

Scottish Council on Human Bioethics

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Position statement:

Advance Directives

1. Advance directives may be considered if they are not legally binding.

Advance directives have been increasingly considered as a response to the demand by patients for a greater amount of autonomy and control concerning decisions and responsibilities with respect to their health. This has arisen in an environment in which a growing lack of familiarity or even mutual trust may exist between patients and the providers of health care.

The SCHB recognises that competent patients are entitled to make their own decisions concerning medical interventions in order to, for example, avoid breaching their personal or religious beliefs. However, autonomy is not a simple issue, especially when another person's autonomy, rights and views are present.

Moreover, even if only a few days old, advance directives may not reflect the patient's contemporaneous wishes. People's attitudes and wishes often change with the onset of a serious disease, with time and with other personal circumstances. In addition, new medical developments may mean that novel forms of treatment may exist which were not foreseen when the advance directives were prepared.

Furthermore, it may be difficult to establish retrospectively whether a person had capacity at the time of making an advance directive. It is also unclear what level of capacity is required in order to revoke a directive, once made.

Thus, because advance directives may not always reflect the real wishes or the specific situation of a patient when a medical decision is being considered, the SCHB considers that they should not be legally binding. This gives those caring for incapacitated persons essential flexibility in the provision of appropriate care and treatment.

2. Advance directives should not be used to address quality of life matters.

It has been suggested that advance directives could be used to avoid degrading and drawn-out treatments for terminal illness in which there is poor quality of life.

In response to this the SCHB notes that:

The fears that a person may have concerning end-of-life issues could be significantly addressed through the application of palliative care. In addition, it has been noted that advance directives may sometimes swing the balance against quality care and rehabilitation that would have enabled patients to live the lives that they value.

3. Legally binding advance directives may impose unworkable obligations upon medical professionals.

It has been suggested that legally binding advance directives could give physicians some protection against legal claims.

In response to this the SCHB notes that:

Legally binding advance directives may impose upon medical professionals interventions which are in conflict with their duty of care or with the law. For example, some legally binding advance directives may amount to the enforcement of circumstances reflecting professional neglect.

In addition, some legally binding advance directives may prevent healthcare professionals giving the most appropriate treatment to the patient that is in his or her best interest. For example, patients who are not treated because of an 'end of life' advance directives may survive and become permanently harmed, bed-ridden or ill as a result, when they could have been effectively treated.

There may also be questions over the legal validity of advance directives since they may be revoked at any time through, for example, a private conversation with a single individual and without any witness.

Moreover, suicide notes could be misconstrued as advance statements. What may have then been a cry for help could become a death warrant.

4. Legally binding advance directives may be abused.

Legally binding advance directives could be open to abuse whereby a vulnerable person may be coerced into preparing an

advance directive which is not to his or her benefit. This can happen if a person is led to believe that he or she is an “unacceptable burden” or “expensive” on relatives, carers or society in general.

In addition, legally binding advance directives may open the door to euthanasia.

5. Advance directives may be misinterpreted.

Badly expressed advance directives may mislead or cause confusion and result in patients being treated differently from the manner in which they intended or not at all.

Moreover, advance directives may not correspond to a real situation since the diagnosis and prognosis of a specific disease are always open to uncertainties and even mistakes.

Finally, advance directives may also reduce rather than enhance the opportunities for discussion. Inhibitions about raising the matter with health professionals may indeed lead some persons to draft them in isolation.

Position Paper on Advance Directives

1. Definitions and general information

Advance Directives: Instructions and expressions of preference made by a competent person concerning future interventions in the event that the person becomes unable to decide or communicate his or her wishes when decisions are being considered. They can either take the form of:

Advance Decisions which may include an:

Oral Declaration: Oral instructions which are made shortly before the intended effect, or an

Advance Statement (also known as a ‘Living Will’): A document containing the relevant instructions.

A Proxy Document: (also known as a Power of Attorney): A document naming another person to give the relevant instructions to the appropriate bodies when decisions are being considered.

