

Psychiatric advance decisions – an opportunity missed

Dr Tim Exworthy*

After a very long gestation the *Mental Capacity Bill*¹ (the *Bill*) was published earlier this year. Among its proposals was the incorporation into statute of advance decisions. These are devices whereby a person, while retaining capacity, can make certain decisions regarding their future treatment for such a time as they have lost capacity and so are unable to make legally binding decisions about their own treatment. As the *Bill* is phrased, advance decisions (ADs) only permit a person to refuse treatment. There is no provision for that person to use ADs to express a positive preference for particular forms of treatment. It will be argued this represents a missed opportunity to allow patients and clinicians to engage in a more constructive approach to treatment planning. Experience from the USA demonstrates psychiatric advance directives (PADs) have a role to play in engaging psychiatric patients and promoting adherence to their treatment plans.

This paper will only address the use of AD in relation to mental health treatment, although it is recognised they have an application far wider than this, including decisions regarding life-sustaining treatment.

Background to the Mental Capacity Bill

The process of delivering a statute codifying the law relating to the assessment and treatment of people lacking capacity dates back to 1989, when the Law Commission embarked on ‘an investigation into the adequacy of the legal and other procedures for the making of decisions on behalf of mentally incapacitated adults’². This programme had been initiated following a Law Society discussion document³ and then the judgment in *Re F*,⁴ which highlighted the lacuna in English law that ‘no procedure [exists] whereby any other person or court can take a medical decision on behalf of an adult patient without capacity to take that decision’.⁵

* Consultant Forensic Psychiatrist who has worked both at Broadmoor (high secure) Hospital and, currently in a medium secure psychiatric unit. He has published in the areas of psychiatric assessment schemes in magistrates courts, forensic psychiatric service provision and mental health legislation.

1 Department of Constitutional Affairs (2004) *Mental Capacity Bill*. Bill 120. London: The Stationery Office.

2 Law Commission (1989) *Fourth Programme of Law*

Reform: Mentally incapacitated adults. Law Com No 185 Cm 800; as summarised in Law Commission (1995) *Mental Incapacity*. Law Com No 231; at para 1.1.

3 Law Society’s Mental Health sub-Committee (1989) *Decision Making and Mental Incapacity: A discussion document*. London: Law Society.

4 *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.

5 Law Commission. (1995) *Mental Incapacity*. Law Com No 231; at para 1.4.

In the interim there have also been two significant cases focussing on the question of refusal of treatment for physical conditions. *Re T*⁶ involved a young woman, Miss T, who was 34 weeks pregnant when she was involved in a car accident. She was admitted to hospital and some time later went into labour, which led to an emergency Caesarian section. Thereafter, Miss T's condition deteriorated and she was admitted to the intensive care unit. The consultant anaesthetist would normally have given Miss T a blood transfusion but, on this occasion, was reluctant to do so because Miss T had twice told clinical staff she did not want a blood transfusion. Both instances had occurred shortly after Miss T had had a private conversation with her mother, who was a Jehovah's Witness. Although Miss T had been brought up by her mother after her parents separated, she was not an adherent to that faith and it was contended Miss T had made her pronouncements under the influence of her mother. Miss T's father applied to the court for a declaration as to whether it would be lawful to give her the blood transfusion that was thought necessary to save her life.

The court of first instance authorised the blood transfusion and held Miss T had neither consented nor refused the transfusion in the emergency that had arisen. To proceed with the transfusion was seen to be acting in her best interests. The case went to the Court of Appeal after Miss T appealed but the importance of providing '*guidance to hospital authorities and to the medical profession on the appropriate response to a refusal by an adult to accept treatment*'⁷ was also recognised.

In his leading judgment, Lord Donaldson, MR, held that

*'Prima facie every adult has the right and capacity to decide whether or not he will accept medical treatment, even if a refusal may risk permanent injury to his health or even lead to premature death. Furthermore, it matters not whether the reasons for the refusal were rational or irrational, unknown or even non-existent. However, the presumption of capacity to decide, which stems from the fact that the patient is an adult, is rebuttable.'*⁸

He also emphasised that '*an adult patient who ... suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered*'.⁹ *Re T* was concerned with refusal of the medical treatment proposed but this did not exclude the possibility of any patient giving consent to the future administration of treatment in particular circumstances.

The case of *Re C*¹⁰ involved a man suffering from chronic paranoid schizophrenia who developed gangrene in his right foot. His surgeon advised amputation of the lower leg as he considered death was imminent without such radical surgery. C refused to consent to such a procedure but did agree to more conservative treatment. Faced with the possibility of a recurrence of the gangrene, C sought an undertaking, in vain, that the hospital would not amputate his leg in any future circumstances. C then approached the High Court seeking an injunction to prevent the hospital operating at that time or in the future without his consent. Judgment from Thorpe, J. confirmed a capacitous patient's entitlement not only to refuse the proposed treatment but also his right to have such a refusal respected in the future even if he should become incapacitated in the meantime.

6 *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649.

7 *Ibid*, per Lord Donaldson, MR, at 660.

8 *Ibid*, at 664. See also *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] 1 All ER 643,

per Lord Templeman at 666.

