Department of Health

Review of the law relating to Advance Decisions to Refuse Treatment

Mental Capacity Act (NI) 2016 section 284

Presented to the Northern Ireland Assembly by the Department of Health

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1. Adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future. An advance decision to refuse treatment is a capacitous decision made by someone aged 18 and over, to refuse specified medical treatment at a time in the future when they may lack the capacity to consent to or refuse that treatment.

2. This paper examines the current legal position in Northern Ireland regarding advance decisions, implications for healthcare professionals, and how to handle disputes and emergencies about advance decisions.

3. Under The Mental Capacity Act (Northern Ireland) 2016, section 284 requires the Department to review the law relating to advance decisions, produce a report setting out the conclusions and lay the report before the Assembly within 3 years of the commencement of section 284. Section 284 came into force the day after Royal Assent meaning the report must be completed and laid before the Assembly by 10 May 2019.

4. This report is not to be considered official Departmental guidance for practitioners, or others, on advance decisions.

Background – The legal landscape

5. There are currently no statutory provisions for advance decisions to refuse treatment in Northern Ireland. The rules of advance decisions in Northern Ireland have been determined largely by English common law which predate the introduction of the Mental Capacity Act 2005 in England and Wales. For questions and answers about advance decisions please see Annex A.

6. The Mental Capacity Act (NI) 2016 ("the 2016 Act") has been passed but has yet to be implemented. Whilst advance decisions have been afforded statutory recognition within section 9 of the 2016 Act, the 2016 Act remains silent in terms of providing detailed codification on advance decisions, preferring instead to be guided by jurisprudential development through the common law.

A summary of the principles

7. There are currently seven legal principles of common law regarding advance decisions to refuse treatment that have been identified by the Courts as follows[1]:

    a. There are no formal requirements for a valid advance decision, it may be oral or in writing.

[1] HE v A Hospital NHS Trust [2003] 2 FLR 408

b. There are no formal requirements for the revocation of an advance decision, an advance decision whether oral or in writing, may be revoked either orally or in writing.

c. All advance decisions are revocable.

d. The existence and continuing validity and applicability of an advance decision is a question of fact. Whether an advance decision has been revoked or has for some other reason ceased to be operative is a question of fact.

e. The burden of proof is on those seeking to establish the existence and continuing validity and applicability of an advance decision.

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

g. If there is doubt, that doubt falls to be resolved in favour of the preservation of life.

8. An advance decision must be valid and applicable to current circumstances. If an advance decision is considered to be valid and applicable, then it has the same effect as a contemporaneous decision that is made by a person who has capacity, and healthcare professionals are bound by it.

9. The Department of Health guidance, the *Reference Guide to Consent for Examination, Treatment or Care*[2], makes it clear that failure to respect an advance decision to refuse treatment can result in legal action against the healthcare professional.

When is an advance decision valid and effective?

10. Advance decisions often have serious consequences for those making them, so before healthcare professionals can apply an advance decision, there must be proof that:

    a. The decision exists (this is more likely to be apparent if the decision is in writing);

    b. The decision applies to the existing circumstances;

    c. The person had capacity to make the decision at the time it was made;

[2] Reference Guide to consent for Examination, treatment or Care (March 2003) Department of Health https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/consent-ref-guide.pdf

d. The person making the decision understood the consequences of refusing treatment; and

e. The person making the decision was not under the undue influence of a third party.

11. To establish clearly whether an advance decision is valid and effective, healthcare professionals must try to ascertain whether the person making it:

    a. Has done anything that clearly goes against their advance decision;

    b. Has withdrawn their decision;

    c. Has subsequently conferred the power to make that decision on an attorney; or

    d. Would have changed their decision if they had known more about the current circumstances.

What if the advance decision if found to be invalid and not effective?

12. If healthcare professionals conclude that an advance decision does not exist, is not valid and/or applicable, but that it is an expression of the person's wishes and feelings, they must then take into account the expression of those wishes and feelings as set out in the advance decision, when making a decision about what is in the person's best interests.

Written advance decisions to refuse treatment

13. A written document can be evidence of an advance decision, but there is no legal requirements for it to be written down. It may be helpful to tell others that it exists and where to find it. There is no prescribed form for written decisions, but when making a written advance decision it may be helpful to include the following:

    a. Full details of the person making the advance decision;

    b. The name and address of the person's GP and whether they hold a copy of the document;

    c. A statement that the document should be used if the person ever lacks capacity to make treatment decisions;

    d. A clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply; and

    e. The signature of the person making it and any person witnessing the signature.