Intervention in the health field: Any intentional activity, withholding of activity or the withdrawal of activity in the health field. Interventions include:

Medical treatment: Any positive intentional activity designed to address a specific physical or mental disorder in the best interest of the person. Artificial nutrition and hydration are not generally recognised as treatments.

Basic care: Any positive healthcare activity which is part of the fundamental needs of a person and does not specifically address a physical or mental disorder.

Advance directives do not generally include basic care which is considered as always being necessary in order to provide humane assistance.

Best interest: The highest level of well-being and welfare that is achievable for a specific person.

Benefit: The clinical advantage or the net gain that a person may receive through a particular intervention.

2. Principles and purpose

An advance directive concerning a future possible intervention may cover any matter upon which an individual has decided views, but is most often considered in connection with decisions about medical treatment and care, particularly those which might be provided as the patient approaches death. In this case advance directives cannot direct the clinician to undertake acts against his or her clinical judgement: only to refrain from treatment which the patient finds unacceptable. Resource limitations will also determine what an advance directive can specify.

3. History

To be developed

4. England and Wales – Legislation, Case Law

4.1. Developments

In January 1994, the BMA Council of the UK approved in principle the concept of limited legislation to translate the relevant common law into statute and clarify the non-liability of doctors who act in accordance with an advance directive [1].

A review of the legislation in England and Wales began with the Law Commission launching a six-year consultation period on all aspects of mental incapacity in 1989. This culminated in 1995 with the publication of a report and draft Bill entitled *Mental Incapacity* [2]. The Government responded in 1997 with a Green Paper entitled *Who Decides?* by the Lord Chancellor's Department. Following a large consultation response to *Who Decides?*, the Policy Statement Making Decisions was published in 1999 which confirmed the Government's commitment to legislate on issues relating to mental incapacity. It proposed establishing a comprehensive decision making framework for adults who cannot make their own decisions but Making Decisions did not include proposals on advance decisions to refuse treatment.

A draft Mental Incapacity Bill was published in June 2003 and examined by a Joint Committee of both Houses of Parliament. The re-named *Mental Capacity Bill* received Royal Assent on 7 April 2005 to become the *Mental Capacity Act (2005)*. This act does include proposals on advance decisions to refuse treatment.

4.2. Present situation

Advance Statements

The *Mental Capacity Act (2005)* confirms that a person aged 18 or over may make a decision in advance to refuse treatment if they should lose capacity in the future. The Act indicates that a decision in an advance statement will have no application to any treatment which a physician considers necessary to sustain life unless it is in writing, signed and witnessed. In addition, there must be an express statement that the decision stands "even if life is at risk" [3].

This means that if an advance statement is both valid and applicable it has the same effect as a contemporaneous refusal of treatment by a person with capacity. That is, the treatment cannot lawfully be given. If given, the person refusing would be able to claim damages for the tort of battery and the treatment-provider might face criminal liability for assault [4].

To be valid the advance statement must not have been withdrawn, nor overridden by a subsequent proxy document giving a proxy decision maker the authority to consent, or refuse consent, to the treatment.

In addition, if the person has acted in a way that is clearly inconsistent with the advance statement, then the advance decision is invalid. For example, if a former Jehovah's Witness converts to Islam and marries a Muslim man, even if she forgot to destroy a written advance statement refusing blood transfusion, her actions could be taken into account in determining whether that earlier refusal remained her fixed decision [5].

An advance statement will not be applicable if the person actually has capacity to make the decision at the particular time. It will also not be applicable to treatments not specified in the statement or if the circumstances are not those specified in the document. Furthermore the decision will not be applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the individual and, if they had been anticipated by him or her would have affected his or her decision. For example, there may be new medications available that radically change the outlook for a particular condition and make treatment much less burdensome than was previously the case [6].

If there is doubt or a dispute about the existence, validity or applicability of an advance statement then the court can determine the issue. Action may be taken to prevent the death of the person concerned, or a serious deterioration in his condition, whilst any such doubt or dispute is referred to the court [7].

