

Advance Directives and Advance Statements

Advance directives and advance statements are documents drawn up by individuals when well to express their wishes as to their future care and medical treatment, when they may be unable to express those wishes themselves. The term 'advance directive' is most commonly used to refer to the anticipatory refusal of medical treatment. 'Advance statements' are more general expressions of an individual's choices about what they would like to happen in regard to their personal and home life, including their wishes related to their culture and religious beliefs, should they come to lack capacity. They may also include reference to particular treatments that an individual does or does not want and specify whom they wish to act on their behalf when unwell, including the choice of a nominated person.

Advance directives and advance statements are important mechanisms for safeguarding and promoting a patient's interests and health. They should have a significant place in the care and treatment of people who fall under the Mental Health Act, for example:

- if a person lacks capacity and is in need of care and treatment, the advance directive would indicate whether the patient had stated that a treatment was to be refused. Advance refusals of treatment would be legally binding unless there were extra reasons why this should be overridden.
- where there is a duty to consult the patient's wishes and feelings, this should include the duty to consult an advance statement.

An advance directive is binding under common law and soon will be binding under statute law. However, an advance directive can be over-ridden if the person is subject to compulsory treatment under the Mental Health Act 1983.

We believe that this discriminates against people with mental health problems. This seems particularly anomalous when the Government is allowing advance refusals in the Mental Capacity Act which would allow people to exercise some dignity and control at the end of their lives, yet is not allowing similar dignity or control over treatment for people in non-life threatening situations, by virtue of them having a mental disorder.

We believe that in the draft Mental Health Bill 2004 an important opportunity has been missed to include, as part of primary legislation, a legal basis for the use of advance directives and statements. The importance of advance directives and statements for patients should not be underestimated: they are a means of giving details of the care and treatment a patient would like to receive should they lose capacity at some time in the future; they allow a patient to specify whom they wish to act as a nominated person should they become unwell; they can promote individual autonomy and empowerment; they can enhance communication between patients and those involved in their care; and they can protect individuals from receiving unwanted or possibly harmful treatment.

It is also likely that the patient's recovery will be assisted by the knowledge that their health, social and personal affairs are being attended to in a way that they have agreed to beforehand. Service users, who have confidence that their doctors will abide by their wishes when they become unwell, experience less concern and stress about future relapses. This is backed up by recent research which has shown that advance statements

in the form of crisis plans can be effective in reducing the number of compulsory admissions to hospital.¹

The Joint Committee on Human Rights, in its report on the 2002 draft Mental Health Bill, recommended that, “*the rights of patients to give directions about their future treatment, during periods when they are capable of doing so, should be respected where doing so would not present a threat of death or serious harm to the patient or anyone else.*”²

Current law

Under English common law the unambiguous and informed advance refusals of treatment of competent adults are legally binding after the loss of capacity. The judgements given in *Re T (Adult: Refusal of Treatment)*³ and *Airedale NHS Trust v Bland*⁴, set out that an advance refusal of treatment which is ‘clearly established’ and ‘applicable in all the circumstances’ is as effective as the decision of a capable adult. An advance directive:

- can only be effective if it was made when the patient had the capacity to make it;
- need not be in writing;
- cannot be used to require a doctor to carry out a positive act which is contrary to his clinical judgement;
- can be overridden by the Mental Health Act (1983) so that a directive which refuses any treatment for mental disorder will be rendered ineffective;
- will be ineffective if at the time when it was made the patient did not appreciate the implications of refusing treatment;
- can be made by a detained patient who possesses the required capacity; and
- can be revoked if the patient has the necessary capacity to do so.

Advance refusals of treatment will be provided for under statute law when the Mental Capacity Act 2005 comes into effect.

However, advance requests for treatment are not legally binding in that no one can require that particular medical treatment be given. The Mental Capacity Act 2005 provides that when determining an incapacitated person’s best interests, any written statement made when they had capacity should be considered.

