

MAKING DECISIONS ALLIANCE

Advance Statements and Advance Directives

Advance statements and advance directives provide the opportunity for adults with capacity, to state their wishes and plans in advance, in case in the future they become temporarily or permanently unable to make decisions or communicate their wishes. Advance statements also protect the principle of consent and ensure that crucial life decisions are not reliant upon the assumptions of professionals involved, particularly with regards to decisions about quality of life.

An advance statement is a declaration that an adult gives about the care and support they would wish to receive. One of the types of statement that can be given is an advance directive where an adult refuses in advance a specific medical treatment or procedure. At present, this is the only form of advance statement that is legally binding on professionals, as established through case law.

The Making Decisions Alliance (MDA) welcomes the inclusion in the draft Mental Incapacity Bill of advance directives – enabling people to make advance decisions to refuse treatment. This codifies and clarifies a number of case law decisions. Clauses 23-25, and 32 of the Bill outline how advance decisions will work. (see Appendix 1 for weblink to the draft Bill and Explanatory Notes). The Bill outlines in considerable detail the safeguards to prevent advance directives being abused; the tests of **validity** and **applicability**.

However the MDA is disappointed that the Bill does not include mention of advance statements. Advance statements enable an individual to express their views and preferences on a large range of issues, including:

- domestic arrangements
- treatment preferences
- financial arrangements
- childcare arrangements
- clarification of who to disclose information to, and the limits of what can be discussed
- whom they would nominate as a 'nominated person' in future Mental Health legislation.

Furthermore, advance statements provide both additional safeguards and direction for someone acting for someone who has lost capacity.

While recognising that there may well be circumstances where an advance statement would need to be over-ridden (see below) the MDA would like to see the Bill giving a similar emphasis to advance statements.

By including advance statements in the Bill they would act as both assisting and safeguarding people who had lost capacity, were likely to lose capacity in the future, or whose capacity was being assessed, in the following ways:

- In Clause 2(2) the existence of an advance statement would provide guidance around the “practicable steps” to assist those helping someone who is unable to make decisions;
- In Clause 4 the existence of an advance statement would give a clear indication of all those involved in making decisions on someone else’s behalf of the person’s **‘best interest’**, especially as an indication of the person’s “past and present wishes” (Clause 4, (2)(c)(I));
- By providing specific guidance for anyone acting under the general authority, under the Lasting Power of Attorney (LPA), or as a Deputy appointed by the Court of Protection. In these situations we would urge that it should be a legal requirement that the person(s) acting in these roles should act in accordance with someone’s advance statement providing that it meets the criteria of **validity** and **applicability**, and is deemed to be **reasonable** and in the person’s **best interests**. If the advance statement is overridden clear reasons for doing so should be recorded. Clause 32 (destroying or concealing an advance directive) should also apply to an advance statement as well as an advance directive,

How would Advance Statements and Advance Directives work?

An advance statement or advance directive helps facilitate communication between the individual and those mentioned in the advance statement or advance directive. The ability to set out an individual’s wishes in advance can only encourage people to discuss their preferences in advance, with all of those who will have an important role in any future care. This could include family members, friends as well as health and social care professionals.

Once an advance statement or advance directive has been made it would still be expected that all those involved in the person’s care would still consult with the person directly even where someone does not have capacity.

What are the advantages of Advance Statements and Advance Directives?

Advance statements and advance directives enable people to document what they would like to happen if they lose capacity. They could include preferences about crucial quality of life decisions but can also include practical details such as who will take care of their pet. The ability to state their wishes in advance can reduce a person’s anxiety about the future, giving them the reassurance that their views and preferences will be taken into account.