Enduring Powers of Attorney

The *Mental Capacity Act (2005)* allows persons aged 18 or over to appoint an attorney to act on their behalf (Lasting Powers of Attorney) if they should lose capacity in the future. It also provides for a system of court appointed deputies who will be able to take decisions on welfare and healthcare matters as authorised by the Court but will not be able to refuse consent to life-sustaining treatment. They will only be appointed if the Court cannot make a one-off decision to resolve the issues[8].

If doubt exists about what the individual intends, the law supports a presumption in favour of providing clinically appropriate treatment.

Since physicians cannot provide treatment that is illegal in the UK, such as euthanasia and assisted suicide, advance directives can only apply to refusals of particular treatments.

5. Scotland

5.1. Developments

In a Green Paper, published in 1999, which preceded the Scottish Act, the Scottish Executive specifically excluded the provision of advance statements that had originally been included in the Scottish Law Commission's original draft. It

summarised its position by indicating that:

"We [The Scottish Executive] have examined carefully a number of other proposals made by the Scottish Law Commission ...and by others. Such proposals have included legislation to give clear legal force to Advance statements ("Living Wills") and to provide for the withholding or withdrawal of treatment from patients who may be in ...PVS. Although such proposals have the sincere support of particular interest groups, we do not consider that they command general support. Attempts to legislate in this area will not adequately cover all situations which might arise, and could produce unintended and undesirable results in individual cases." [9]

5.2. Present situation

Adults with Incapacity (Scotland) Act 2000

Advance Directives General

In para. 2.62 of the Code of Practice it is indicated that:

"Nothing in the Act authorises acts or omissions which harm, or are intended to bring about or hasten the death of a patient.

During Parliamentary debate on the Act there was extensive discussion of this matter. Ministers made it absolutely clear that the Act does not permit any form of euthanasia, which remains a criminal act under Scots Law.

As the then Deputy Minister for Community Care, Iain Gray, said in the Scottish Parliament,

"Any health professional, like any individual, who acted by any means – whether by withholding treatment or by denying basic care, such as food and drink – with euthanasia as the objective, would be open to prosecution under the criminal law."

All interventions under the Act (including some omissions to act) must comply with the general principles that all interventions must benefit the adult, and that any intervention must be the least restrictive option in relation to the freedom of the adult. Clearly, an intervention under Part 5 of the Act which adversely affects the well-being of an adult or causes harm or even death to that adult cannot be described as bringing a benefit to that adult.

Section 47 of the Act only allows intervention to "safeguard or promote the physical or mental health of the adult". This does not impose a duty to provide futile treatment or treatment where the burden to the patient outweighs the clinical benefit."

Advance Statements

Advance statements are not specifically covered by the *Adults with Incapacity (Scotland) Act 2000* nor by any case law in Scotland. But since there has been common law in England that suggests [10] that persons may refuse, in advance, undesired procedures if they become incapacitated, a body of opinion believes that the courts in Scotland would not take a different approach. However, a clear position does not exist.

The Code of Practice of the *Adults with Incapacity (Scotland) Act 2000* states that:

"A competently made advance statement made orally or in writing to a medical practitioner, solicitor or other professional person would be a strong indication of a patient's past wishes about medical treatment but should not be viewed in isolation from the surrounding circumstances. The status of an advance statement should be judged in the light of the age of the statement, its relevance to the patient's current healthcare needs, medical progress since the time it was made which might affect the patient's attitude, and the patient's current wishes and feelings. An advance statement cannot bind a medical practitioner to do anything illegal or unethical. An advance [sta]jement] directive is a document which specifically refuses particular treatments or categories of treatment. Such documents are potentially binding. When the medical practitioner contemplates overriding such a directive, appropriate guidance should be sought." [11]

In an emergency, however, treatment should not normally be delayed in order to look for an advance directive if there is no clear indication that one exists [12].

Since physicians cannot provide treatment that is illegal in the UK such as euthanasia and assisted suicide, advance directives can only apply to refusals of particular treatments.

Finally, it is agreed that advance requests for treatment that do not benefit the patient are not legally binding.

