=w%2Bvo48

¹⁵⁴ Para 292, Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II

¹⁵⁵ *Ibid* para 296

¹⁵⁶ *Ibid* para 170

the Bill's provisions but did make various recommendations relating to the provision of some independent advocacy services.¹⁵⁷

In its response to the Joint Committee, the Government agreed that independent advocacy has a role to play in supporting those who may lack capacity, and indicated that it was considering the whole issue of advocacy:

The Bill already provides that rules of court can make provision for a person to be represented by any suitable person, as well as by the Official Solicitor (cl 41(2)(d)). The Official Solicitor is the independent expert currently used by the Courts as an advocate for those with incapacity. We are considering whether there is a role for lay advocates. As is the case with the current Court of Protection, we do not intend the new court to adopt formalistic or legalistic procedures excluding anyone who can promote the interests of the person concerned.¹⁵⁸

3. The Bill

Clauses 34 to 39 of the Bill provide details of a new scheme, the independent consultee service. The function of this scheme would be to support the decision-making process of people who lack capacity and have no close family or friends to assist them. For certain important areas of decision-making, such as welfare and health, an independent consultee would be appointed to advise on such decisions and to ensure that the interests of the incapacitated person are protected.

The independent consultee (IC) should be independent of the individual or authorities that are making the decision for the person who lacks capacity. The IC must be allowed to meet with the incapacitated person privately and be given full access to any relevant records. Regulations would set out details of the appointment and functions of the IC.

The advice of an IC would not be required if the person who lacks capacity already has somebody to help make the decision. This may be an attorney or deputy.

a. Serious medical treatment

Clause 35 would impose a duty on an NHS body to seek advice from an independent consultee (IC) in relation to serious medical treatment for a person who lacks capacity. The definition of serious medical treatment would be provided in the regulations. The IC must consider the best interests of the person in deciding whether or not the treatment should be provided.

¹⁵⁷ *Ibid* paras 292-308

¹⁵⁸ Cm 6121, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm#part2>

The clause would allow urgent medical treatment to be carried out without seeking advice from an IC.

b. Providing accommodation

Clauses 36 and **37** would impose a duty on an NHS body, and the local authorities respectively, to seek advice from an IC before arranging accommodation for a person who lacks capacity. Again the decision must be made in the best interests of the person. Provisions in this clause would allow for urgent placements.

4. The draft Code of Practice

The draft Code of Practice relating to the Bill, which was published on 9 September 2004, refers to the role of independent advocacy services:

4.35 Reference has been made in this chapter to the potentially useful role of independent advocacy services in providing a focus on the views and wishes of a person who may lack capacity in the determination of their best interests. The following situations might indicate the need for the involvement of an independent advocate when determining best interests:

- Where the person lacking capacity has no close family or friends to take an interest in his/her welfare
- Where family members are in dispute or disagree about the person's best interests
- Where the person lacking capacity is already in contact with an advocate¹⁵⁹

I. Codes of practice

1. The draft Bill

The draft Bill proposed that the Lord Chancellor should prepare Codes of Practice for the guidance of various categories of people affected by the Bill. Much of the detail about how the Bill would actually operate in practice would be in the Codes of Practice which, accordingly, would be of fundamental importance.

2. The Report of the Joint Committee

The Joint Committee commented that there was universal agreement in evidence that the Codes of Practice would be essential to the proper implementation and operation of the new legislation, and that it had been difficult to scrutinise the draft Bill without having

¹⁵⁹ *Ibid*, p40

sight of the draft Codes of Practice.¹⁶⁰ The Joint Committee recommended that, although it did not wish to delay matters, the Bill should not be introduced to Parliament until the draft Codes of Practice were also available to be considered.

Under the provisions of the draft Bill, only those acting in a professional capacity or for remuneration were required to have regard to the relevant Codes of Practice. The Joint Committee agreed that only those categories should be obliged to abide by the Codes of Practice but recommended that family members and carers should be strongly encouraged to follow the Codes.¹⁶¹

The importance accorded to the Codes of Practice is reflected in the fact that many of the Joint Committee recommendations set out matters they considered should be covered by the Codes including, for example, an express duty of care for attorneys acting under an LPA and for Court Appointed deputies;¹⁶² the standards of expected conduct of decision makers;¹⁶³ the processes and requirements relating to the assessment of capacity;¹⁶⁴ the concept of best interests;¹⁶⁵ and details about the supervisory role of the Public Guardian and the sanctions for non-compliance with required standards.¹⁶⁶

3. Government response

The Government confirmed its aim to have as substantial an outline as possible of the Code of Practice ready by the Committee stage of the Bill. The Government also confirmed that the final Code would be subject to consultation.¹⁶⁷ The draft Code of Practice has now been published.¹⁶⁸ Further details about this are included in section III of this Research Paper.