9 *Ibid*, at 652–3.

10 *Re C (Refusal of medical treatment)* [1994] 1 All ER 819.

The Law Commission's final report¹¹ in 1995 considered '*Advance Statements about Health care*'¹² and distinguished between '*an advance expression of views and preferences and an advance decision..*'.¹³ It pointed out many model advance directives take the form of anticipatory consent to types of treatment in relation to physical conditions.¹⁴ Indeed, surgery under general anaesthesia, except in an emergency situation, requires an anticipatory decision to consent to the proposed procedure.¹⁵ The Law Commission also made the point that case law in this area will focus on advance decisions to refuse particular forms of treatment, since if the person has already consented, prior to losing capacity, to the type of treatment the treating physician later wishes to administer, there will be no dispute and the treatment will be given. However, this presupposes there is no conflict between the treatment specified by the patient and the treatment considered appropriate by the physician. For example, both patient and psychiatrist may agree on the desirability of restarting antipsychotic medication but while the former is only willing to consider oral medication the latter may believe the long acting preparations given by depot injections are necessary.

Advance consent is considered in three paragraphs with the remaining 25 being concerned with advance refusals of treatment. The Commission's Report does argue that '*to maintain the effect of the present law (by incorporating the judgments of Re C and Re T into statute) is consistent with our policy aim of enabling people to make such decisions as they are able to make for themselves*'.¹⁶ This appears to sidestep the issue of advance consent although does not exclude it. Patients with capacity are able to make decisions to give consent as well as to refuse treatment options. The common law, however, would recognise the latter but not the former as an advance decision.

Advance Statements in England and Wales

The General Medical Council (GMC) acknowledges capacitous adult patients '*can express their wishes about future treatment in an advance statement*' but notes only a valid advance refusal of treatment is legally binding.¹⁷ It makes no distinction between treatment for physical and mental disorders.

The British Medical Association (BMA) has drawn up a Code of Practice on advance statements.¹⁸ It recognises that accommodating a patient's views, values and attitudes about his treatment is both fundamental to good practice but also a curb on clinical decision-making. Advance statements can take many forms, varying from a general description of a person's preferences and belief systems to a clear instruction not to provide certain treatments (advance directive). However, any advance statement is limited by existing statute and so could be overridden by the provisions permitting

11 *Ibid.* This report had been preceded by four consultation papers published in 1989 (1) and 1993 (3).

12 *Op cit* Note 5. Law Commission 1995, Part V.

13 *Ibid*; at para 5.1. This is later expanded on (at para 5.10) and the difference between 'anticipatory decisions' and mere statements of wishes made in advance of the person's loss of capacity is emphasised.

14 *Ibid*; at para 5.11.

15 Francis, R. and Johnston, C. *Medical Treatment: Decisions and the Law.* (2001). Butterworths: London; at p22.
Technically all consents or refusals are given in

advance of the proposed treatments, albeit the period between consent and providing the treatment is almost always very short. 'Treatment without consent or despite a refusal of consent will constitute the civil wrong of trespass to the person and may constitute a crime' – Lord Donaldson in Re T at 653.

16 *Op cit* Note 5; at para 5.16.

17 General Medical Council (2002) *Withholding and withdrawing life-prolonging treatments: Good practice in decision-making.* London: GMC.

18 British Medical Association (1995) *Advance Statements about medical treatment – Code of Practice.* London: BMA.

compulsory treatment for mental disorder under the Mental Health Act 1983. Such statements also cannot direct a clinician to act in a manner that is harmful, illegal, inappropriate to accepted clinical practice or contrary to their conscience.

In psychiatry, clinical guidelines for the treatment of schizophrenia, commissioned by the National Institute for Clinical Excellence (NICE), have advocated 'advance directives about the choice of medication' should be filed in patients' records.¹⁹ This would permit positive choices as well as refusal of particular medication to be documented. The report's actual recommendations withdraw from this absolute position, recognising 'there are limitations with advance directives regarding the choice of treatment for individuals with schizophrenia' but encouraging they are developed as part of the care programme.²⁰ The nature of those limitations is not spelt out in the report.

Judging by the published research there is little practical experience of the use of advance statements or directives in psychiatry. One group, at the Maudsley Hospital, London, encouraged the use of 'crisis cards' among known psychiatric patients.²¹ 'Crisis cards' record, among other details, a patient's current treatment and 'preferences in anticipation of a later occasion when the patient might be too ill to express them directly'. The cards were drawn up in discussion with the patient's clinical team so as to produce an agreed plan of action to manage the next crisis for the patient. 65% of patients stated certain treatment preferences and 53% made advance refusals of specific medication. At follow up one year later the rate of hospital admission for this group of patients had been reduced by 30% and the researchers also commented on the psychological benefits to the patients accruing from working collaboratively with the psychiatric services. However, another research team, also in London, found that patients who had completed an 'advance directive' did not have a lower readmission rate compared to patients without such a document.²² As Geller has pointed out, these were not 'directives' but rather 'preference statements' and this may account for the lack of a demonstrable reduction in readmission rates.²³ While more research is required to isolate the 'active ingredient(s)' in such documents, Geller's comments highlight a problem: the literature is replete with examples of loose terminology in this area. Advance statements may be decisions, or directives or simply a record of certain preferences by the patient. As such they contain differing blends of collaboration, directive force and import.