Enduring Powers of Attorney

The *Adults with Incapacity (Scotland) Act 2000* allows the appointment of a proxy decision maker (a guardian, welfare attorney or person authorised under an intervention order) who is entitled to give consent to the medical treatment of an incapacitated patient over the age of 16. Where such a proxy is appointed, he or she must be consulted (where reasonable and practicable) about proposed medical treatment.

The authority of a proxy to refuse treatment on behalf of an incompetent patient would, it is thought, depend largely on whether the refusal conformed with the patient's own wishes and whether those could be shown to be informed and applicable. No case of refusal by a proxy has yet been heard in Scotland [13].

Mental Health (Care and Treatment) (Scotland) Act 2003

An advance statement can be made under the terms of the *Mental Health (Care and Treatment) (Scotland) Act 2003*. However, in this Act only medical treatments for mental disorders are addressed. Medical treatments for physical disorders are not authorised by the Act.

An advance statement under the terms of this Act can only be acceptable if (a) it is in writing, (b) it is subscribed by the person making it and (c) it is witnessed by a person who certifies that, in his or her opinion, the person making the statement has the required capacity at the time. When a medical decision needs to be taken, the relevant body or person giving medical treatment shall then have regard to the wishes specified in the advance statement [14].

6. Legislation, Case Law and Regulations - International

6.1. International

European Convention on Human Rights and Biomedicine, ETS - No. 164 [15] (legally binding). Entered into force on 1 December 1999 (the UK has not signed nor ratified this instrument). The following articles state that :

Article 5 – General rule

An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.

The person concerned may freely withdraw consent at any time.

Article 9 – Previously expressed wishes

The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.

Furthermore, in the Explanatory Notes corresponding to this article it is indicated that: *"taking previously expressed wishes into account does not mean that they should necessarily be followed. For example, when the wishes were expressed a long time before the intervention and science has since progressed, there may be grounds for not heeding the patient's opinion. The practitioner should thus, as far as possible, be satisfied that the wishes of the patient apply to the present situation and are still valid, taking account in particular of technical progress in medicine."*

6.2. Other countries

Europe

The following replies from 35 member states of the Council of Europe were given (in 2003) with respect to a questionnaire relating to Euthanasia [16].

Do laws regulating living wills or advance directives exist in your country?

Yes: 7, No: 18, Not Specified: 10

Are the wishes expressed in living wills or advance directives (legally) binding?

Yes: 8, No: 5, Not Specified: 22

Are the wishes expressed in living wills or advance directives retractable at any time?

Yes: 13, No: 1 (Latvia), Not Specified: 20

USA [17],[18]:

Most states have adopted some form of law on advance directives which are legal written documents (in some states, oral directives are also legally permitted) including Living Wills and Durable Powers of Attorney. In the 40 states where legislation relating to "Living Wills" exists, a person may request that various kinds of medical care (including food and water) may be terminated in the event that he or she becomes incapable of doing so.

The Federal Patient Self Determination Act (1990) states that any health care facility receiving federal money under the Medicare / Medicaid program must:

1. Inform patients of their right under state law to create an advance directive.
2. Ask if the patient has an advance directive and place a copy in the patient's file.

France [19]:

French legislation puts the expression of the will of the patient at the centre of the sick person / physician relationship and affirms the principle of shared decision-making between the patient and his or her physician. A sick person can refuse or interrupt a treatment and no medical intervention nor treatment can be undertaken without his or her free and informed consent which can be withdrawn at any time.

When a person loses the ability to express his or her will, the limitation or the discontinuation of a treatment having the possibility of endangering the person's life cannot be undertaken without having observed the collegial procedure defined by the medical code of ethics and without consulting the person of confidence or the family or, failing this, one of the patient's close personal contacts and, if relevant, taking into account the patient's advance statement [20].

Germany [21]:

Germany has no statutory provisions comprehensively regulating advance directives. Written instructions by a person to undertake or omit specific future medical measures may be given in the shape of:

- Advance statements for the physician in attendance: The instructions are binding insofar as they are clear, specifically address the situation of the patient and are believed to reflect his or her current wishes. Any shortcoming as to clarity weakens the obligatory effect of a patient's instructions.
- Advance statements for the care person: These are instructions relating to medical care for the person in charge of care.
- Health Care Proxy Document.

