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Advance statements in old age psychiatry

Lisa Williams & John Rigby

Abstract Advance statements, originally designed for situations of terminal illness, are becoming increasingly relevant in psychiatry. This article examines their background, rationale and use in old age psychiatry. The difference between advance statements and advance directives is highlighted, and different roles are suggested for each. We discuss the advantages, and the possible limitations, of advance statements, including the unique issue of the Mental Health Act 1983.

An advance statement details one's wishes for future medical treatment, anticipating a time when the capacity to make, or express, a treatment decision has been lost. Advance statements can exist in a number of forms: stating specific wishes, describing values that are important to the individual, naming a person who should be consulted in the event of future incapacity and, perhaps most well known, an advance treatment refusal or advance directive (also known as a living will).

Patients with mental health problems often have conditions that may, at times, impair their capacity to make treatment choices. Importantly, because of the relapsing nature of these conditions, many will have had previous experience of psychiatric services and are therefore particularly well placed to make decisions when healthy about their treatment options during future illness. Therefore advance statements, originally designed for terminally ill patients, are becoming increasingly relevant in psychiatry. This article focuses on the use of advance statements in old age psychiatry, where we believe they have a useful role in clinical practice.

Background

The concept of advance statements dates back to the 1960s in the USA and developed from the 'right to die' movement. It arose in the context of advances in medical technology that sometimes had the unwanted effect of prolonging the process of dying, rather than enhancing life. Although the principle of self-determination, and therefore the right to refuse medical treatment, had long been recognised, it was only after the well-publicised case of Karen Ann Quinlan, a young woman who was left in a persistent vegetative state (PVS) following a road traffic accident, that specific legislation was first enacted. The resulting Natural Death Act of California (1976) allowed terminally ill people to sign a legally enforceable document to refuse medical treatment.

The UK experience of advance decision-making has followed the USA, but at a slower pace. Here the legal basis of advance treatment refusals was recognised by the House of Lords when considering the Tony Bland case (*Airedale NHS Trust v Bland* [1993]) and this and other case law (*Re T* [1992]; *Re T (Adult: Refusal of Treatment)* [1992]; *Re C (Adult: Refusal of Treatment)* [1994]) make it clear that these are legally binding provided certain criteria are met. Guidance on consent from the Department of Health (2001) has also reiterated the legality of advance treatment refusals. Although the *Making Decisions* consultation paper (Lord Chancellor's Department, 2002) did not include any proposals on advance directives, the Draft Mental Incapacity Bill for England and Wales (Department for Constitutional Affairs, 2003) has now included them within the decision-making framework. The draft bill seeks to clarify the existing common law position on advance directives, stating that provided an advance refusal is both valid and applicable, it should be respected in the same way as a contemporaneous refusal of treatment from a person with capacity.

The Law Commission (1995) also considered a variety of situations relating to those with long-term incapacity, and suggested the introduction of a health care proxy to function in a similar way to a financial power of attorney. This theme has been taken up in Scotland in the Adults with Incapacity (Scotland) Act 2000, where, in addition to conferring a financial power of attorney to deal with financial matters, it is also possible to confer a welfare power of attorney.

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This welfare attorney can decide on care arrangements, access confidential records, consent to research, and consent to medical treatment on behalf of another. The recent Draft Mental Incapacity Bill, which applies to England and Wales, suggests the similar concept of a 'lasting power of attorney' as a wider form of the current enduring power of attorney that could include welfare and health matters.

The difference between advance statements and advance directives

Although the terms are often used interchangeably, advance statements and advance directives are different (Box 1).

Advance statements are made by individuals about their future health care, foreseeing a time when they may lack the capacity to make a decision or express their wishes. These statements are usually framed in a positive way, stating the person's wishes regarding how they would like to be treated or what treatments they would like to be considered. Although advance statements can be used to express one's wishes about a variety of possible future decisions in the event of mental incapacity, e.g. place of residence or who should care for a pet, for the purposes of this article only health care decisions will be considered. Although advance statements should be respected wherever possible, they are not legally binding on clinicians as no patient can demand treatment, only refuse it. Advance statements can be quite specific, particularly if a patient has already experienced treatment, or they can be more general, giving advice about the values that are important in a person's life or factors that they would wish to be considered if they were unable to make a future health care decision, e.g. placing emphasis on personal independence. In addition, advance statements can nominate a proxy who should be consulted about treatment decisions if the patient loses mental capacity.