The interpretation of ADs may also be problematic. In one study health professionals, presented with a hypothetical vignette concerning a patient with dementia, came to very different conclusions as to how to proceed.²⁴ Those who chose to override the AD seemed to be prepared to make subjective interpretations on quality of life issues when to uphold the AD was regarded as not being in the patient's best clinical interests. The authors cautioned that anyone completing

19 National Collaborating Centre for Mental Health (2003) *Schizophrenia: Full national clinical guidelines on core interventions in primary and secondary care*. London: Gaskell and the British Psychological Society. At para 7.10.3.

20 *Ibid*; at para 7.10.4.

21 Sutherby, K., Szmulker, G.I., Halpern, A. et al (1999) A study of 'crisis cards' in a community psychiatric service. *Acta Psychiatrica Scandinavica* 100, 56–61.

22 Papageorgiou, A., King, M., Janmohamed, A. et al

(2002) *Advance directives for patients compulsorily admitted to hospital with serious mental illness*. *British Journal of Psychiatry*, 181, 513–519.

23 Geller, G.L. (2003) *Advance directives about treatment preferences had little impact on compulsory readmissions for people with serious mental illness*. *Evidence-Based Mental Health*, 6, 88.

24 Thompson, T., Barbour, R. and Schwartz, L. (2003) *Adherence to advance directives in critical care decision making: vignette study*. *British Medical Journal*, 327, 1011–1014.

an AD cannot be assured of a particular outcome in a particular situation. Another commentator advised when an AD appeared to advocate a course of action that would be detrimental to the patient, its validity should be carefully scrutinised to ensure it was applicable to the situation under discussion.²⁵

A patient has no enforceable right to demand a particular type of treatment. However, is advance consent for a particular drug a demand for that drug and no other; or is it consent to take that drug should it be prescribed by the doctor who has, in the exercise of professional judgment, decided it is the most appropriate treatment? In one respect at least, psychiatric patients have an advantage over other people drawing up advance statements with regard to, for example, end of life decisions. Having had a previous episode of illness they have their own experiences to draw on and these can inform their subsequent decisions as to what treatment strategies, including medication, were helpful and which were not. Intuitively, advance treatment plans are likely to be most successful if they have been constructed in a collaborative fashion, rather than either party taking up unrealistic or dogmatic positions.

Psychiatric Advance Directives in the USA

Szasz is credited with first proposing what he termed a '*psychiatric will*'²⁶ but psychiatric advance directives became more prominent with the passage of the *Patient Self-Determination Act* in 1991. This Act required hospitals receiving federal funding to inform all admitted patients of their right to formulate an advance directive. As elsewhere, in the United States of America advance directives can be divided into instructional directives, which record the person's decisions regarding treatment in anticipation of the time when they do not have the capacity to take such decisions, and proxy directives, which may also be combined with specific directions regarding treatment. These appoint another person who is empowered to take health care decisions whenever the individual is lacking capacity.

All American states now have advance directive statutes, covering healthcare generally, and 14 states have explicit laws addressing psychiatric advance directives.²⁷ An example is North Carolina's *Advance Instructions for Mental Health Treatment*.²⁸ The advance directive can be used to consent to or refuse specific psychiatric treatment.²⁹ Although the person can specify his options for mental health treatment these can be set aside if the instructions are not consistent with established standards of appropriate practice or with the availability of the treatment requested. This has raised concerns that non-clinical factors may determine whether an advance instruction is honoured or not.³⁰ In addition an individual can appoint a proxy decision-maker to act on his behalf when he is incapable of making a decision, through the Health Care Power of Attorney Act.

25 Treloar, AJ. (1999) *Advance Directives: Limitations upon their applicability in elderly care*. *International Journal of Geriatric Psychiatry*, 14, 1039–1043.

26 Szasz, T.S. (1982) *The psychiatric will: A new mechanism for protecting persons against 'psychosis' and psychiatry*. *American Psychologist*, 37, 762–770. See also: Appelbaum, P.S. (1991) *Advance directives for mental health treatment*. *Hospital and Community Psychiatry*, 42, 983–4.

27 Bazelon Center for Mental Health Law. *Analysis of state laws*. In: *Power in Planning: Self-determination through psychiatric advance directives*.

www.bazelon.org/issues/advancedirectives/publications/powerinplanning/index.htm Accessed 4 June 2004.

28 North Carolina General Statute. Chapter 122C-71, et seq. This was modelled on Oregon's statute and was later amended by the passage of the Health Care Power of Attorney Act (1998).

29 Overview of PADs in the US at present. Accessed on 1 June 2004 from: <http://pad.duhs.duke.edu/background.html>

30 Op cit Note 27.

The appointee is obligated to act in accordance with the individual's previously stated decisions.