4. The Bill

Under the Bill, the Lord Chancellor would have to prepare and issue codes of practice, which would effectively supplement the Bill, for the guidance of various categories of persons as set out in **Clause 40(1)**. Two further categories have been added to those obliged in the draft Bill to have regard to any relevant code (those acting in a professional capacity and/or for remuneration). The added categories are those given lasting power of attorney and court appointed deputies (**Clause 40(4)**). The draft codes would have to be laid before both Houses of Parliament for 40 days and would then be issued provided that

¹⁶⁰ Paras 228-9, Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II, <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>

¹⁶¹ *Ibid* para 232

¹⁶² *Ibid* para 154

¹⁶³ *Ibid* para 98

¹⁶⁴ *Ibid* para 245

¹⁶⁵ *Ibid* para 247

¹⁶⁶ *Ibid* para 254

¹⁶⁷ Cm 6121, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm#part2>

¹⁶⁸ *Mental Incapacity Bill: Draft Code of Practice*, <http://www.dca.gov.uk/menincap/mcbdraftcode.pdf>.

nether House has resolved to reject the draft (**Clause 41**). The Lord Chancellor would have a duty to bring the codes to the attention of persons likely to be affected by them.

J. International Protection of Adults

1. Background

The Hague Conference on Private International Law is an inter-government organisation whose aim is to promote co-operation on matters of private international law.¹⁶⁹

The Convention on the International Protection of Adults was signed at The Hague on 13 January 2000. The aims of the Convention are to:

- provide for the protection in international situations of adults, who by reason of impairment or insufficiency of their personal faculties, are not in a position to defend their interests.
- establish rules on jurisdiction, applicable law, and international recognition and enforcement of protective measures which are to be respected by all States.

The Convention was drawn up in response to the increasing number of incapacitated adults who are involved in situations where the jurisdiction of more than country may apply. An example of this is someone who retires to another country, so may then have financial affairs and perhaps property in both countries. If this person then loses capacity due to dementia, there may be problems deciding which legal jurisdiction should be responsible for the protection of the person and their affairs.

Articles 1 and 2 describe the scope of the convention and set out its objects:

1. This Convention applies to the protection in international situations of adults who, by reason of an impairment or insufficiency of their personal faculties, are not in a position to protect their interests.
2. Its objects are -
 - a) to determine the State whose authorities have jurisdiction to take measures directed to the protection of the person or property of the adult;
 - b) to determine which law is to be applied by such authorities in exercising their jurisdiction;
 - c) to determine the law applicable to representation of the adult;

¹⁶⁹ <http://www.hcch.net/e/conventions/text01e.html> on 29 June 2004

d) to provide for the recognition and enforcement of such measures of protection in all Contracting States;

e) to establish such co-operation between the authorities of the Contracting States as may be necessary in order to achieve the purposes of this Convention.¹⁷⁰

2. The Bill

Clause 59 and **Schedule 3** would give effect to the Convention on the International Protection of Adults.

The provisions of Schedule 3 are explained in the Government's Explanatory Notes to the Bill.¹⁷¹

K. Miscellaneous

1. Excluded decisions

The Law Commission Report recommended that certain treatments or procedures should not be lawful in relation to a person who lacks capacity under certain circumstances.

The Bill would not authorise certain specified decisions to be made on behalf of another person. This would include, for example, consent to marriage or divorce. (**Clause 27**) Similarly, it would not be possible to make a decision on voting for another person. (**Clause 28**)

Patients who are detained and treated under part 4 of the *Mental Health Act 1983* would not come under the remit of the Bill for decisions on medical treatment relating to their mental disorder. This would allow the patient to retain the statutory protection of the safeguards, relating to medical treatment, that are contained in the *Mental Health Act*.

The Bill would apply for all other types of decision regarding a person who lacks capacity and who is detained under the *Mental Health Act*.

2. Transplants

The provisions of the draft Bill would not allow any decision to be made on behalf of a person lacking capacity in relation to the *Human Organ Transplants Act 1989*.

The *Human Tissue Bill* currently before Parliament would replace the *Human Organ Transplants Act 1989*. **Clause 6** of the Bill relates to activities involving material from

¹⁷⁰ <http://www.hcch.net/e/conventions/text35e.html> on 29 June 2004

¹⁷¹ Bill 120-EN, paras 147 to 161, <http://www.publications.parliament.uk/pa/cm200304/cmbills/120/en/04120x--.htm>

adults who lack capacity to consent. This would allow the taking of tissue samples under certain specified circumstances. The Explanatory Notes to the Bill state:

It is envisaged that the regulations will provide for consent to be deemed to be in place where the activity would be in the adult's best interests - for example, it could be in their best interests to donate tissue to a close relative for transplantation. The regulations will also be able to provide that where consent has been given by a proxy in accordance with Schedule 1 to the Medicines For Human Use (Clinical Trials) Regulations 2004/1031, storage and use of material from the adult lacking capacity as part of the trial should be treated as done with consent.¹⁷²

The interpretation of the patient's best interests will be addressed in regulations.¹⁷³

3. Ill treatment or neglect

The Bill would create a new criminal offence of ill-treatment or neglect of a person who lacks capacity by an attorney or deputy, or someone who has care of the person who lacks capacity (**Clause 42**). The maximum sentence on conviction on indictment would be 5 years imprisonment or a fine or both (revised from a maximum 2 year sentence in the draft bill). This underlines the intended seriousness of the offence and puts the penalty in line with the maximum penalty for such offences as inflicting grievous bodily harm¹⁷⁴ and assault occasioning actual bodily harm.¹⁷⁵ The Government rejected the Joint Committee's recommendation¹⁷⁶ that the statutory authorities should be given additional powers of investigation and intervention in cases of alleged physical, sexual or financial abuse of people lacking the capacity to protect themselves from the risk of abuse:

The Committee recommended that the draft Bill should go further in the protection it offers against abuse and exploitation of those lacking capacity. However, the Government is already taking action to protect vulnerable adults against abuse. In particular, the 'No Secrets' guidance requires Councils to liaise with other public authorities and other agencies in their area and to produce written and agreed, local procedures for handling incidents of abuse concerning vulnerable adults. It is right that this extends beyond adults who lack capacity to all vulnerable adults. The new Public Guardian under the Bill would have a role working with Councils and other agencies. The new criminal offence of ill-treatment or wilful neglect would also be another valuable tool in tackling potential abuse.¹⁷⁷

¹⁷² Human Tissue Bill, Bill 94-EN, paragraph 22

¹⁷³ HL Deb 22 July 2004 c411

¹⁷⁴ *Offences Against the Persons Act 1861* section 20

¹⁷⁵ *Offences Against the Persons Act 1861* section 47

¹⁷⁶ Para 73, Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>

¹⁷⁷ Cm 6121, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm#part2>

The Government also rejected the Joint Committee recommendation that the new criminal offence should be extended to include the misappropriation of the property and financial assets of the person lacking capacity¹⁷⁸ on the basis that this is already covered by the law on theft.¹⁷⁹

4. Payment for necessary goods and services

Clause 7 would provide that if necessary goods or services are supplied to a person who lacks capacity, he must pay a reasonable price for them. The Government's Explanatory Notes set out the background to this provision:

This revises and extends the statutory rule in section 3(2) of the Sale of Goods Act 1979 insofar as it applies to people who lack capacity to contract. In general, a contract entered into by a person who lacks capacity to contract is voidable if the other person knew or must be taken to have known of the lack of capacity. This does not apply if "necessaries" are supplied - in those circumstances the person lacking capacity must still pay a reasonable price. The rule in section 3(2) of the 1979 Act only applies to "necessary" goods, but there is a matching common law rule about "necessary" services. The clause combines these rules to set out a single statutory rule to cover "necessary" goods and services. Subsection (2) repeats the established legal definition of what is 'necessary'. Thus, for example, if the milkman carries on delivering milk to the house of someone who has a progressive dementia, they can expect to be paid. If, however, a roofer puts a completely unnecessary new roof on to that person's house, when all that was required was a minor repair, then the rule will not apply.¹⁸⁰

III The draft Code of Practice

The draft Code of Practice was published on 9 September 2004 and is available online.¹⁸¹ In the preface to the draft Code, Lord Filkin, then Parliamentary Under-Secretary of State at the Department for Constitutional Affairs emphasised that it is only a first draft for consideration:

Last year a Parliamentary pre-legislative scrutiny committee considered the Bill, and in their report they specifically recommended that the Bill should not be introduced to Parliament until it could be considered alongside draft Codes of Practice. It is unusual to provide a draft Code at such an early stage in the legislative process. However, the Government accepted this recommendation and undertook to provide a first draft in time for Committee stage in Parliament.

¹⁷⁸ Para 272, Joint Committee on the draft Mental Incapacity Bill, *Draft Mental Incapacity Bill*, 28 November 2003, HL 189-I & II, HC 1083-I & II

¹⁷⁹ Cm 6121, <http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm#part2>

¹⁸⁰ Bill 120-EN, para 37, <http://www.publications.parliament.uk/pa/cm200304/cmbills/120/en/04120x--htm>

¹⁸¹ *Mental Incapacity Bill: Draft Code of Practice*, <http://www.dca.gov.uk/menincap/mcbdraftcode.pdf>

We are now fulfilling this commitment, though I must emphasise that this draft represents the first stage in what will be a lengthy and thorough process to produce a final Code of Practice. It may be that the final Code of Practice will look quite different, both to reflect changes in the Bill that Parliament decides to make, and also as a result of the formal consultation that must follow the passing of any Act. Such consultation will be vital in ensuring that the ultimate code is helpful to stakeholders and others who will be responsible for implementing future legislation. And unlike this first draft, the final Code will contain extensive cross-referencing and signposts to other relevant guidance and sources of information.¹⁸²

The draft Code of Practice includes further detail (including scenarios) and guidance about how the Bill's provisions might operate in practice. The role of the Code is stated as follows:

1.4 The Code provides guidance to all those working with and/or caring for adults who lack capacity, including family members, professionals and carers and describes their responsibilities when acting or making decisions with, or on behalf of, individuals who lack the capacity to do these things themselves. As noted above, however, relevant messages for those affected by the Act will also be provided in other formats suitable for their audience. In effect, the Code explains how the legal rules set out in legislation will work in practice.¹⁸³

Certain categories of people would be under a duty to have regard to the Code, namely, those working in a professional capacity, those being paid for their work in acting in relation to a person without capacity, attorneys and court appointed deputies. The draft Code states that failure on the part of any of these individuals to comply with the Code could be used in evidence in civil or criminal proceedings. Other people, although not under the same legal duty to comply, would still be expected to follow the guidance in the Code.

