

POLICY ON:

- (I) ADVANCE STATEMENTS UNDER THE MENTAL HEALTH (CARE AND TREATMENT) (SCOTLAND) ACT 2003**

- (II) ADVANCE STATEMENTS/DIRECTIVES CONCERNING HEALTH CARE DELIVERY (not covered by the Mental Health (Care and Treatment) (Scotland) Act 2003)**

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1. Introduction

- 1.1 NHS Lanarkshire believes that people should have the opportunity to plan for their future care if they so wish.
- 1.2 Making decisions in advance may help to ensure that the care a person receives is what they would want in given circumstances, subject to certain legal restrictions, but there are disadvantages. Preconceptions which healthy people have about illness may change when they are unwell.
- 1.3 It is also possible that a badly worded statement could be open to misinterpretation, and be implemented in a way the person had not foreseen or wanted.
- 1.4 This policy is concerned not only with clear instructions regarding the refusal of some or all aspects of health care delivery/treatment but also with statements which reflect an individual's aspirations and preferences, statements of general belief and aspects of life which an individual values, and with statements which name another person who should be consulted, on the individual's behalf, about health care delivery/treatment decisions.
- 1.5 Advance statements/directives should not be viewed as a substitute for good communication between individuals/carers and health care professionals, although clear documentation in the clinical notes of discussions with individuals, families and carers about care decisions is an essential part of modern health care delivery.
- 1.6 It is, therefore, essential that persons wishing to make advance statements or directives are aware of the advantages and disadvantages before deciding to do so.
- 1.7 Courts have made it clear that any person with legal capacity can authorise or refuse treatment, subject to the provisions of the Mental Health (Care and Treatment) (Scotland) Act 2003. Moreover, the Code of Practice of the Adults with Incapacity (Scotland) Act 2000 specifies that an advance statement is potentially legally binding. As euthanasia and assisted suicide remain illegal, advance directives requesting these cannot be valid. No advance statement precludes the giving of basic care.
- 1.8 In April 1995 the British Medical Association (BMA) published a Code of Practice, which provides advice to health professionals on advance statements/directives. An example of an acceptable End of Life Advance Statement/Directive is attached - see Appendix 1.

2. Policy on Advance Statements under the Mental Health (Care and Treatment) (Scotland) Act 2003

- 2.1 The Mental Health (Care and Treatment) (Scotland) Act 2003 was passed by the Scottish Parliament in March 2003. It is intended to improve services for, and protect the rights of, people experiencing a mental disorder (people with mental health problems, personality disorders and learning disabilities). Its main role is to make sure that people with mental disorder receive effective care and treatment.
- 2.2 In November 2003, the Health Minister announced that most parts of the Act are effective from October 2005. Some parts of the Act are particularly relevant to issues surrounding advance directives. These are the sections relating to advance statements and named persons and the right of access to independent advocacy.
- 2.3 People experiencing a mental disorder have the right to make an advance statement under the Act. An advance statement is a written, witnessed document made when a person is well, setting out how he or she wishes to be treated (or not treated) for that mental disorder if they were to become unwell in the future. An advance statement must be taken into account when those who are responsible for a person's care take decisions about the service user's care and treatment.
- 2.4 An advance statement can include the person's wishes in relation to medications, therapies and particular treatments. If a decision is made which goes against the person's advance statement they must be given the reasons in writing. A copy must also be given to their named person, welfare attorney and guardian if they have any of these, and to the Mental Welfare Commission.
- 2.5 Service users aged 16 or over, can choose someone, a named person, to help protect their interests if they have to be given care or treatment under the new Act. If a service user is being treated under the Act any person involved in their care must take account of the views of the named person. A named person also has the right to be informed and consulted about aspects of the service user's care and new powers to make certain applications under the Act.
- 2.6 An independent advocate is a person who enables a service user to express their views about the decisions being made about their care and treatment by being a voice for them and encouraging them to speak out for themselves. From October 2005 every person with a mental disorder has a right of access to independent advocacy.