In Washington D.C. the *Health Care Decisions Act* of 1988³¹ made provision for a person's treatment preferences to be included in a durable power of attorney for health care, which would be followed by the appointee or any other substitute decision-maker. In 2001 the *Mental Health Consumers' Rights Protection Act*³² emphasised the importance of a psychiatric advance directive. Medication could only be administered with the consent of the patient. If incapacitated then the patient's proxy decision-maker was bound by the treatment decisions contained within the patient's advance directive or durable power of attorney.

Psychiatric advance directives are regarded as potentially powerful, non-coercive instruments that make the clients the 'active agents' and so enhance their 'sense of autonomy, control and dignity'.³³ By engaging the person in the process of deliberating on their illness history and the factors, including medication, that had been effective during previous psychiatric episodes it is believed advance directives could improve the therapeutic alliance between clinicians and patient and may improve the person's treatment adherence³⁴ with its consequent benefits in terms of quality of life and reduced need for hospitalisation. Through such a process a PAD could be beneficial even if the person does not lose their capacity for decision-making and the document is never formally enacted. Perhaps not surprisingly, patients have been more enthusiastic about PADs than clinicians, who tend to have concerns over their clinical autonomy and legal liability in following or not following the person's advance instructions.³⁵

There is also a perceived risk that PADs could increase the use of commitment orders permitting psychiatrists to bypass the patients' advance instructions³⁶ or, alternatively, if drafted with too many caveats may be frequently ignored and leave patients feeling further marginalized in their own treatment decisions.³⁷ However, used sensitively, they have been advocated as 'a means of reconciling (patient) autonomy and the initiation of non-consensual treatment at an early stage of relapse', which could avert the need for rehospitalisation and, in the future, the need for more coercive community treatment orders.³⁸

31 D.C. Code Ann. ss21-2201 et seq. 1998.

32 Title II, section 101, et seq.

33 Swanson, J.W., Tepper, M.C., Backlar, P. and Swartz, M.S. (2000) Psychiatric Advance Directives: An alternative to coercive treatment? *Psychiatry*, **63**, 160-172.

34 American research has demonstrated active engagement with the patient during decision-making enhances treatment compliance even when the outcome is contrary to the patient's original wishes. See Monahan et al (1996) Coercion to in-patient treatment: initial results and implications for assertive treatment in the community. In: *Coercion and aggressive community treatment: A new frontier in mental health law*. Editors

D. Dennis and J. Monahan. Kluwer Academic Publishers.

35 Swanson, J.W., Swartz, M.S., Hannon, M.J. et al (2003) Psychiatric Advance Directives: A survey of persons with schizophrenia, family members, and treatment providers. *International Journal of Forensic Mental Health*, **2**, 73-86.

36 Ibid.

37 Op cit Note 33.

38 Halpern, A. and Szmukler, G. (1997) Psychiatric advance directives: reconciling autonomy and non-consensual treatment. *Psychiatric Bulletin*, **21**, 323-327.

The Mental Capacity Bill for England and Wales³⁹

The *Mental Capacity Bill*⁴⁰ (the *Bill*) was presented to Parliament in June 2004. A *draft Mental Incapacity Bill*⁴¹, published the previous year, had been subjected to pre-legislative scrutiny by a Joint Committee from the two Houses of Parliament.⁴² A number of recommendations were made and responded to by the Government.⁴³

The *Bill* applies to people over the age of 16 years, who lack decision-making capacity. It is not concerned with the compulsory detention or treatment of patients suffering from mental disorder⁴⁴ but its provisions will replace Part VII Mental Health Act (MHA),⁴⁵ as well as the Enduring Powers of Attorney Act 1985.⁴⁶ The *Bill*'s purpose is 'to clarify a number of legal uncertainties and reform and update the current law where decisions need to be made on behalf of others. The *Bill* covers a wide range of decisions, on personal welfare as well as financial matters and substitute decision-making and clarifies the position where no such formal process has been adopted.'⁴⁷

The Expert Committee reviewing reform of the MHA⁴⁸ placed importance, in its General Principles, on 'respect for patient autonomy [which] implies respect for the treatment choices of those who have the capacity necessary to make them. Patient autonomy therefore brings with it an inevitable emphasis on capacity'.⁴⁹ The *Mental Capacity Bill* includes, as its first principle, a presumption in favour of capacity; adding that a person cannot be said to lack capacity for a particular decision 'unless all practicable steps to help him' have been tried or, conversely, simply because he makes 'an unwise decision'.⁵⁰

Clause 2 of the *Bill* defines a person lacking capacity as one who is unable to make a decision 'because of an impairment of, or a disturbance [whether permanent or temporary] in the functioning of, the mind or brain'.⁵¹ It is a functional test which is both specific in time and to the type of decision to be made. Clause 3 then defines the four bases on which a person may be unable to make a decision: being unable to understand, retain or use the relevant information in making a decision, or unable to communicate the decision using any means. The test thus codifies the threshold of capacity articulated in *Re C*.⁵²

39 Scotland passed its *Adults with Incapacity (Scotland) Act* in 2000. This statute does not provide for advance directives although proxy decision-making does permit cognisance to be taken of the patient's past and present wishes.

40 *Op cit* Note 1.