The decisions made in an advance directive can be ignored by a doctor if the Mental Health Act 1983 is used to override a person’s express wishes regarding treatment. A patient who is detained under certain sections of the Mental Health Act (for example Section 2, Section 3, Section 37) can have their refusal to have a specific treatment overridden if the proposed treatment is for ‘mental disorder’. However, their treatment preferences should always be considered with respect by mental health professionals.

The Mental Capacity Act 2005

¹ Henderson C, Flood C, Leese M, Thornicroft G, Sutherby K, Szukler G. (2004) *Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial*. British Medical Journal, July 2004;329(7458):p122-3.

² 25th Report of the Joint Committee on Human Rights, Session 2001-02: Draft Mental Health Bill, 11 November 2002, HL 181, HC 1294, para 91

³ Re T (Adult: Refusal of Treatment) [1992] WLR 782

⁴ Airedale NHS Trust v Bland [1993] AC 789

The Mental Capacity Act 2005 for England and Wales provides a statutory basis for advance decisions to refuse treatment (advance directives). Under the Act, if an advance refusal is deemed valid (i.e. a true representation of someone's wishes) and applicable (i.e. is specific to the circumstances and treatment being proposed), it must be adhered to even when it involves life-sustaining treatment. The Act also provides a number of safeguards to ensure that advance directives are not misused, for example allowing a doctor to treat if there is uncertainty about the directive.

However the Act also provides that an advance directive can be overridden if the person is subject to compulsory treatment under the Mental Health Act 1983. This would therefore appear to discriminate against people with mental disorders who should have the same rights as people with physical disorders; unless there are exceptional circumstances such as the likelihood of causing imminent and serious harm to self or others. This seems particularly anomalous when the Government is allowing advance refusals in the Mental Capacity Act which would allow people to exercise some dignity and control at the end of their lives, which many members of the Mental health Alliance fully supports, yet seems to be allowing no dignity or control over treatment for people in non-life threatening situations, by virtue of them having a mental disorder.

Section 4(6)(a) of the Mental Capacity Act explicitly states that when determining a person's best interests when that person lacks capacity, any written statement made when they had capacity should be considered. Although this does not go as far as Scottish mental health legislation (for example, there is no requirement to record why, if a different course of action was taken, the wishes expressed in an advance statement were overridden), it does provide further legal support for a person's right to choice, autonomy and self-determination in deciding in advance the type of care and treatment they would like, should they lose capacity to do so in the future.

Expert Committee Recommendations

The 1999 Expert Committee Review of the Mental Health Act addressed the issue of what they termed 'advance healthcare statements'. They considered recommending that advance directives be given statutory recognition in any future mental health legislation but concluded that it would be difficult to accord statutory recognition only to directives about care and treatment for mental disorder.

They recommended that the necessary provision be introduced in statute and complemented by the Code of Practice. The details of the form to be taken by advance agreements and the matters they might include should be contained in the Code of Practice, together with guidance as to how an advance agreement can be constructed. These ways would achieve recognition in law to ensure both that the creation of an 'advance agreement about care' is routinely considered by care teams and patients and that when created these agreements would have sufficient formality to be regarded as proper statements of a patient's capable wishes.

They recommended that an obligation be placed on the care team to provide all patients, prior to discharge from compulsion, with information about, and assistance with, the creation of an advance agreement regarding care and, further, that any discussion concerning an advance agreement should involve the patient's nominated person and/or advocate and, with the patient's consent, any relevant carer. The Committee concluded that the creation and recognition of advance agreements about care would greatly assist in

the promotion of informal and consensual care. Patients and care teams would become used to negotiating an agreed package of care to be implemented in the case of relapse.

White Paper proposals

The White Paper (2000) acknowledged that advance agreements about the types of treatments an individual would prefer should they lose capacity in the future may be an important factor in determining what care and treatment is in a patient's best interests. No mention was made, however, of advance refusals to treatment. The White paper agreed that clinical teams should be expected to help patients develop advance agreements. It further stated that when a patient is subject to assessment and initial treatment under compulsory powers, the clinical team would be expected to take account of any recent advance agreement developed in consultation with specialist mental health services. Guidance on advance agreements would be included in the Code of Practice on the new legislation.