Areas covered by the draft Code include the following:

- The guiding principles of the Bill and its relationship to other relevant legislation
- The provisions relating to capacity, lack of capacity and assessment of capacity
- How the provisions relating to “best interests” and “the least restrictive option principle” might be interpreted
- Acts in connection with care or treatment, including
 - an explanation of the protection from liability provisions in the Bill (including examples of the type of acts which would attract such protection)
 - the restrictions and limitations on this protection and

¹⁸² *Ibid*, p1

¹⁸³ *Ibid*, p5

- the circumstances in which a carer, acting without formal authority, could buy goods or organise necessary services for a person lacking capacity, and arrange for these to be paid for out of the person's money
- The provisions relating to Lasting Powers of Attorney, and guidance on their practical implications, including the duties and responsibilities of attorneys and their expected standard of conduct and the various duties which this involves
- The role of the Court of Protection and the circumstances in which it might be necessary or there is a requirement to apply to the Court, including examples of the types of cases when an application for a single order from the Court of Protection might be appropriate
- The appointment of deputies, including their powers and duties and responsibilities
- The practical implications of advance decisions to refuse treatment, including
 - what constitutes an advance decision
 - guidance on advance decisions concerning life-sustaining treatment
 - the safeguards in the Bill
 - the effects of advance decisions
 - the duties and responsibilities of healthcare professionals and
 - the actions that can be taken in the event of a dispute or disagreement about an advance decision
- The new independent consultee service (the Government indicates that as this is the most recently developed area of policy in the Bill and has not been subject to the same formal consultation as other parts of the Bill, this part is likely to be subject to further development)
- The provisions relating to research
- Data protection and confidentiality issues

The draft Code also includes a section which explains how professionals, attorneys and deputies are expected to interact with the relevant agencies responsible for the protection of adults who lack capacity. This explains what is meant by abuse, the role of the Public Guardian under the provisions contained in the Bill, the new criminal offence of ill treatment or wilful neglect, and other protective measures which already exist.

A further section deals with resolving disagreements and includes information about different methods which might be adopted, complaints procedures and public legal funding (formerly known as legal aid).

IV Comment on the draft Bill and the Bill

A. The Law Society

The President of the Law Society, Carolyn Kirby, welcomed the draft Bill but also drew attention to an area she felt was missing:

"The Law Society has campaigned for more than 10 years for this necessary and worthwhile legislation. We are delighted that the Government has now put it on

the Parliamentary agenda, and we urge them to find Parliamentary time for it as soon as possible.

"We are particularly pleased that this legislation is being considered in parallel with the Mental Health Bill, as the two are closely linked."

However, the Law Society expressed disappointment that the Draft Mental Incapacity Bill does not contain a provision to require local authorities to protect vulnerable people from abuse.

Carolyn Kirby said: "A valuable opportunity to increase the protection for older, mentally incapacitated, and other vulnerable people is being lost. We urge the Government to include measures to protect vulnerable people – especially older people in care homes.

"We will continue to make the case for increased public protection as this important legislation proceeds through Parliament."¹⁸⁴

B. Making Decisions Alliance

The Making Decisions Alliance comprises a wide range of organisations and groups working with people who may, for a range of different reasons, have difficulty in making or communicating decisions.¹⁸⁵

The Making Decisions Alliance welcomed the provisions relating to advance directives:

A broad coalition of 30 charities today welcomed the planned improvements to 'living wills' from Department of Constitutional Affairs Minister Lord Filkin. The plans are part of the long-awaited Mental Capacity Bill which is set to give millions of people more control over their day to day lives.

The Bill allows people to write advance directives (sometimes known as living wills) setting out specific medical treatments that they wish to refuse in specific circumstances should they lose the capacity to make or communicate decisions - through dementia, mental ill health or a head injury for example. The Making Decisions Alliance (MDA) which includes charities from across the range of areas affected by the Bill has welcomed the proposals, but urged the Government to go further.

"These proposals will give people far greater control of their lives and the treatment they receive and they also set out some important safeguards to make sure they truly reflect the individual's wishes," said Richard Kramer, co-chair of the MDA.

¹⁸⁴ Law Society, *Law Society Calls For More Protection For Older People In Mental Incapacity Bill*, 27 June 2003,

<http://www.lawsociety.org.uk/newsandevents/pressreleases/view=newsarticle.law?NEWSID=445>

¹⁸⁵ <http://www.makingdecisions.org.uk/alliance.htm>

"However, we would also like legislation to recognise people's right to make advance statements setting out what they want to happen should they lose capacity, including what medical treatment they would want. We think these should have the same legal status as advanced refusals of treatment. It's also important to note that these proposals and the Bill as a whole do not affect the law on Euthanasia."

Euthanasia is illegal and will remain so under the Bill. If anything, the MDA argues that the new legislation will protect the rights of individuals and prevent many cases of abuse or ill-treatment. In the cases where individuals are unable to make decisions - those who have suffered head injuries for example - it allows family or care partners to have more say in how those people are treated.

The current lack of legislation means there's still a gap in the law around those who find it difficult to make or communicate decisions. People are being left vulnerable and unsupported to make decisions for themselves. Carers are unsure of their rights to be consulted on the treatment the people they care for receive. Legislation will mean that individuals have the legal right to make decisions for themselves.¹⁸⁶

The Making Decisions Alliance also expressed concern at the lack of provision for advocates:

The Making Decisions Alliance (MDA) says the Mental Capacity Bill, due to be published today, has the potential to transform people's lives for the better, but this is at risk if the Government does not give more emphasis in the Bill to the role played by advocates.