41 Department of Constitutional Affairs (2003) *Draft Mental Incapacity Bill*. Cm 5859. London: The Stationery Office.

42 House of Lords, House of Commons Joint Committee on the Draft Mental Incapacity Bill (2003) *Draft Mental Incapacity Bill*. Session 2002–03. Volume I. HL Paper 189-1, HC 1083-1. London: The Stationery Office. Accessed on 20 January 2004, at: www.parliament.uk/parliamentary_committees/jcmib.cfm

43 The Government Response to The Scrutiny Committee's Report on the draft Mental Incapacity Bill. February

2004. Accessed from the Department of Constitutional Affairs website on 20 April 2004.

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

44 *Op cit* Note 1; Explanatory Notes para 86.

45 *Dealing with the 'Management of Property and Affairs of Patients'*.

46 *Op cit* Note 1; Explanatory Notes para 5.

47 *Op cit* Note 1; Explanatory Notes para 4.

48 Expert Committee (1999) *Review of the Mental Health Act 1983* (Chair: Professor G. Richardson). London: Department of Health.

49 *Ibid*; at para 2.4.

50 *Op cit* Note 1; Clause 1.

51 *Op cit* Note 1; Clause 2(1).

52 *Op cit* Note 10.

Outline of the new Statutory Scheme for Decision-Making

The concept of 'best interests' provides the overriding consideration for decisions taken on behalf of incapacitated people and it appears throughout the proposed statutory scheme. Even for people lacking capacity the *Bill* encourages their participation 'as fully as possible in any act done for him and any decision affecting him'.⁵³ Best interests is broader than just focussed on medical interests but includes the person's 'past and present wishes and feelings ... and the other factors ... he would be likely to consider if he were able to do so'. Additionally, views on the same issues should be sought, if 'practicable and appropriate' from any person nominated by the person, any carer or those 'interested in his welfare', donee of a lasting power of attorney and any court appointed deputy (see below).⁵⁴ However, none of the views is binding but need only be 'take(n) into account'.⁵⁵ Indeed, it may not be appropriate to involve a donee or deputy if their role is related to decision-making in a different sphere of the person's life.

(i) Acts in connection with care or treatment

This provision provides 'statutory protection against liability for certain acts done in connection with the care and treatment of another person'.⁵⁶ Previously the power of 'General Authority' in the draft *Mental Incapacity Bill*,⁵⁷ this provision relates to everyday decisions taken by a carer on behalf of an incapacitated person but hitherto on an informal, and potentially unlawful, basis. It aims 'to clarify aspects of the common law principle of necessity as it applies to key actions done for people who lack capacity'.⁵⁸ Its informality persists as the power will be assumed by, rather than given to, the provider of care. Its assumption is based on a reasonableness test: that the carer 'reasonably believes' the person lacks capacity and the act is in the person's best interests'.⁵⁹ It will exist for the duration of the task under consideration. The Joint Committee recommended recognition of a concept of 'general incapacity' for people with on-going incapacity, which would avoid the necessity of a series of repeated decision specific assessments of capacity.⁶⁰ This was not accepted in the Government's Response and has also failed to appear in the *Bill*. The *Bill* places certain limitations on the exercise of this provision⁶¹ but as the Government's Response made clear it is not expected to be limited entirely to everyday, routine matters.⁶²

(ii) Lasting Power of Attorney

A capacitous person (donor) may elect to confer on another person (donee) the authority to make decisions in the spheres of personal welfare and/or property and affairs when the donor no longer has capacity⁶³ (otherwise known as lasting power of attorney: LPA).⁶⁴ The authority has to be conferred via an instrument, which may contain conditions or restrictions, and is subject to the overriding principle of being in the donor's best interests.⁶⁵ In the sphere of personal welfare, the scope of LPA extends to health care decisions, namely, the 'giving or refusing consent to the carrying

53 *Op cit* Note 1, Clause 4(4).

54 *Op cit* Note 1, Clause 4(6).

55 *Ibid.*

56 *Op cit* Note 1, Explanatory Notes para 30.

57 *Op cit* Note 41; Clause 6.

58 *Op cit* Note 1; Explanatory Notes; at para 30.

59 *Op cit* Note 1; Clause 5(1).

60 *Op cit* Note 42; at para 68.

61 *Op cit* Note 1; Clause 6.

62 *Op cit* Note 43; Response to Recommendation 36.

63 *Op cit* Note 1; clause 9(1).

64 Under existing provisions in the *Enduring Powers of Attorney Act 1985* (which would be repealed by the *Bill* on becoming law) the appointed donee has no authority to act for the donor in matters of healthcare.

65 *Op cit* Note 1; Clause 9(4).

out or continuation of a treatment'⁶⁶ but does not extend to giving or refusing consent to life-sustaining treatment unless the donor has expressly stated that is his intention before he loses capacity.⁶⁷ Depending on the degree of thoroughness and specificity in the instrument, the authority of LPA may be restricted to enacting previously made decisions on behalf of the incapacitated person or it may take the form of substituted decision making.

(iii) Court of Protection and its deputies.