The Mental Health (Care and Treatment) Scotland Act 2003

The Scottish Mental Health Act provides for advance statements that specify:

- how a person wishes to be treated for mental disorder; and
- how that person wishes not to be treated.

According to the Act:

- a person giving medical treatment authorised by virtue of the Act shall have regard to the wishes specified in an advance statement; and
- where the Tribunal or designated medical practitioner takes a decision that conflicts with those wishes, they are required to record the reasons for this, to notify the person who made the advance statement and to place a copy of that record in the person's medical records.

Draft Mental Health Bill 2004 proposals

There is no mention of advance statements or advance directives on the face of the draft Mental Health Bill and no obligation for clinical teams to refer to them when choosing a nominated person or making treatment choices. There is, however, a duty in the draft Bill "*to consult the patient's wishes and feelings.*" The Government says that the Code of Practice will cover advance statements.

Recommendations of the Joint Committee on the Draft Mental Health Bill

The Committee considered the interface between the Mental Capacity Bill and the draft Mental Health Bill. It recommended that, before the Bill passes through Parliament, a clearer analysis of the interrelation between the two pieces of legislation be presented. The Committee recommended that the Government should bring forward legislation, either in the Mental Health Bill or separately, which would enable people to make advance

statements and to record advance decisions, particularly if there is a treatment they would prefer not to receive. The Committee also recommended that the arrangements provide for these statements (in relation to further mental health treatment) to be taken into account by, but not become binding on, clinicians in determining the provision of medical treatment for mental disorder under the Act. They also recommended that patients be able to appoint an enduring nominated person which could be done through an advance statement.

Alliance policy

The Alliance welcomes provision for advance directives and some legal recognition for advance statements when determining someone's best interests in the Mental Capacity Act, although we would have liked to see these being given legal status, more akin to advance statements as in the Scottish Act. However we remain concerned that advance statements are not included in mental health legislation. To ensure equity and parity between the two Acts in both legal and practical terms advance statements must be included within future mental health legislation. This would also be in keeping with the Alliance's demands for principles to be incorporated at the beginning of any new mental health legislation, including a principle of non-discrimination. For the same reasons we believe that mental capacity legislation should be implemented at the same time as or before mental health legislation.

The Mental Health Alliance seeks the following provisions on the face of the Mental Health Act:

The clinical team should discuss advance directives and statements with the patient prior to discharge and help with their preparation.

In the Alliance's view, patients should be encouraged by professionals to develop advance directives and statements with the knowledge that these will be taken into account when making treatment decisions. As the White Paper (2000) states, the clinical team should be obliged to discuss advance statements with the patient as a component of care planning prior to discharge and to give help with their preparation. This would bring legislation into line with the principle of patient involvement and patient choice.

The clinical team should consult an advance directive/statement at all times in the exercise of compulsory powers.

Mental Health Foundation researchers have reported that service users are discouraged from preparing advance statements because they are aware that they are not followed if they are sectioned.⁵ We see no reason why England and Wales should not follow the example set by Scotland in its Mental Health Act, whereby the right to make advance statements was included in legislation. The Alliance recommends that there should be a duty on the clinical team to consult an advance directive/statement at all times in the process of the exercise of compulsory powers. This duty should be in addition to the requirement to consult the nominated person.

Wishes expressed in an advance directive or statement should be a part of the information taken into account by professionals involved in drawing up a preliminary care plan and for nominated persons and advocates to take into account when carrying out their legal

⁵ The Mental Health Foundation, 2005. *Advance Statements in Mental Health Practice – Lessons from Bradford*.

responsibilities. It is also particularly important that the Tribunal should be required to take account of any advance directive or statement when making a treatment order.

An advance directive to refuse medical treatment for physical or mental disorder should be legally binding on the clinical team

The fact that an advance directive is in most circumstances legally binding, but can be overridden if a person is subject to compulsory powers under the Mental Health Act, gives too little acknowledgement of the patient's wishes at the time when that patient had capacity.