- 2.7 There are duties placed on local authority and NHS staff to advise people of these rights and to ensure that advance statements and the views of a named person, if the person has them, are taken into account. Joint procedures have been produced to assist local authority and NHS colleagues to fulfill their duties under the new Act - one for *North Lanarkshire* and one for *South Lanarkshire*. The procedures have been developed in collaboration with North and South Lanarkshire Councils, NHS Lanarkshire, NHS Greater Glasgow, the NHS State Hospital and service users and carers. Staff working with mental health clients should be fully aware of the protocols and procedures developed for advance statements and named persons, which can be downloaded from www.lanarkshirementalhealth.org.uk.

Advance statements direct link:

www.scotland.gov.uk/library5/health/mhgas-00.asp

Named persons direct link: www.scotland.gov.uk/library5/health/mhgnp-00.asp

3. Policy on Advance Statements/ Directives concerning Health Care Delivery (not covered by the Mental Health (Care and Treatment) (Scotland) Act 2003)

3.1 Aims

NHS Lanarkshire aims to achieve a balanced partnership between health professionals and persons utilising health care. It acknowledges that it is the right of every competent adult (over the age of 16 years) to determine whether or not to accept health care. There might however be circumstances where persons under the age of 16 years wish to discuss with their clinicians the possibility of them not being given treatment if a particular situation arose. Clinicians would require to satisfy themselves of the child's capacity to understand the issues in such circumstances. [Children (Scotland) Act (1995)]

It is also recognised that a person under the age of 16 years shall have legal capacity to consent on his own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment. [Age of Legal Capacity (Scotland) Act 1991]

3.2 Objectives

The objective of this policy document is to raise awareness in the following areas:

- The advantages and disadvantages of making an advance statement/directive;
- The legal issues surrounding advance statements/directive;

- Guidance on writing an advance statement/directive; and
- Caring for persons who present with an advance statement/directive.

3.3 Background

3.3.1 Introduction

Many people are afraid that the use of modern medical treatments will prolong life when its quality has become unacceptable to them. To afford a measure of control over the end of their life, increasing numbers of people are completing an “advance statement”, often known as a “living will” or an “advance directive”. This document allows them to state in advance their refusal to consent to specified health care delivery in defined circumstances. It therefore provides them with an “insurance” against the possibility of being unable to express their refusal to consent to health care, either through inability to communicate or mental incapacity, at a future date. These are probably the most common reasons for the writing of advance statements/directives. However, there are others e.g.: relating to maternity, blood transfusion (there is a separate policy in relation to Jehovah’s Witnesses), mental illness, and cultural and religious beliefs.

3.3.2 What is an Advance Statement/Directive?

Advance statements/directives are declarations made by mentally competent persons of 16 years or over (see paragraph 3.1) which define in advance their refusal of specified health care should they become mentally or physically incapable of making their wishes known (BMA 1995). Further guidance is available from the General Medical Council (GMC): “Seeking patients consent: the ethical considerations” (1999) and “Consent: Patients and doctors making decisions together” (2008); and the Royal College of Nursing (RCN) “Living Wills: Guidance for nurses” (1994).

An advance statement/directive can be of various types:

- A requesting statement reflecting an individual’s aspirations and preferences;
- A statement of that individual’s general beliefs;
- A statement naming another person (proxy) who should be consulted on behalf of the person. In Scotland, some treatment decisions may be taken by a proxy under the Adults with Incapacity (Scotland) Act 2000. The authority of a nominated proxy to refuse treatment on behalf of the adult who lacks capacity would, it is thought, depend largely on whether the refusal conformed with the patient’s own wishes and whether these could be shown to be informed and applicable. It is important to note that no such case of refusal of treatment by a nominated proxy has yet been heard in Scotland.

- A clear instruction refusing certain medical procedures or interventions (known as an advance directive);
- A clear instruction concerning medical procedures should the person lapse into a persistent vegetative state; and
- A combination of any of the above (BMA 1995).