Verbal advance decisions to refuse treatment

14. There is no set format for verbal advance decisions to refuse treatment. However, where possible, healthcare professionals should record a verbal advance decision to refuse treatment on the person's healthcare record. The record should include:

    a. A note that the decision should apply if the person lacks capacity to make treatment decisions in the future;

    b. A clear note of the decision, the treatment to be refused and the circumstances in which the decision will apply;

    c. Details of someone who was present when the oral advance decision was recorded and their role (family member, friend, social worker, nurse, medical practitioner etc); and

    d. Whether they heard the decision, took part in it or are simply aware that it exists.

The implications of advance notices for healthcare professionals

15. Healthcare professionals should be aware that:

    a. A patient they propose to treat may have refused treatment in advance; and

    b. Valid and effective advance decisions to refuse treatment have the same legal status as decisions made by people with capacity.

16. Where appropriate, when discussing treatment options with people who have capacity, healthcare professionals should enquire if there are any specific types of treatment they do not wish to receive if they ever lack capacity to consent in the future. If someone informs a healthcare professional that an advance decision exists for a patient who now lacks capacity to consent, they should make reasonable efforts to ascertain what that decision is. Reasonable efforts will normally include at least having discussions with relatives and perusing the patient's GP or hospital notes.

17. Once healthcare professionals know that a written or verbal advance decision exists, they must determine whether it is valid, and applicable to the proposed treatment. If healthcare professionals are satisfied that an advance decision exists and it is valid and effective they must follow it as it is legally binding.

18. Where healthcare professionals are not satisfied that an advance decision exists that is valid and effective, they can treat the person without fear of liability but the treatment must be in the person's best interests. They should make a clear note explaining why they have not followed an advance decision in these circumstances.

Dispute and Emergencies

19. It is the responsibility of the healthcare professional with responsibility for the person's care and treatment to decide whether a valid advance decision exists.

Dispute

20. Where there is a dispute or genuine doubt as to the existence, validity and effectiveness of an advance decision to refuse treatment, professionals can provide or continue a course of treatment whilst the questions are being resolved.

21. Ultimately the inherent jurisdiction of the High Court is the arbiter of disagreements arising in regards to advance decisions. Healthcare professionals should refer the matter to the court if resolution cannot be achieved.

Emergency

22. In emergencies, a healthcare professional must provide treatment in the patient's best interests, unless they are satisfied that a valid and effective advance decision exists.

23. The provision of treatment should not be delayed to ascertain whether there is an advance decision, where there is no clear indication that one exists. However, if it is clear that a person has made an advance decision that is likely to be relevant, professionals should assess the validity and effectiveness as soon as possible.

Failing to follow a valid and effective advance decision

24. Valid and effective advance decisions to refuse treatment are legally binding. Healthcare professionals must follow them. Failure to do so could lead to criminal and civil liability.

The advantages of an advance decisions to refuse treatment

25. An advance decision to refuse treatment enables an individual to think about what they would like to happen to them in the event that they lose the capacity to take informed decisions about their care. Examples of such decisions include:

    a. The use of intravenous fluids and parenteral nutrition.

    b. The use of cardiopulmonary resuscitation.

c. The use of life-saving treatment (whether existing or yet to be developed) in specific illnesses where capacity or consent may be impaired - for example, brain damage, perhaps from stroke, head injury or dementia.

d. Specific procedures such as blood transfusion.

Limitations of an advance decisions

26. An advance decision to refuse treatment cannot be used to:

    a. Ask for specific medical treatment;

    b. Request something that is illegal (e.g. assisted suicide);

    c. Choose someone to make decisions for you; or

    d. Refuse treatment for a mental health condition if the treatment is in accordance with the Mental Health (Northern Ireland) Order 1986.

27. A medical practitioner may decide not follow an advance decision if:

    a. The individual makes changes which invalidate the decision (e.g. a change to a religion which prohibits the refusal of treatment);

    b. There have been advances in treatment which may have affected the initial treatment (unless the individual specified in the decision that such advances would be declined); or

    c. There is ambiguity in the wording of the decision (e.g. the wording is not relevant to the current medical condition).

28. An advance decision to refuse treatment may be invalid:

    a. If there is reason to doubt authenticity;

    b. If it is felt that there was duress; or

    c. If there is doubt as to the person's state of mind (at the time of signing).