Advance directives are one specific type of advance statement and are based on the legal principle of self-determination – that any competent adult has the right to refuse medical treatment. An advance directive simply allows this same legal principle to be applied in advance. Whereas advance statements can be a general expression of a patient's values or wishes, advance directives are more specific and are advance refusals of treatment. As such they should be considered legally binding on health professionals, provided certain criteria have been fulfilled.

Only medical treatment decisions can be covered by advance directives, as they are by definition treatment refusals. Financial matters are dealt with by conferring enduring power of attorney, where an individual nominates another to take financial decisions on their behalf and in their interests.

Box 1 Advance statements and advance directives

Advance statements
- Usually positively framed treatment choices or requests
- Not legally binding, but should be honoured where possible
- Can be vague and open to interpretation

Advance directives
- One of many types of advance statement
- Treatment refusals, therefore more specific
- Legally binding if capacity and applicability criteria fulfilled

Why have an advance statement?

The main advantage of an advance statement is that it promotes autonomy. Autonomy is the ability to be self-governing, and in Western culture has become the pre-eminent principle of medical ethics. By using an advance statement, patients are able to make decisions about their future health care at a stage when they retain the capacity to do so.

This has a number of potential consequences. First, it can provide reassurance for patients facing the prospect of mental incapacity by knowing that they have made their wishes clear in advance and that their future health care will be guided by these wishes even when they are unable to express them. Communication may be enhanced between professionals and patients through open, collaborative discussions about diagnosis, prognosis and treatment options.

Second, it is of benefit to relatives. Although no one can consent on behalf of another adult in English law at present, it is considered good practice to consult relatives when decisions have to be made for incapacitated adults. Knowing that an advance statement exists, and that the explicit wishes of the person have been previously communicated, can relieve a great sense of burden on relatives.

What constitutes an advance statement?

An important practical question is what exactly constitutes an advance statement? Does it have to be written on a special form or in a particular format?

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Should it be drawn up by a solicitor? What are the criteria for consideration when presented with an advance statement?

First, an advance statement must be applicable to the present situation. Some advance statements give details of the circumstances in which they apply, for example that no active treatment should be given for an infection occurring during end-stage dementia. This advance treatment refusal would not be applicable if someone developed a chest infection while their dementia was still at an early stage.

Second, an advance statement is only active once the patient has lost their capacity; before that stage their current consent or refusal of consent must be respected.

Third, the patient must have possessed sufficient capacity at the time of making the statement to make the treatment decision. Capacity is not an 'all or nothing' concept but is best thought of as context- or decision-specific. Thus, a person's capacity relates to the particular decision to be made, and blanket labels of 'capable' or 'incapable' are not appropriate. In addition, a person's capacity to make a decision may fluctuate, depending, for example, on their current mental state, medication or circumstances. In assessing the capacity to make a decision, doctors should take steps to maximise the patient's capacity – information might have to be provided in a different way or communication difficulties addressed to enable the person to express their decision.

The issue of capacity is crucial in advance statements and it can be a problematic area, particularly if a retrospective assessment is being made. There should always be a presumption of capacity unless there is evidence to the contrary. The criteria for assessing capacity to make a medical treatment decision were defined in *Re C (Adult: Refusal of Treatment)* [1994] (Box 2). In essence, to demonstrate capacity, an individual should be able to understand what the medical treatment is, why it is being proposed, and its benefits, risks and alternatives. They should also be able to understand the consequences of refusal, to retain this information long enough to make a decision and to make a choice free from pressure (British Medical Association & Law Society, 1995). A significant recent development is that the Adults with Incapacity (Scotland) Act and the Draft Mental Incapacity Bill have, for the first time in the UK, given a statutory definition of incapacity. This development will aid clinicians in the process of assessing mental capacity.