The *Bill* will create a new Court of Protection⁶⁸ with extended jurisdiction '(1) to make substitute decisions about personal welfare or property and affairs for persons lacking capacity, or (2) to appoint a deputy to do so.'⁶⁹ The Court will also have the authority to make declarations.⁷⁰

In the realm of welfare matters the court appointed deputy will be permitted to decide on health care issues including 'giving or refusing consent to the carrying out or continuation of a treatment'.⁷¹ In the *draft Bill*, deputies also had the authority to give consent to the withdrawal of life-sustaining treatment. The Joint Committee 'strongly urged' the Government to exclude such a provision when the *Bill* was redrafted and reserve such decisions to the Court of Protection itself.⁷² The Government declined to take up this recommendation, believing it was not necessary to have 'a blanket exclusion of a power to refuse treatment'.⁷³ However, the *Bill* now requires the Court of Protection to give 'express authority' to the deputy to refuse consent for life sustaining treatment.⁷⁴

Advance Decisions in the Mental Capacity Bill

The Minister of State for the Government Department responsible for the *Bill*, the Department of Constitutional Affairs, has declared that '*advance decisions are just one aspect of a Bill that will empower vulnerable people to make as many decisions for themselves as possible*'; adding that '*positive requests for treatment will need to be taken account of when making a decision on behalf of a person lacking capacity*'.⁷⁵

Clause 23 of the *Bill* defines an '*advance decision*' as

- 'a decision made by a person, after he has reached 18 and when he has capacity to do so, that if –
- (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
 - (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.'⁷⁶

Thus the *Bill* permits anticipated decision making by the person concerned since it is made while the person retains capacity but only becomes operative after capacity has been lost and when the

66 *Op cit* Note 1; Clause 11(6).

67 *Op cit* Note 1; Clause 11(7)(a).

68 Described in Part 2 of the *Bill*: 'The Court of Protection and the Public Guardian'.

69 *Op cit* Note 1; Explanatory Notes, para 58.

70 *Op cit* Note 1; Clause 15. The Court may make declarations as to whether a person has capacity for a particular decision or whether 'an act or proposed act was or would be lawful'. In its exercise of the latter power the Court would function as a superior court of record with a

range of powers and authority similar to the High Court (see Explanatory Notes to the *Bill*, para 57).

71 *Op cit* Note 1; Clause 17(1)(d).

72 *Op cit* Note 42; para 184.

73 *Op cit* Note 43; Response to Recommendation 54.

74 *Op cit* Note 1; Clause 20(5).

75 Lord Filkin: Department of Constitutional Affairs Press Release 180/04, 22 April 2004.

76 Clause 24 (1).

treatment specified is being contemplated. While the person retains capacity the AD may be amended or withdrawn at any time.⁷⁷ The AD will become invalid if the person does ‘*anything else clearly inconsistent with the advance decision remaining his fixed decision*’.⁷⁸ It will also not apply if the proposed treatment is not included in the AD, the circumstances described are absent, or novel circumstances exist which the person did not foresee but had they been anticipated ‘*would have affected his decision*’.⁷⁹ The last point calls for an element of ‘*substituted judgment*’ on the part of the health professional, in deciding whether to make the AD inapplicable but the wording sets the higher threshold of ‘*would*’ rather than ‘*may have*’ affected the decision. An AD can also be overridden when the person subsequently makes a lasting power of attorney that specifically relates to the treatment detailed in the AD.⁸⁰ Furthermore the effect of an AD can be suspended pending a declaration by the Court of Protection as to whether or not it is applicable to the proposed treatment.⁸¹

Advance decisions ‘*give statutory confirmation to existing court rulings*⁸² that a treating doctor is obliged to respect a lawfully-made advance decision about a specified treatment’.⁸³ Many of the submissions to the Joint Committee scrutinising the *draft Bill* were concerned with the withdrawal of life-sustaining treatment and ADs. The Committee rejected the argument this would bring euthanasia a step closer; instead regarding an AD as ‘*appropriate continuation of respect for a patient’s individual autonomy*’.⁸⁴ Among the Committee’s recommendations the importance of having access to professional advice when preparing an advance decision was mentioned, as was the need for guidance in the Code of Practice as to what constituted a valid and applicable AD. The Government signalled its willingness to work with health professionals and patient groups in formulating the Codes of Practice⁸⁵ and ADs are specifically included in the Codes required of the Lord Chancellor by the *Bill*.⁸⁶

Advance Decisions and Mental Health Treatment

The *Bill* has an ‘*enabling*’ philosophy⁸⁷ and is constructed around the concept of capacity whereas the Mental Health Act 1983 is concerned with compulsion, which is not reliant on the lack of capacity. Views have been expressed that the next Mental Health Act should be based around capacity⁸⁸ or, indeed, that there would be little need for one if a Mental Incapacity Act was comprehensive.⁸⁹

77 Clause 24 (3).

78 Clause 25(2)(c).

79 Clause 25(4)(c).

80 Clause 25(2)(b).

81 Clause 26 (4). While the declaration is awaited, interventions to prevent the death of the person or to prevent a serious deterioration in the person’s condition are permitted.