Effects of an advance decision to refuse treatment

29. Under the current common law in Northern Ireland, advance decisions to refuse treatment are legally recognised. Section 11 of the 2016 Act, which relates to protection from liability when an advance decision exists, recognises this position, but does not further provide for/prescribe how advance decisions should operate.

Conclusions

30. The Department of Health has reviewed the legislation surrounding advance decisions to refuse treatment and has identified the approaches taken between our neighbouring jurisdictions to the legal recognition of advance decisions.

31. Presently, the 2016 Act does not propose any changes with regards to the legal status of advance decisions to refuse treatment. The 2016 Act provides for the statutory recognition for advance decisions, but not a statutory provision. The 2016 Act does require an 'effective' advance decision to be complied with, if it is valid and applicable under common law.

32. The Department of Health explained its decision not to include statutory provision for advance decisions to refuse treatment in the draft Mental Capacity Bill, on a number of occasions, making reference to the evolution of law in this new area of fused mental health and mental capacity legislation and, in what the Department perceives as, a lack of consensus on the way forward.

33. It is the Department of Health's view that the 2016 Act goes as far as possible at the moment in giving statutory recognition to advance decisions to refuse treatment. The Department fully appreciates the strength of views on this and has given careful consideration to all the arguments that were put forward, of which not all were in favour of codifying the rules for advance decisions. There continues to be a lack of consensus on the way forward.

34. The Department of Health continues to take the view that it is better to let society debate the issue, and let the common law develop, reflecting as much as possible of that in the code of practice and then allowing the code of practice to be updated as common law evolves. The Department of Health believes that this approach can inform future legislation, should there be clarity and consensus on what the rules should be.

35. In conclusion, it is the view of the Department of Health that the present situation of the common law doctrine of necessity allows health and social care professionals to give life-saving treatment to patients who cannot consent, until such times as the common law case law evolves for this new legislation and/or the way forward can be agreed.

Annex A – Questions and answers relating to Advance Decisions to refuse treatment

What is a valid advance decision?

There is no statutory definition in Northern Ireland what constitutes a valid advance decision. In common law from England and Wales a valid advance decision is a decision to refuse treatment in the future when the person lacks capacity. It has to be made by a capacitous, competent and informed adult. It has to be relevant to the treatment provided and it can be made orally or in writing.

What is an effective advance decision?

An effective advance decision is an advance decision that is valid and that relates to a type of treatment to which the courts have found that a person can make an advance decision about.

What is the difference between a valid advance decision and an effective advance decision?

The validity of the advance decision relates to the formalities, the capacity of the person who makes it, the age of the person, how it is made etc.

The effectiveness of the advance decision includes both the validity of the decision and the nature of the decision, i.e. what it relates to.

Are there any negative consequences for the person if advance decisions are not codified?

The Department believes that not codifying advance decisions will provide better protection than if advance decisions were to be codified. Leaving advance decisions to common law ensures that persons can be protected and may prevent adverse decisions such as suicide and euthanasia.

Can an advance decision to refuse treatment be used to refuse treatment for mental disorder?

The advance decision has to be valid and has to relate to an area which the court has found that an advance decision can be made. If the health care professional is uncertain guidance can be sought from the court and treatment that is life-sustaining or that is necessary to prevent a serious deterioration can be provided while waiting for direction from the court.

Can an advance decision to refuse treatment be used to refuse admission to hospital?

An advance decision can only be made to refuse treatment. If a compulsory admission to hospital or other setting is required a person can be deprived of their liberty against their wishes as long as it is within the procedures prescribed by law.

Can an advance decision be used to commit suicide?

For an advance decision to be valid it has to be made by a capacitous adult who understands the consequences of the decision to refuse treatment. If a person is seeking to commit suicide and provides an advance decision to prevent life-saving treatment it can be questioned if he or she had capacity when the decision was made.

If the healthcare professional is uncertain of the effectiveness or validity of the decision a ruling should be sought by the courts. A court *may* find that an advance decision which equates to suicide cannot be an *effective* advance decision and therefore authorise the life-saving treatment. However, it is for the court to determine this.

Can an advance decision be used for euthanasia?

An advance decision can only be made to refuse treatment. Professionals cannot be required by such directives to provide particular treatments. This would include treatments that would equate to euthanasia.

Are there different requirements for life saving treatment?

There are no limitations or special requirements for treatment that is life saving or life sustaining. If the treatment is life sustaining or if it is to prevent a serious deterioration in condition and there is uncertainty over the advance decision such treatment can be provided while a decision by the court is being sought.