Richard Kramer, co-chair of the MDA, said:

'We have been waiting for legislation for 15 years. But this Bill will not achieve its aim of enabling people to take more control of their lives if advocates are not given more of a central role in representing those affected.

'Advocacy is vital to ensuring that people have a say in the decisions that affect their lives, and their availability protects the rights of those who need support to make decisions.

'This Bill is an opportunity for the Government to commit resources and support to independent advocacy that have been absent from many previous initiatives, where independent advocates have received little more than kind words from Government.'

¹⁸⁶ Copyright of the Making Decisions Alliance, *Charity Campaigners welcome proposals for Living Wills*, 22 April 2004, http://www.makingdecisions.org.uk/news_release_04.htm

The Mental Capacity Bill will set out people's right to make their own decisions and there will be a presumption that people have the capacity to do so unless it is proved otherwise. The MDA believes this is vital for the millions of people who are currently, often wrongly, judged incapable of making decisions. It will also give those caring for these people more confidence in their rights to be consulted on the treatment and care that they receive.

Advocates help people to have a say in their own lives. Ideally they are independent, understand the abilities of the individual and are focused on that individual's needs.

The Bill is likely to only recognise the contribution of advocacy in limited cases, where people do not have any friends or family to help them make decisions.

The MDA is calling for advocacy to be made available in other circumstances in order to provide additional safeguards against abuse and exploitation when life-changing decisions need to be made - on topics such as invasive surgery, long-term treatment or where people live and to help resolve areas of dispute.

Richard Kramer said: 'Above all, advocacy can play a critical role in assisting people to make and communicate decisions and to help enforce their rights.'¹⁸⁷

C. Mind

The mental health charity, Mind, welcomed the draft bill saying that new laws on incapacity are desperately needed and urging the Government to bring the Bill before Parliament at the earliest opportunity:

Mind's Head of Policy Development Rowena Daw said: "The new Bill, if made into law, would give people with mental health problems who are sometimes in crisis and unable to make decisions for themselves the security of knowing that someone of their choosing will look after their health and welfare."¹⁸⁸

On its website, Mind also states that it is working with the Making Decisions Alliance to make the Bill as effective as possible by ensuring:

- Effective, clear and well-resourced professional training and public information about the bill's principles and provisions. It is important to raise expectations, and to maintain standards and principles of care among both carers and cared-for.

¹⁸⁷ Copyright of the making Decisions Alliance, *Charity alliance warns new Bill will be 'toothless' without advocates*,

18 June 2004, http://www.makingdecisions.org.uk/news_release_05.htm

¹⁸⁸ *Mind welcomes Mental Incapacity Bill*, 27 June 2003,

http://www.mind.org.uk/News+policy+and+campaigns/Press/PRincapacity.htm?wbc_purpose=Basic&WBCMODE=PresentationUnpublished

- Much greater provision for independent advocacy. This includes greater clarity about the role of advocacy, and to give independent support to people who also have family, friends and informal carers.
- Measures are put in place to ensure that people who lack capacity have practical access to advocacy, legal advice and the Court of Protection.
- Greater safeguards against misuse of the Lasting Power of Attorney and for the protection of vulnerable adults.
- That advance decision-making about medical treatment is strengthened and developed.¹⁸⁹

D. Citizens Advice

The Citizens Advice service is a network of independent charities that helps people resolve their money, legal and other problems by providing information and advice and by influencing policymakers.¹⁹⁰

Citizens Advice welcomed the Bill:

Citizens Advice welcomes the publication of the new Mental Capacity Bill, which aims to offer greater rights to those with reduced mental ability.

However, Citizens Advice does have some concerns in relation to the Bill's scope for protecting mentally ill people as consumers.

Dan Vale, Head of Social Policy for Citizens Advice, said: "Sadly, it is the evidence of our bureau-based advisors that those with reduced mental capacity are all too often targeted by rogue traders looking to exploit them. We would like to see more scope for the Court of Protection to intervene in contracts against traders who see the mentally ill as an easy target for ethically dubious money-making schemes."¹⁹¹

E. The Royal College of Psychiatrists

The Royal College of Psychiatrists welcomed the Bill but pointed to a number of areas of concern:

The Mental Capacity Bill is an important piece of legislation which will enhance the rights of people who lack capacity, clarify the roles of their carers and the professionals who work with them, and enable people to determine aspects of their future health and social care.

¹⁸⁹ <http://www.mind.org.uk/News+policy+and+campaigns/Policy/Making+Decisions+Alliance.htm>

¹⁹⁰ http://www.citizensadvice.org.uk/index/pressoffice/press_index/press-040618.htm

¹⁹¹ Citizens Advice, *Citizens Advice welcomes Mental Capacity Bill*, 18 June 2004, http://www.citizensadvice.org.uk/index/pressoffice/press_index/press-040618.htm

(...)