82 *Op cit* Notes 6 (Re T) & 10 (re C).

83 *Op cit* Note 42; para 194.

84 *Op cit* Note 42; para 199.

85 *Op cit* Note 43; Response to Recommendation 61.

86 *Op cit* Note 1; Clause 40(1)(e).

87 *Op cit* Note 42; para 29.

88 *Op cit* Note 48: The Expert Committee reviewing the MHA put the principle of patient autonomy and the ‘*notion of capacity which flows from it*’ as one of its Guiding Principles. See also Szukler, G. and Holloway, F. (2000) Reform of the Mental Health Act: Reform or safety? *British Journal of Psychiatry*, 177, 196–200.

89 Oral evidence taken before the Joint Committee on the Draft Mental Incapacity Bill. Wednesday 8 October 2003. Response to Q298 (Dr Zigmund). The Bill is not seen as comprehensive enough to fulfil that function. For example, separate legislation would still be required for mentally disordered offenders but the suggestion of a Mental Disorder Offenders Bill would be seen by many in the profession as discriminating and highly stigmatising to many patients. In addition, many of the safeguards of the MHA are absent from the Mental Capacity Bill.

Under the provisions of the *Bill* it would be possible for treatment for mental disorder to be given under the authority of Clause 5⁹⁰ or within the scope of LPA⁹¹ and even in the face of resistance from the person concerned.⁹² These provisions would give a statutory footing to the provision of psychiatric treatment, which was both necessary and in their best interests, to *Bournewood* patients⁹³ who, by definition, would not be detained under the MHA. To the Joint Committee, the *Bournewood gap* represented the lack of statutory safeguards⁹⁴ for such patients. It highlighted the current paucity of safeguards in the *Bill* and clarification as to what measures might be incorporated to fill ‘*the gap*’ was called for.⁹⁵

Clause 28 specifically excludes the mechanisms in the *Bill* from being applied to treatment for mental disorder if that treatment is ‘*regulated by Part IV of the Mental Health Act*’.⁹⁶ The Government has clarified that when a person is subject to the relevant powers of the MHA then the provisions of the *Bill* will be inapplicable.⁹⁷ However, Clause 28 will still not apply to the majority of psychiatric patients receiving treatment, including voluntary patients in hospital, those detained under the MHA but not subject to Part IV MHA⁹⁸ and those in the community and not liable to be detained.⁹⁹ Nonetheless, this would mean that an otherwise valid and applicable advance decision would be overruled for detained patients for whom Part IV, MHA applies.

The position of advance decisions in the proposed reform of the Mental Health Act also requires consideration. The White Paper ‘*Reforming the Mental Health Act*’¹⁰⁰ made brief reference to what it termed ‘*advance agreements*’¹⁰¹. It noted patients may draw on their past experiences of treatment to state ‘*what sort of treatment he or she would prefer if the mental disorder deteriorates*’, adding that such a record would be an important source to consult in determining ‘*what care and treatment is in a patient’s best interests*’. Advance agreements, as their name suggests, should be drawn up in consultation with the clinical team, who would ‘*be expected to take account of any recent advance agreement developed in consultation with specialist mental health services*’¹⁰².

As set out in the White Paper advance agreements could state positive preferences for treatments. This would incorporate the express principle of patient autonomy espoused by the Expert Committee reviewing the Mental Health Act 1983.¹⁰³ The Expert Committee also suggested that ‘*advance directives be recognised as expressions of a patient’s capable wishes, and that they be allowed to*

90 *Op cit* Note 1; Clause 5: Acts in connection with care or treatment.

91 *Op cit* Note 1; Clause 11(6)(c).

92 *Op cit* Note 1; Clauses 11(1) to 11(5).

93 That is, compliant but incapacitated patients. From: *R v Bournewood Community and Mental Health NHS Trust, ex parte L* [1998] 3 All ER 289.

94 *Ibid*; at 308, per Lord Steyn. This was made in reference to the MHA 1983.

95 *Op cit* Note 42; at para 225.

96 *Op cit* note 1; Clause 28(1).

97 *Op cit* Note 43; Response to Recommendation 67.

98 As defined in section 56, MHA and comprising those patients detained under sections 4, 5(2), 5(4), 35, 135, 136 and conditionally discharged restricted patients.

99 In other words those receiving treatment as out-patients on a voluntary basis and not subject to section 17

MHA.

100 Department of Health and Home Office (2000) *Reforming the Mental Health Act. Part I: The new legal framework*. Cm 5016-I. London: The Stationery Office.

101 *Ibid*; paras 5.14–5.15.

102 A literal interpretation of this phrase would suggest the advance agreement need only be considered but not necessarily followed, even if the circumstances envisaged in the document correspond to those prevailing at the time; that ‘old’ agreements could be disregarded as could those produced unilaterally by the patient.