What about DNARs?

A Do Not Attempt Resuscitation note can constitute an advance decision to refuse treatment if it was done whilst the person had capacity, was informed and was over 18. If the DNAR is effective it has to be adhered. However, if there is uncertainty over the validity of the DNAR such treatment can be provided while a decision by the court is being sought.

What is required for an advance decision by the Courts?

Currently advance decisions must be voluntarily made by a competent, capacitous and informed adult. A statement including an advance decision does not need to be signed or witnessed but increases legal standing if signed and witnessed. The

information in the statement must be clear and devoid of ambiguity but may prescribe different decisions depending on external circumstances.

What is meant by an advance decision has to be made voluntarily?

An advance decision is not valid if the person making it is under pressure by someone else to make it.

What is meant by an advance decision has to be made by an informed adult?

For an advance decision to be valid the person making the decision must have some information on, or knowledge of, what the decision means. This is to ensure that the person doesn't think they are doing something which they are not doing.

Does an advance decision have to be witnessed?

No. There are no requirements as to the form of an advance decision.

However, a statement that is signed or witnessed can increase its legal standing and provide certainty to the healthcare professional.

What if a person changes their mind after making an advance decision?

If a capacitous adult who has previously made an advance decision makes a new, contradictory, advance decision or removes the advance decision, the advance decision is no longer valid.

What is the age limit for an advance decision?

Only a competent adult over the age of 18 can make an advance decision.

Can a competent child make an advance decision?

No - only a competent adult over the age of 18 can refuse medical treatment. As a person who is 16 or 17 years of age is a minor and not an adult, it follows that such a person cannot make an effective advance decision under the existing common law. This aligns with the effect of section *4(1) of the Age of Majority Act (NI) 1969*.

Would leaving advance decisions to common law provide a way for medical practitioners to ignore the wishes of the person?

Current guidance from the Department makes it clear that failure to respect an advance decision can result in legal action against the medical practitioner.

Will the Department's position not lead to an increased burden on the courts?

The Department's position represents the current practices on advance decisions. Currently practical guidance can be found in the *Reference Guide to Consent for Examination, Treatment or Care (2003)*. This guidance states that if there is any uncertainty over the validity a ruling should be sought by the courts. As such the Department does not believe there will be any increased burden on the courts.

What is the position in England and Wales?

Advance decisions in England and Wales are codified and contained in the Mental Capacity Act 2005. That Act provides that a person who is aged 18 or over, who has the capacity to make the decision, who specifies a treatment and who identifies the circumstances which are to apply can provide an advance decision to refuse treatment.

What is the position in Scotland?

Scotland has not codified advance decisions and relies on common law.

What is the position in Republic of Ireland?

Republic of Ireland has not codified advance decisions. *The Assisted Decision-Making (Capacity) Act 2015* does include provisions for advance decisions, however, it is not yet commenced.

How is the 2016 Act different?

The Mental Capacity Act 2005 codifies advance decisions and does not provide any discretion to the court to interpret what an effective advance decision is. In England and Wales a person must be aged 18 or over; must have the capacity to make the decision; must specify a treatment; and identify circumstances which are to apply. The advance decision is then valid and has to be adhered to. However, it is important to note that England and Wales have retained mental health legislation which provides powers to compulsorily treat persons. Such provisions will not exist in Northern Ireland after the full commencement of the 2016 Act. The position in Northern Ireland after the full commencement of the 2016 Act will therefore be significantly different to that in England and Wales and direct comparisons cannot be made.

Why were advance decisions codified in England and Wales?

In England and Wales the decision to codify advance decisions was linked to the creation of the Court of Protection as this court would not have jurisdiction to determine what an effective advance decision is. Not doing so would have led to confusion between the Court of Protection and the High Court.

Why is the 2016 Act different?

On full commencement of the 2016 Act Northern Ireland will be operating in an entirely different statutory framework to that of England and Wales. The 2016 Act fuses mental health and capacity legislation and on full commencement there will no longer be separate mental health legislation here.

Is there or will there be a register for advance decisions?

There is currently no register of advance decisions and the Department has no plans to create such a register.

Are there any costs involved in making an advance decision?

As an advance decision to refuse treatment can be made in many ways there are no costs involved. An advance decision can be made orally to the treating professional or anyone else or can be made in writing. There are no prescriptive rules on what form such document must take and there are no requirements to consult with professionals, medical or legal, before making an advance decisions.