The Netherlands [22]

The Termination of Life on Request and Assisted Suicide (Review Procedures) Act (2000) provides for advance directives. A patient capable of making a reasonable appraisal of his or her own interests may make a written declaration requesting that his or her life be terminated if suffering becomes unbearable, there is no prospect of improvement and he or she is unable to express his or her will. This declaration may be regarded as a voluntary and well-considered request for euthanasia.

An advance directive has legal force only if it is in written form and the patient was capable of making an informed decision at the time of its drafting. An advance directive requiring the withdrawal of treatment is binding as long as it is sufficiently clear that it applies to the actual situation. Neither an oral nor a written request for euthanasia confers any right to euthanasia on a patient. Physicians are not required to perform euthanasia but those physicians who are willing to do so must regard an advance directive as an expression of the will of the patient.

7. Links

Council of Europe, Recommendation No. R (99) 4 of the Committee of Ministers to Member States on Principles Concerning the Legal Protection of Incapable Adults (Adopted by the Committee of Ministers on 23 February 1999), <http://cm.coe.int/ta/rec/1999/99r4.htm>

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Lord Chancellor's Department, "Who Decides?", Making decisions on behalf of mentally incapacitated adults, A consultation paper issued on December 1997, <http://www.lcd.gov.uk/menincap/meninf.htm>

Adults With Incapacity (Scotland) Act 2000, The Stationary Office Ltd, UK.
http://www.scotland.gov.uk/health/cmo/incapacity_act_toc.asp

Christian Medical Fellowship: Living Wills - Should we support them? (1992),

<http://www.ethicsforschools.org/euthane/livwills.htm>

References

1. British Medical Association: Advance statement - views (November 1992, Revised May 1995)
<http://www.bma.org.uk/ap.nsf/Content/advancestatements>
2. Mental Incapacity, Law Commission Report 231, published 1 March 1995, <http://www.lawcom.gov.uk/549.htm>
3. Mental Capacity Act 2005 – summary, <http://www.dca.gov.uk/menincap/bill-summary.htm>
4. Mental Capacity Act 2005 – Explanatory Notes, <http://www.publications.parliament.uk/pa/ld200405/ldbills/013/en/05013x-a.htm>
5. *ibid.*
6. *ibid.*
7. *ibid.*
8. *ibid.*
9. Making the Right Moves published by the Scottish Executive 1999, <http://www.scotland.gov.uk/rightmoves/docs>
10. No agreement has yet been reached in England concerning the full extent of case law relating to the legally binding nature of advance statements.
11. Paragraph 2.29 of the Code of Practice relating to the Adults with Incapacity (Scotland) Act 2000.
<http://www.scotland.gov.uk/health/cmo/mcpasprint.pdf>
12. British Medical Association, Medical treatment for adults with incapacity: guidance on ethical & medico-legal issues in Scotland, www.bma.org.uk/ap.nsf/Content/adults+with+incapacity+
13. *Ibid.*
14. Sections 275 and 276 of the Mental Health (Care and Treatment) (Scotland) Act 2003,
<http://www.hms.gov.uk/legislation/scotland/acts2003/20030013.htm>
15. Convention on Human Rights and Biomedicine, ETS No.164, <http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc>
16. Replies to the questionnaire for member States relating to euthanasia, Council of Europe, 20 January 2003,
http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/Activities/Euthanasia/Answers%20Euthanasia%20Questionnaire%20E%2015Jan03.asp
17. Voluntary Euthanasia Society of Scotland: Submission to the Select Committee of the House of Lords on Medical Ethics (5 May 1993), <http://www.euthanasia.org/lords.html>
18. Replies to the questionnaire for member States relating to euthanasia, Council of Europe, 20 January 2003,
http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/Activities/Euthanasia/Answers%20Euthanasia%20Questionnaire%20E%2015Jan03.asp
19. *Ibid.*
20. Proposition de Loi relative aux droits des malades et à la fin de vie: adopted by the French National Assembly on the 30th of November 2004.
21. *Ibid.*
22. *Ibid.*