There are a number of key areas of concern to psychiatry which the College will be looking at in more detail. These include:

- under what circumstances should people who are deemed to lack capacity be entitled to an advocate?
- when should people who are unable to consent to medical treatment be entitled to an independent ‘second opinion’ before the treatment is given?
- ensuring advanced decisions to refuse treatment are clear and reflect the individual’s real wish.
- the scope of the newly created Lasting Power of Attorney (this will make it possible to nominate ‘donees’ to make health, welfare or financial decisions on behalf of the ‘donor’ once he/she is incapacitated).¹⁹²

F. The Royal College of Physicians

The Royal College of Physicians welcomed the Bill:

We believe it provides sensible protections for the interests of vulnerable patients. We also believe it provides additional clarification on what may or may not be done when acting on behalf of people lacking mental capacity.

However it also pointed to various issues and areas of concern including:

In relation to defining mental incapacity:

Hitherto, defining someone as lacking mental capacity has been a medico-legal decision. As the Bill requires this assessment to be made in the context of every decision that must be taken, lay people will be expected to form judgments as to whether the person has the capacity to make a particular decision.

(...)

The Royal College of Physicians has some concerns on the ability of lay people to assess mental capacity on a decision-by-decision basis, even if the onus on them is only to act in good faith.

On observing that many critics of the Bill, such as pro-life groups, would like advance decisions refusing treatment to be advisory, that is to give the doctor discretion to ignore them:

¹⁹² The Royal College of Psychiatrists, *Mental Capacity Bill welcomed*, 18 June 2004, http://www.rcpsych.ac.uk/press/preleases/pr/pr_582.htm

If the patient has been able to precisely predict the circumstances that they are in, then they will be binding. However, this is unlikely and so the doctor will need to interpret the wishes of the patient, with the advice of the patient's relatives. Thus in most circumstances they will not be binding. They will also not be binding if the doctor is in any doubt about the intentions of the patient, whether the patient was competent at the time of writing the directive or its validity. Thus suicide notes will not be binding.

Currently advance decisions can be verbal, but there are concerns about their validity. Thus it may be that in order to be valid they must be written, witnessed and registered. This will be more restrictive e.g. if people are not literate and may be more difficult to revoke. However, [they] will be less open to abuse by relatives not acting in the best interests.

In order to be more certain about the validity of the advanced decision, it is likely that they will need to be registered. The electronic patient record will be an obvious place to do this in due course. In the meantime there is discussion about the best means to ensure that it is as simple as possible for doctors to record and check advance decisions. There are also concerns about the workload for doctors, especially GPs, if lots of patients want advice on drawing up advance decisions.

In relation to research:

The Mental Capacity Bill has 'best interests' of the person with mental incapacity at its core. However, the 'best interests' test is not used within the provisions on research. It is impossible to guarantee that even well evaluated treatments will produce benefits and no risk, thus it is only feasible to consider risks in terms of balance of probability. There is likely to be even more uncertainty around anticipated benefits and risks in the research context.

The increased workload for doctors:

It is not clear whether the giving of advice when a patient is writing an advance decision is an expected part of the current role of doctors. This may depend on whether a patient is currently healthy or is asking for information about prognosis and treatment options in the future. Guidance is required on the legal standing of this advice.

The Royal College of Physicians is also concerned about additional obligations on doctors to check whether a patient has made an advance decision, and if they have to check that it is valid. This responsibility may be particularly difficult to discharge in emergency situations when rapid decisions must be made.¹⁹³

¹⁹³ Royal College of Physicians, *Mental Capacity Bill*, July 2004, http://www.rcplondon.ac.uk/college/statements/response_mcb.htm

G. The Catholic Bishops' Conference of England and Wales

The Catholic Bishops' Conference of England and Wales (CBCEW) welcomed the inclusion of Clause 58 in the Bill (the declaratory provision relating to murder, manslaughter and assisting suicide) but considered that there were still a number of weaknesses in the Bill:

We had argued that the inclusion of a clause such as Clause 58 was the minimum required to provide the necessary assurance that nothing in the Bill permits euthanasia. With such a clause now in the Mental Capacity Bill, together with other important changes made to meet our concerns, we do not believe that the Bill can be described correctly as a Bill introducing a permission for euthanasia, which would have to be opposed for this reason.

That is not to say, however, that the Bill is now adequate as it stands. In fact there are a number of important weaknesses in the Bill which we believe still must be addressed. Indeed, our position paper pointed out that adding a declaratory clause preserving the law against euthanasia and suicide, though the essential minimum, would not by itself be a sufficient safeguard against euthanasia and suicide by omission, because it would not remedy an existing serious deficiency in the law about hastening death by omission which has been in disarray since the decision of the highest court in the Bland case in 1993.¹⁹⁴

The CBCEW considered that two important amendments were needed:

In line with the general motivation of cl. 58, our [first] amendment will make it clear that, just as doctors should not do anything to patients in order to bring about their death, so too those whom the Bill authorises to make decisions which can then bind doctors must not make those decisions in order to bring about the patient's death. Decisions made with that improper purpose will not be made criminal or tortious by the amendment, but will simply be deprived of their statutory effect, leaving doctors free to give or withhold treatment according to their professional judgment of the patient's best interests. We believe the Government should welcome this amendment, which is entirely in line with its oft stated intention not to change the law, and not to introduce euthanasia or assisted suicide.