103 *Op cit* Note 48; at p22. The Committee themselves recommended that ‘advance agreements about care’ be introduced by statute and that they should ‘address the patient’s treatment preference (if any) in relation to any possible future care and treatment for mental disorder’ (at p106).

prevail in the same circumstances under the new act as those in which the wishes of the patient with capacity at the time would be allowed to prevail'.¹⁰⁴

By the time the *draft Mental Health Bill*¹⁰⁵ was published advance statements had been relegated to the Code of Practice¹⁰⁶ but they are still framed as positive statements allowing patients to identify 'what sort of treatment they would prefer if they become unwell' (emphasis added). However, as befits an advance statement as opposed to an advance directive, they need only 'be taken into account' during the formal assessment and should be recent as well as drafted 'in consultation' with the mental health professionals.¹⁰⁷ On the face of the *draft Mental Health Bill* negative phraseology is used. Clause 121 refers to circumstances when informal treatment is not available because

- '(a) the patient is not capable of consenting to the treatment, and
- (b) he either –
 - (i) would resist the treatment if given, or
 - (ii)
- (4) it is to be assumed that a patient who has at any time indicated that he does not want to receive treatment for mental disorder or particular treatment would resist such treatment.'

The Explanatory Notes to this *draft Bill* reinforces that the advance statement 'whether in writing or otherwise' would be couched in terms of withholding consent.¹⁰⁸ Moreover, the contents of an advance statement could be overridden 'in a case of urgency' or if the proposed treatment was included within the terms of a (mental health) order made under the provisions of Part II of the Bill.¹⁰⁹

In cases of informal treatment of patients not capable of consenting¹¹⁰ the role of the 'nominated person'¹¹¹ becomes an important safeguard. 'If it appears to the nominated person' that the patient would not have consented to the proposed treatment, had he been capable, then the nominated person 'must inform the clinical supervisor' who 'must then ensure' that the proposed treatment is not used 'except in a case of urgency'.¹¹² This could occur when the nominated person is aware of the patient's advance statement, which refers to the circumstances proposed.

Conclusion

This paper, although it describes the proposed decision-making scheme for proxy directives contained within the *Mental Capacity Bill*, is primarily concerned with instructional directives. The *Bill* is promoted as 'enabling' and 'empowering' but, by restricting the instructional directives to recognition only of a refusal to consent to treatment, it places a significant impediment on the expression of an individual's ability to have his choice respected after he has lost the capacity to make legally competent decisions. The *Bill* does permit positive preferences for treatment to be expressed. However, these have to be mediated through the proxy of a lasting power of attorney

104 *Op cit* Note 48; at p106.

105 Department of Health (2002) *Draft Mental Health Bill*. Cm 5538-I. London: The Stationery Office.

106 Department of Health (2002) *Mental Health Bill*. Consultation Document. Cm 5538-II. London: The Stationery Office. At p20.

107 *Ibid*.

108 *Ibid*; Explanatory Notes, at p45.

109 *Op cit* Note 105; clause 121(2).

110 *Op cit* Note 105; Part 5.

111 The successor person to the nearest relative from the 1983 Mental Health Act.

112 *Op cit* Note 105; clause 128(2).

rather than via a directive giving advance consent to a specified treatment.¹¹³

In *Re T* Butler-Sloss, LJ. quoted, with approval, from the Canadian case of *Malette v Shulman*:

*‘The right to determine what shall be done with one’s own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based. Free individual choice in matters affecting this right should, in my opinion, be accorded very high priority’.*¹¹⁴

In English law it is accepted that ‘an advance refusal made with capacity simply survives any supervening incapacity’.¹¹⁵ Equally, in surgery advance consents survive the incapacity of general anaesthesia. A surgeon can discuss the possibility of needing a more extensive operation than the one anticipated and the patient is asked to consent to that, as well as the planned operation, in advance and without knowing whether the ‘second’ consent will be acted upon after he has lost (temporarily) capacity.

Advance decisions in favour of specified psychiatric treatments offer the prospect of more than just a ready reference to a person’s legally competent choices after he has lost capacity. The process of formulating an appropriate and relevant advance decision demands a dialogue between the individual concerned and the mental health professionals. This can be beneficial in its own right and can also have a more pervasive effect on the therapeutic relationship and the person’s subsequent psychiatric career. However, ultimately, advance decisions, to consent and to refuse, are about the limits we place on the person’s right to self-determination and for that autonomy to exist beyond the time when capacity has been lost.

The *Mental Capacity Bill* has squandered the opportunity to go beyond statutory recognition of the existing common law and create a law that could have been truly therapeutic in intent and practice. Perhaps the debate over advance decisions is ultimately less to do with missing that opportunity and is more concerned with opposing further moves towards capacity-based mental health legislation.

Acknowledgements

Part of the research for this paper was carried out with funding for a Fellowship from the Winston Churchill Memorial Trust. I also wish to express my sincere gratitude to Professor John Monahan (University of Virginia) and Professors Marvin Swartz and Jeffrey Swanson (Duke University, North Carolina) for their assistance during this part of the Fellowship. The views expressed are mine alone.

113 Absurdly, it would be possible to use advance refusals to give consent, for example, to a particular drug – by, for instance, giving advance refusal to all antipsychotic medication, both in oral and in injectable forms, except for drug A!

114 (1990) 72 OR (2d) 417; per Robins JA at 432.

115 Op cit Note 5; para 5.14.