Box 2 Criteria for assessing the capacity to make a medical treatment decision

The patient must be able to:

- comprehend and retain treatment information
- believe it
- weigh it in the balance to arrive at a choice

(after *Re C (Adult: Refusal of Treatment)* [1994])

In terms of format, an oral statement is no less valid than a written one, but there are advantages to having a written advance statement. If witnessed by a doctor or solicitor, then later questions about mental capacity at the time of writing are less likely to arise. An advance statement can be a record of a discussion in a patient's medical notes. This can become part of a continuous process, which can alter with changing circumstances. A consistent oral expression of views, particularly if reliably witnessed, could constitute an advance statement. However, a casual remark about 'not wanting to live like that' would be unlikely to constitute an advance statement. Advice on writing an advance statement and on the format to use is given in the 'Practical issues' section of this article.

Advance decision-making in old age psychiatry

Advance statements have evolved over time and they are now regarded as useful in a range of situations where a patient may face future mental incapacity. Appelbaum (1991) argues that advance statements are particularly useful in mental illness.

There are three areas within old age psychiatry in which advance decision-making may be applicable: dementia, functional mental illness and psychiatric research. The applicability of advance statements and advance directives depends on the type of situation.

Dementia

A major concern of those developing dementia is the future loss of control over their lives once their mental capacity to make decisions has been lost. Fazel *et al* (1999) found that 20% of patients with dementia (mean Mini-Mental State Examination score 15.5) at first presentation to a community mental health team still had the capacity to complete an advance directive. Arguably, since the introduction of acetylcholinesterase inhibitors, and with increased public awareness of treatments for dementia, patients are now presenting earlier and the percentage capable of considering their own future treatment is likely to be even higher. This gives a window of opportunity for dementia services to

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discuss the diagnosis and possible treatment decisions with patients in advance. This is particularly important as dementia is a terminal condition and end-of-life decisions may well have to be faced. Although the general concept of advance statements can be helpful in dementia care, we believe that this is the one area of old age psychiatry where advance directives are most useful, especially as the types of decision to be faced are often about physical care and can be made in advance (concerning, for example, percutaneous endoscopic gastrostomy (PEG) feeding, resuscitation or active treatment in the event of a life-threatening infection).

Old age psychiatrists already participate in advance planning with patients with dementia – advice is routinely given on conferring power of attorney, making a will and so on. We believe it is time to take the next step and to discuss possible future treatment issues with patients while they still have the capacity to make their own decisions.

Functional mental illness

Here the issues are rather different. Patients often have previous experience of psychiatric services and are able to engage in the process of advance treatment planning. They know what treatments have worked, or not, in the past and are often aware of previous side-effects. End-of-life issues are less relevant with this group, and although the role of legally binding advance directives may be limited because of conflict with the Mental Health Act 1983, this is an area of great potential for the helpful use of advance statements.

Patients should be encouraged to think about their previous experiences of psychiatric treatment and to use an advance statement to give details of how they would like to be treated in the future. Many factors could be included. Patients may have preferences about the type of environment they would wish to be nursed in, and they may express a preference between equally appropriate types of medication or treatment options. Patients could nominate a person to act as a proxy or someone whom the clinical team should consult about future treatment decisions in the event of their incapacity.

The practice of old age psychiatry should be about collaboration between the clinical team and the patient to make the best treatment decisions possible. Advance statements are a way of extending the process of collaboration to a time when the patient lacks the capacity to participate in it.

Psychiatric research

Psychiatric research might be considered a separate topic and may be of less direct relevance to the majority of old age psychiatrists, but as the population ages, the need for research into psychiatric conditions in the elderly increases. Therapeutic research can be justified, even in incompetent patients, under the principle of acting in their best interests, as they may directly benefit from it. However, non-therapeutic research, which has no prospect of producing direct benefit to the patient, is much harder to justify ethically in incompetent patients. Advance statements may be one solution to this dilemma, allowing patients to consent to non-therapeutic research in the future when they have lost the capacity to consent.