13. The second amendment would ensure that the patient's interest in life and health is taken into account in determining their "best interests". Taken together, these amendments would lay to rest many reasonable fears about the Bill's impact.¹⁹⁵

¹⁹⁴ *Airedale NHS Trust v Bland* [1993] 1 All ER 821

¹⁹⁵ Archbishop Peter Smith and Professor John Finnis, *Briefing note on the Mental Capacity Bill*, July 2004, <http://www.catholic-ew.org.uk/cbc/respcit/dmicb/040719briefing.doc>

H. The Society for the Protection of Unborn Children (SPUC)

SPUC has described the Government's *Mental Capacity Bill* as "the legalisation of intentional killing":

John Smeaton, SPUC's national director, said: "The bill will fulfil one of euthanasia movement's key goals – legalised denial of food and fluids from vulnerable patients, in order to create demand for supposedly more humane deaths by lethal injection. The Mental Capacity Bill will undoubtedly legalise voluntary and non-voluntary euthanasia by neglect. Euthanasia by neglect means deliberately killing patients. It is not the same as allowing a dying person to die peacefully. That is already entirely legal.

Mr Smeaton was responding to the Bill's introduction into Parliament last Thursday.

Mr Smeaton continued: "Patients with dementia, stroke, brain injury and similar conditions would be most at risk. The bill would allow for them to be killed by withholding their basic medical care, or even food and fluids. The law would apply to people who could not communicate and would apply to them whether or not they had requested it. It will mean telling doctors to end their patients' lives.

"The bill would not only enshrine in statute law the 1993 Bland judgement, when the judges admitted they were involved in intentional killing through the removal of assisted food and fluids, but would greatly extend the provisions of the Bland judgement to cover potentially any mentally incapacitated patient.

"Also, the bill would make 'advance decisions', commonly called 'living wills', legally enforceable, including those with a suicidal intent. It must not be forgotten that 'living wills' were invented and are heavily promoted by the euthanasia movement. The international euthanasia movement has declared that the legalisation of euthanasia by neglect is a key step in its campaign to legalise euthanasia by lethal injection.

"The bill's "anti-euthanasia" clause is purely cosmetic, because the sections of the bill which allow euthanasia by neglect into statute law will not be affected by this. The clause is aimed at deceiving people about the Bill's real purpose – to allow intentional killing by omission of basic care and reasonable medical treatment.

"The revised Bill features new sections which would allow the government to appoint "independent consultees" who would have power to tell NHS doctors not to give life-saving treatment to huge numbers of mentally incapacitated patients.

“Any MP who is genuinely opposed to euthanasia must in conscience vote against the Bill at 2nd reading”, Mr Smeaton concluded.¹⁹⁶

I. The Linacre Centre

The Linacre Centre states that it “exists to help Catholics, and others, explore and understand the Church's position on bioethical issues. Its perspective is informed by Catholic moral teaching; however, in defending such teaching it seeks also to appeal to non-religious, philosophical reasoning to enable dialogue with those of no religious faith. Under the trusteeship of the Catholic Trust for England and Wales, The Linacre Centre is the only Catholic centre for bioethics in the UK and Ireland.”

In its briefing on the Bill the Linacre Centre pointed out those areas which it considered would threaten the lives and welfare of vulnerable groups:

We wish to protest those aspects of the Mental Capacity Bill (MCB) which threaten – if unintentionally - the lives and welfare of vulnerable groups in our society.

Particularly under threat are those who, at some stage in their lives, have expressed the view that life is not worth living if one is seriously disabled. In a society where negative views of disabled people's lives are very common, many able-bodied people, and some disabled people themselves, will hold such a view, and make advance refusals of treatment which are suicidally motivated. Instead of protecting such a person, the Bill may give his/her suicidal feelings lasting effect.

On the face of it, the Bill does not permit doctors and nurses to save the lives of those who were suicidally motivated, but had ‘capacity’, in making an advance decision. Those who save the lives of such suicidal patients may be liable to criminal proceedings, if the patient was mentally competent in refusing treatment. In contrast, carers are apparently free to withhold life-saving treatment even with the aim of causing death.

(...)

There is nothing in the Bill which explicitly prevents intentional homicide by omission, which the Bland judgement has already legalised in the case of PVS patients. While we note Clause 58 to the effect that nothing in the Bill will change the law on homicide or assisted suicide, it should be remembered that the law in these areas has already been seriously weakened by Bland and other judgements. The Bill does not say that homicidally-motivated denials of life-saving treatment by doctors or proxy decision-makers will be invalid. Nor does it

¹⁹⁶ *Mental Capacity Bill legalises intentional killing, says SPUC*, 21 June 2004, <http://www.spuc.org.uk/releases/20040621.htm>

exclude suicidally-motivated advance decisions from those which are given legal force.

Even patients who have never wished to end their own lives will be at risk. The Bill does not acknowledge that doctors or proxies may have a homicidal motive in denying treatment to a patient. In the case of proxies, there are other dangers in allowing those with no medical qualifications to veto treatment which a doctor sees as medically required. Some vetoes will be aimed at causing death, while others will be, at very least, harmful to the patient, even if well-intentioned. The onus will be on the doctor to take such cases to court: a burdensome option many doctors (and NHS Trusts) will not wish to pursue. Moreover, the court may simply confirm the proxy's decision – particularly if the proxy claims, sincerely or otherwise, that the patient 'would not have wanted' to be treated or tube-fed.