Advance Statements can:

- Empower people.
- Reassure people that their views and wishes will be considered irrespective of any future health problems.
- Act as an important safeguard for people who are liable to be subject to a 'general authority to act' in the future, to ensure that whoever acts under these powers will have a clear understanding of the individual's wishes.
- Indicate who the person would want to act under the 'general authority' should they lose capacity at some point in the future.
- Improve communication around difficult subjects and will encourage people to think and plan for the future while they are still able.
- Record decisions and preferences, communicate them with others and therefore involve others in the discussions.
- Clarify and inform decision making for professionals in difficult, and often fraught, situations.
- Facilitate important discussions around decision-making and will prompt further discussion at the point of their completion.
- Ensure that anyone acting as a health, welfare or financial proxy will have a written record of the individual's wishes.
- Redress the power balance in situations where individuals feel powerless to assert their own wishes against the perceived dominant views of professionals.
- Prevent the lack of information or representation that could result in decisions being made which are contrary to the person's views or culture.
- Be responsive to the needs of those with fluctuating capacity.
- Turn case law into statute and give those involved clearer guidance and support.
- Enable the wishes of individuals with capacity to refuse treatment even when they are not able to communicate them.
- Offer concrete protection from neglect. It is an opportunity for an individual to record their wish for their life to be sustained and for them to be kept alive by any means reasonable (this could be over-ridden if a doctor considers the advance statement is not in the individual's best interest).
- Act as another process by which an individual's view can be taken into account when they have lost capacity. This may be important for those who are isolated and for which there may not automatically be someone in their lives who would know them, and their views well enough, to act with **general authority**.
- Provide a vital form of self-advocacy that would offer crucial protection for the individual.

An advance statement or advance directive should be made in writing and signed and witnessed. Copies should be included in all relevant health and social service records.

The MDA would like to see clear guidance on the process by which advance statements and directives should be recorded, witnessed and registered.

Don't we already have the ability to set out our wishes in advance?

Advance statements would complement the existing systems of Single Assessment Process, Community Care Assessment and Care Programme Approach and help to ensure that an individual's views are discussed and documented. The aim is to solidify the present guidance on good practice.

The Bill sets out options for an individual to nominate a person to make decisions about health, welfare and finances in advance through a Lasting Power of Attorney (LPA). These are very welcome. However, for some people, particularly those with fluctuating capacity, a lasting power of attorney will be bureaucratic and expensive. Advance statements would offer a flexible, less bureaucratic alternative while offering reassurance to individuals that their wishes will continue to be considered when they do not have capacity.

Advance statements also help to ensure that those given authority to make decisions on behalf of someone who has lost capacity have discussed future care options and decisions. This includes family, friends as well as care professionals. This would then provide a mechanism for ensuring that anyone who acts under the **general authority** will have had detailed discussions around what the individual's views would have been. Advance statements would provide additional safeguards for those who have lost capacity. They provide evidence, which would enable other people to challenge an LPA donee who wasn't acting according to the person's views

Can an Advance Statement be over-ridden?

There may be times when an individual uses an advance statement to request something that is not practical or in their best interest. As a result, the principles of **reasonableness** and **best interests** of the individual should also apply to an advance statement. We would expect further guidance in the accompanying Code of Practice.

If an advance statement is over-ridden for any reason we believe there must be a legal requirement for the reasons to be given and recorded. This would also apply to a person subject to compulsory powers under the Mental Health Act.

As with advance directives, as laid out in Clause 32 of the Bill, It should be made a criminal offence to destroy any evidence relating to an advance statement while that individual is still living.

Can an Advance Directive be over-ridden?

The Bill clearly lays out the grounds on which an advance directive can be overridden. These relate to the tests of **validity** and **applicability**.

Those acting under the **General Authority** to act, as proposed in the Draft Mental Incapacity Bill, should **not** be able to over-ride an advance directive.

Advance statements, advance directives and mental health legislation

While we accept that an advance directive may be over-ridden if an individual is detained under current or new mental health legislation the Making Decisions Alliance fully supports the Mental Health Alliance's proposals for advance statements/directives on this issue (see Appendix 2)

Advance Statements and Advance Directives must satisfy the following conditions in order to be considered valid (where not indicated as being in the Bill the MDA would expect reference to be made in the Code of Practice):

- The person had mental capacity when the advance statement or advance directive was written (*as currently stated in the Bill*)
- It was not made under conditions of undue influence or compulsion.
- The person has made informed choices, which are the result of having relevant information and of careful thought.
- It is clear, so that there are no doubts about the individual's intentions.

Advance Directives must also satisfy the following:

- It is specific and applicable to the person's medical condition and treatment at the time the advance directive comes into force (*as currently stated in the Bill*)
- It does not request anything that is against the BMA's code of ethics.
- The person making the directive gives a clear indication of whether they would wish the directive to be over-ridden where treatment is available that was not available at the time of the directive being made, or the treatment has much greater prospects of success and much less serious implications than could have been envisaged when the directive was made. (*as currently stated In the Bill*) NB. Not all members of the MDA share this view.