Advance statements and the Mental Health Act

Psychiatry is the one area where advance refusals can be overridden and treatment given without consent under the provisions of the Mental Health Act 1983. For example, someone with schizophrenia might write an advance directive refusing further hospitalisation or antipsychotic medication in the event of a relapse. This treatment refusal can be overruled in the interests of the individual's health, safety or for the protection of others, by use of the Mental Health Act. This is why many consider the use of advance directives (in the strict sense) to be limited in psychiatry (British Medical Association, 1995), although others have argued for a change in mental health legislation to respect psychiatric advance directives, even in the event of conflict with the Mental Health Act (Halpern & Szmukler, 1997).

However, even when the Mental Health Act is used, advance statements may still be honoured – patient's wishes should still be respected wherever possible. Following a previous experience of hospitalisation, a patient might have expressed a preference for one drug over another, or for one particular class of drug (e.g. atypical antipsychotics over traditional ones). Although particular treatments cannot be demanded, a refusal to honour a patient's request or to override a treatment refusal should not be done lightly, and the decision and reasons for it should be carefully discussed and documented.

The unique situation of the Mental Health Act, and the limitations it puts on advance statements in general and advance directives in particular, emphasises how important it is that patients drafting an advance statement have input from a member of their multidisciplinary health care team. The reason for this is to avoid potential conflict at a later date, by informing patients about the types of decision that could or could not be honoured.

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What advance directives and statements cannot do

In addition to the limitations relating to the Mental Health Act discussed above, there are further situations in which an advance directive may be invalid even though the applicability and capacity criteria are fulfilled. There are limits on refusal of treatment, as the public good has to be considered as well as the rights of the individual. Situations where public health might be jeopardised, such as in the case of an infectious disease, may limit the applicability of an advance directive. In addition, it is not possible in an advance directive to refuse basic care such as mouth care or measures related to hygiene such as changing soiled sheets (British Medical Association, 1995). Similarly, it is not possible to refuse analgesia in an advance directive, as it would be considered burdensome and inappropriate for staff to have to care for a patient who was obviously in pain.

Limitations

There are a number of limitations to the use of advance statements, some practical, others more philosophical. First, and most important, is the inability of an advance statement to cover all possible scenarios. Some advance statements are so specific that they cannot cover all events that might arise. Alternatively, although general statements of values may be applicable to all situations, they may not be specific enough to be helpful to the medical team and are less likely to be implemented in a consistent way, as a degree of interpretation is required. One possible solution would be to have a general advance statement with a nominated proxy to help implement those wishes in specific situations.

A further concern is that access to new medical technologies may be denied unless the advance statement is regularly reviewed to take account of recent advances in medical treatment. Although this may be true, it strengthens the case for regularly reviewing the directive rather than being a reason not to have one.

On a more philosophical note, there may be difficulties in predicting the type of health care that one would want in the future when suffering from a particular condition. It has been argued that this may be especially the case with dementia, where the condition is so devastating that people contemplating these decisions cannot fully enter into what it must be like to have the condition and therefore cannot know how they would want to be treated. However, using an advance statement allows the person concerned to make choices based on the values and life experiences that they have known, assuming that some elements of the 'person' they are currently will persist even in a condition such as dementia.

Another difficulty is the inability to change one's mind once capacity has been lost. Contemporaneous consent or refusal can be withdrawn at any time, but in the case of an advance directive, treatment refusal is immutable once capacity has been lost. This is one reason why much thought needs to be given to any advance statement, and to advance directives in particular, and is a reason why drafting should ideally be done in collaboration with the clinical team, who can emphasise the permanence of the statement once capacity has been lost.

Practical issues

Starting the process

Writing an advance statement has implications for sharing the diagnosis and discussing the prognosis with patients. Although there is still a reluctance in some quarters to inform patients, particularly when the diagnosis is of dementia, patients who have the capacity to understand their diagnosis have a right to know. This process has to be handled sensitively and verbal and non-verbal cues are important, as some do not want to hear about their condition or be involved in a discussion about their future care. Similarly, a discussion about advance directives and future care planning can be difficult. Ideally, it should occur with a team member who the patient knows, building on the therapeutic relationship that already exists, and a number of sessions may be necessary. With a diagnosis such as dementia it is important that patients do not rush into making advance statements, but have time to think the issues through and discuss them with the team. There should not, however, be too much delay as the capacity to make these decisions may be lost.