Alliance members have consulted widely on this issue. The ideal position would be that as a general rule an advance directive to refuse medical treatment for physical or mental disorder should be legally binding on the clinical team, in situations where it is clear they were intended to apply, whether or not the individual is subject to compulsory powers under mental health legislation. We acknowledge however that a person with capacity, but with impaired decision making capacity in relation to treatment for his mental disorder, can have his/her consent overruled if s/he is subject to compulsion. It would be anomalous for there to be a completely different regime for those who lack capacity but who have indicated in advance their refusal of treatment. There needs to be a mid point between consulting an advance refusal and being automatically bound by it. Accordingly we believe that before a refusal is overridden extra safeguards are required. At the very least in this situation, the clinical team should be required to consider all alternatives courses of action and record reasons for overriding the advance directive.

In overriding an advance directive the professional should be required to consider all alternatives and, in recording reasons for overriding the advance refusal, indicate why alternatives have been rejected.

In this situation the Tribunal should be required to take account of any advance directive/statement in making a care and treatment order. Any decision to override an advance directive/statement should only be taken by the Tribunal (except in the situations described above), who should record decisions for doing so.

The advance nomination of a person to act on the patient's behalf should only be over-riden by a Tribunal.

Any decision to provide treatment under compulsory powers which conflicts with an advance directive should only lie with the Tribunal, with opportunities for the patient and the nominated person to have any objections heard. This measure would help to reassure service users that advance directives will be given the weight that they deserve and would also accord with the principle of participation. If the Tribunal overrides an advance directive/statement, they should record their reasons for doing so.

The Mental Health Alliance seeks the following provisions in the Code of Practice of a new Mental Health Act:

The Code of Practice should set out the legal requirements for an advance statement/advance directive

The Code of Practice should set out that advance directives/statements should be in writing, meet minimum standards of completion and allow the person to express their reasons for the views expressed. They should be witnessed by a suitable person who should certify that, as far as they are aware, the maker has mental capacity.

The Code of Practice should provide that assessments of people's health and care needs and care plans should include consideration of making advance directives/statements.

We believe that a formal link should be established between the care programme approach and the formulation of advance statements to ensure that all people under mental health services are given the opportunity, if they wish to so, to make legally binding advance statements and directives.

Annex 1: Example of an advance statement

The following is an example of what might be included in an advance directive/statement:

- 1) *'Should I become incapable of making decisions for myself, I make the following advance statement:*
- 2) *I do not wish to be prescribed the drug Haloperidol because I am thyrotoxic.*
- 3) *I do not wish to be treated by electro-convulsive therapy (ECT) because I become very distressed as a result of it.*
- 4) *I should like my sister, [name] to act as my nominated person under the Mental Health Act.*
- 5) *I agree that my sister [name] and my mother should be involved in assessing my needs and planning my treatment and care.*
- 6) *I should like my mother to be given sufficient information to enable her to care for me effectively but I do not wish any personal information about me to be shared with her*
- 7) *I should like my cat to be looked after by [name].*
- 8) *I should like my social security benefits to be cashed by [name].*
- 9) *I am a vegetarian and wish to eat vegetarian food.*

Annex 2: Case study

The following was a letter in The Guardian on 12 March 2003:

As someone admitted to hospital for occasional bouts of severe mental health problems, I have been in the invidious situation of being unable to communicate my needs.

Having had bad experiences, I drew up an 'advance directive' with my psychiatrist (who thought that I was being obsessively over-cautious) to try to ensure I would receive the care I needed. Among other concerns, I requested that food be brought to my room, as, when ill, I am terrified of eating in public.

This advance directive was mislaid three times by my psychiatrist, and each time I gave her another copy. When finally I was admitted to hospital, no food was brought to me, nor any attempt made to check I was eating. Consequently, I lost one and a half stone in a few weeks and fainted several times while being administered strong medication on an empty stomach. It was clear that my advance directive had never been consulted.

I pursued a complaint with the chief executive of the NHS trust concerned and I'm now requesting an independent review. If my long and completely fruitless exchange of correspondence is anything to go by, I don't hold out much hope of steps being taken to protect vulnerable patients.'