Can an advance directive lead to the withdrawal or withholding of basic medical treatment?

The Making Decision Alliance supports the BMA guidelines on advance directives as laid out in *Withdrawing and Withholding Life Prolonging Medical Treatment*. Artificial nutrition and hydration (for example, tube feeding, intravenous drip) are forms of medical treatment and as such can be refused in advance if specified when a person makes an advance directive.

This is clearly distinct from good practice in the provision of direct nutrition and hydration, such as moistening the lips. We believe that the existence of an advance directive should not prevent the provision of such care and other measures such as effective pain control, to ensure the person is as comfortable as possible.

Does a person need professional help to prepare an advance statement or directive?

At the moment, an adult with capacity can make a legally binding advance directive without having to see a solicitor or a doctor. We recommend that the individual's doctor should sign an advance directive so that he or she fully understands the wishes about future treatment and to indicate that the person had capacity when making the directive. A copy should be logged in all health and social care records. As regards advance statements we would recommend the same. We want to make sure that the process of making an advance directive or advance statement will be very accessible and made at no cost to the individual. We do, however, believe that a person should have access to advocacy support in drawing up an advance directive or statement, which we discuss in a separate paper.

Do we need additional safeguards to prevent somebody exerting undue influence upon a vulnerable person in their completion of the advance directive or an advance statement?

A person needs to be protected against the following:

- Failure to take choices expressed in advance statements or directives into account
- Making an advance statement or directive under conditions of undue influence or compulsion. It has to be believed that the person has made informed choices
- There should be no evidence to suggest that the advance statement or directive has been, withdrawn or superseded

Concerns have been expressed about the potential for undue pressure to be exerted on vulnerable individuals. The Alliance would expect that guidance relating to this issue would be included in any Code of Practice under forthcoming Mental Incapacity legislation.

The MDA would also recommend that as with other important aspects of the Bill and stipulated in Clause 30, that there should be a requirement on the Department of Constitutional Affairs to prepare a code or code of practice concerning advance statements and advance directives.

The MDA would also recommend that such codes must be taken into account in any civil or criminal proceedings as opposed to "may", as stated in Clause 30 (7)(b).

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Appendix 1

See Clauses 23-25, and 32 (pages 12-16) of the Bill at:

<http://www.lcd.gov.uk/menincap/meninc.pdf>

and Clauses 81-87, and 94 (pages 31-34) of the explanatory notes at:

<http://www.lcd.gov.uk/menincap/explannotes.pdf>

Appendix 2

Mental Health Alliance proposals for mental health legislation

Mental Incapacity legislation should be considered at the same time as or before mental health legislation. The Mental Health Alliance seeks the following on the face of mental health or mental incapacity legislation:

1. The clinical team should be required to discuss making advance statements with individuals who have capacity to make them prior to hospital discharge and give help with preparing them. This would bring legislation into line with the principle of patient involvement.
2. The clinical team should have a duty to consult an advance directive/statement at all times in the process of the exercise of compulsory powers, in addition to consulting the patient and the nominated person.
3. Advance directives refusing particular invasive medical treatment for physical and mental disorders, e.g. ECT, an endoscopy, and advance statements should be legally binding upon the clinical team in situations in which it is clear they were intended to apply, whether or not an individual is subject to compulsory powers under mental health legislation.
4. 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.
5. However, an advance directive may be over-ridden if the clinical team decide that it should be where there is imminent danger to the person or another. In this situation, the clinical team should be required to

consider all alternatives courses of action and record reasons for over-riding the advance directive.

6. If the Tribunal over-ride an advance directive, they should record their reasons for doing so.
7. The advance nomination of a person to act on the patient's behalf should only be over-riden by a Tribunal.
8. Preferences expressed in an advance statement, e.g. to be treated at home rather than in hospital, should be taken into account when decisions are made under compulsory powers. If they are overridden, the reasons should be recorded.

Alliance proposals for the Code of Practice

1. Advance directives/statements should be in writing, meet minimum standards of completion and give the opportunity for the maker 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.
2. A formal link should be established between the Care Programme Approach and the formulation of advance statements.