Some proxies – attorneys - will be nominated by the patient; however, such proxies will have no medical expertise, will not be controlled by a professional body such as the GMC, and may easily have a conflict of interest – for example, a wish to be relieved of the patient's care. Other proxies – deputies - will be appointed by a court: the question then arises why a non-medical decision-maker the patient has not chosen should be able to override a doctor's judgement on what treatment he or she needs.

Competent patients have rights in existing law to refuse treatment in advance. We have no problem with respecting advance refusals of treatment which are well-informed (i.e., where the relevant medical facts have been explained by health professionals) and which are not suicidally motivated. However, this will not apply to many advance decisions, and busy doctors may not be willing or able to establish if an advance decision is suicidal, ill-informed, written under duress, has been formally revoked, or if the patient's views have changed. Such doctors may nonetheless comply with the advance decision, as this will be the easier option. (Note that there is nothing in the Bill itself to prevent an advance decision from being both presented, and supposedly witnessed, by someone who will benefit financially from the patient's death.)

In any case, we believe that no advance refusal should be binding in regard to basic care - including the provision of pain relief, hygienic care and feeding, whether orally or by tube. Patients should be given a minimal level of appropriate care, both for their own sake and for the sake of protecting an ethic of care among doctors and nurses. Since 'treatment' in the Bill includes tube-feeding, the Bill will create a legal and social climate where withholding food and fluids, even where these are not burdensome, is seen as beneficial to patients precisely in ending their lives. The support of the Voluntary Euthanasia Society for the Bill is therefore understandable.

The MCB is deeply flawed in its approach to best interests, which are described solely in terms of the patient's actual or hypothetical desires. The Bill nowhere refers to life and health in listing the best interests of the patient. By focusing solely on subjective criteria for determining best interests, the MCB encourages the view that it is in some patients' interests to die, because this is 'what they

wanted.’ Such a view goes against the whole practice of suicide prevention, and support for those who see their lives as worthless at some particular time.

Finally, the MCB permits invasive, non-therapeutic experiments on mentally incapacitated people, if the risks are ‘likely to be negligible’. This is dangerous, in view of the attitudes of some in the medical profession to such patients. It is one thing to do research which is intended to benefit the patient, as well as increasing human knowledge; it is something quite different to carry out invasive procedures which are solely for the benefit of others. We should not create structures which will, or may, allow mentally disabled people to be abused.¹⁹⁷

J. The Prolife Party

The Prolife party states that it is “Europe's first Pro-Life Political Party. We seek to ensure the right to life of all, the most basic and fundamental human right.”¹⁹⁸

It expressed its view that some of the Bill is useful and necessary but that other aspects are dangerous:

The government has recognised many people's concern that it will lead to widespread euthanasia and have added what are intended to be reassuring words. These are mostly mere verbiage. The government says that euthanasia is and will remain illegal, but this bill redefines euthanasia to mean only active killing, not so-called passive killing by dehydrating or starving to death, which is morally, and used to be legally, the same.

(...)

The Bland judgement established euthanasia. It should be overturned by statute, not institutionalised by this bill. The bill still includes "advance decisions" or "living wills" by which doctors could be forced to be complicit in the suicidal intention of a patient. These are also dangerous because it is common for people to feel they would not wish to go on living in certain circumstances, but to change their minds when the circumstances actually happen to them.

As drafted it would prevent a doctor from saving an suicidal young person, unconscious from an overdose, who had felt unhappy enough to comply with any conditions about "in writing" and "witnessed" etc. IT IS NOT POSSIBLE TO DRAFT A CLAUSE SO THAT IT EXCLUDES THIS CASE without saying blatantly that the government wants to kill the disabled, old and ill but not the young, healthy and temporarily unhappy.

¹⁹⁷ The Linacre Centre, *Briefing on the Mental Capacity Bill*, August 2004, <http://www.linacre.org/frames.html>

¹⁹⁸ <http://www.prolife.org.uk/about.htm>

The bill still does not state that it can never be in a patient's "best interests" deliberately to kill him or her, and in fact implies the opposite. The lasting powers of attorney should never give a non-medically-qualified person the right to refuse treatment for a patient: the dangers are obvious. Doctors are already entitled to consider whether treatment would be too burdensome to be worthwhile for the patient.

The bill allows a mentally incapable patient to be the subject of experimentation not in that patient's own interest. The latest version of the bill does say "non-intrusive" and this has been said informally to rule out for example taking a blood sample. There are stringent sounding safeguards, including an automatic opting out if the patient appears to dislike it, or if any carer or relation objects, but can we trust experimenters to observe these? I think not. There needs to be some adequate check to prevent abuses. Without it, the temptation to experimenters who think they are near a cure would be irresistible. This applies to the whole bill.

THERE SHOULD BE SOMEONE WHOSE JOB IT IS TO BE SUSPICIOUS, AND MAKE RANDOM INVESTIGATIONS AS WELL AS FOLLOWING UP ANY SUGGESTIONS OF MALPRACTICE OR ABUSE. Without this, the bill is an invitation to abuse.¹⁹⁹

¹⁹⁹ Prolife, *The Prolife Party's Comment on the Mental Incapacity Bill*,
<http://www.prolife.org.uk/document.asp?id=mibcomment04.htm&se=3&st=4>