Writing an advance statement

Although an advance statement can be oral, there are many advantages of having a written statement. A written statement can ensure that one's wishes are recorded as clearly as possible. It can also help to avoid future questions about the applicability of the statement and the person's capacity at the time it was made.

As mentioned above, ideally the statement should be written in collaboration with the medical team. They should be able to give information about the diagnosis, prognosis and treatment options, to discuss potential situations and likely choices that

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Box 3 Useful UK websites

The following websites contain information and blank forms for advance statements:

http://www.ageconcern.org.uk
http://www.alzheimers.org.uk
http://www.mind.org.uk

might have to be made and to advise on what would, or would not, be suitable to include in an advance statement or directive.

What format to use

There is no legal requirement that an advance statement follow any particular format. A solicitor can be consulted to draw up a suitable document, but this is not necessary. Various blank forms are available free of charge on the internet, from voluntary organisations such as those listed in Box 3, and from some National Health Service trusts. Patients should be warned that many forms on the internet are North American and relate to specific legislation in the USA.

Ideally there should be two witnesses to an advance statement. If the statement nominates a proxy then this person should not also be a witness. Although any two people may witness an advance statement, if one is a doctor or solicitor, this implies that consideration has been given to the person's capacity at the time of signing, which may avoid later questions.

Storage and dissemination

It is in the patient's interest to ensure that as many relevant people as possible know about the existence of their advance statement, to ensure that it is followed in a time of crisis. Copies should be kept by the patient and by a family member, friend or carer. There should also be a copy in the medical notes (this may have to be duplicated if the medical and psychiatric notes are separate). The individual's keyworker and general practitioner should also each have a copy.

Review arrangements

These will depend on the individual's circumstances. There is no time limit on the validity of an advance statement, but it would seem sensible to review it regularly. An opportune occasion may be after a further episode of illness for patients with functional disorders or during a routine out-patient review for patients living in the community. In cases of dementia we feel there should be at least an annual review, with the awareness that an advance statement cannot be changed once capacity has been permanently lost.

Conclusions

Advance statements are one method of extending a patient's autonomy to a time when they lack the mental capacity to make their own contemporaneous decisions, and are increasingly relevant to psychiatry. Because of the Mental Health Act there are limitations to the role of legally binding advance directives, particularly in patients with functional illnesses, but we believe that such directives have an important part to play in dementia care, where decisions about appropriate care towards the end of life are often required.

Writing an advance statement is neither quick nor easy and there are implications for old age psychiatry services if their introduction were to become widespread. However, they do give us the opportunity to help our patients to plan for their future and make their own decisions.

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Re T [1992] WLR 782.

Re T (Adult: Refusal of Treatment) [1992] 4 All ER 649.

Multiple choice questions

1 Advance directives are:

a potentially legally binding
b presumed invalid unless witnessed by a doctor
c a way of nominating a health care proxy
d useful in extending a person's autonomy
e treatment refusals.

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2 An advance statement cannot:
a request illegal treatment
b nominate a health care proxy
c request inappropriate treatment
d refuse basic nursing care
e decline basic analgesia.

3 The criteria for assessing capacity to make a medical treatment decision include:
a the reasonableness of the decision
b the ability to comprehend and retain treatment information
c the diagnosis of the patient
d the ability to believe the treatment information given
e the ability to retain the information and reach a decision.

4 Advance statements should be:
a witnessed by three people
b widely disseminated
c regularly reviewed
d compiled in isolation from the clinical team
e written on a prescribed form.

5 Advance statements:
a can be written or oral
b are the same as advance directives
c may be used in dementia
d can be overridden by use of the Mental Health Act 1983
e can be used in terminal illness.

MCQ answers

1	2	3	4	5
a T	a T	a F	a F	a T
b F	b F	b T	b T	b F
c F	c T	c F	c T	c T
d T	d T	d T	d F	d T
e T	e T	e T	e F	e T

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