3.3.3 The current legal position of advance statements/directives

An advance statement/directive is potentially binding under common law and providing it meets the criteria listed below; legal action could follow against the staff and medical facility concerned if it is knowingly ignored.

- The person must have legal capacity and be over 16 (see paragraph 3.1) when he or she makes the advance statement/directive. It should be noted that legally a person is assumed to have legal capacity until proven otherwise;
- The person was not pressurised or influenced by anyone else when he/she made the decision to issue the statement/directive;
- The advance statement/directive covers specific situations identified by the person. Unless these relate specifically to the person's current situation, the advance statement/directive will not apply;
- The person has not rescinded the advance statement/directive either verbally or in writing since it was drawn up;
- The person is now incapable of making any contemporaneous decision because they are unconscious or otherwise unable to communicate their wishes; and
- The terms of the Mental Health (Care and Treatment) (Scotland) Act 2003 take precedence and prevail regarding treatment for mental illness. However, a detained competent adult can make the same decisions (including making an advance statement/directive) as any other competent adult with regard to treatment not covered by the Mental Health legislation.

3.3.4 Adults with Incapacity (Scotland) Act (2000)

In Scotland, the Adults with Incapacity (Scotland) Act (2000) allows competent people over 16 to appoint a proxy decision maker (Welfare Guardian/Welfare Power of Attorney) who has the power to give consent to medical treatment when the person loses capacity. Unless to do so is unreasonable or impracticable, the proxy must be consulted about treatment decisions. Proxy decision makers cannot demand treatment which is judged to be against the person's interests. The Act also requires doctors to take account, so far as is reasonable and practicable, of the views of the person's nearest relative and his or her primary carer. Nothing in the Act authorises euthanasia, which is unlawful.

A new offence is created in terms of Section 83 of the Act, which states that it is an offence for any person exercising powers under the Act in relation to an adult's personal welfare to ill-treat or wilfully neglect the adult.

3.3.5 Other legal considerations

Only refusals of specified health care are valid or potentially legally binding. A person cannot demand medical treatments as of right if this goes against the clinical judgement of the senior doctor in charge of caring for the patient.

Although it is good practice that relatives should be consulted in cases where the person is unable to communicate, they have no legal rights to either demand or refuse treatment on behalf of the person unless appointed as a proxy when the person is capable or by the Courts via 'Adults with Incapacity'. The clinical responsibility otherwise rests with the doctor in charge.

3.3.6 Restrictions on use of Advance Statements/Directives

Pertinent advance statements/directives cannot contain advance notification of refusal of fundamental healthcare procedures. Fundamental healthcare procedures means those procedures essential to keep an individual comfortable and includes:

- a) the offer of nutrition and hydration by ordinary means such as cup, bowl, spoon etc.
- b) the administration of medication or the performance of any procedure solely or primarily designed to provide comfort to the patient or alleviate that person's pain or distressing symptoms
- c) Warmth, shelter and hygiene.

A competently made advance statement/directive 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.

3.4 Guidelines for Staff dealing with Advance Statements or Directives

3.4.1 Identifying the existence of an Advance Statement or Directive

- It is the person's responsibility to let the health care professionals know that they have made an advance statement/directive;
- A person with a written advance statement/directive will be required to provide a copy that relates to the appropriate episode of care and that should be kept in their clinical notes. If this is not possible, the person's close relatives may be asked to provide a copy; and

- Reasonable steps should be taken to consult relatives or close friends to establish the existence or otherwise of an advance statement/directive of an unconscious, dysphasic or incapacitated adult.

3.4.2 Documentation and communication

- The existence of an advance statement should be clearly documented in the person's medical and nursing notes
- If the person is conscious, nursing and medical staff should be vigilant about documenting conversations, which either confirm or retract a refusal of healthcare; and
- Relatives have no legal status in decision-making for a person lacking capacity (other than a Welfare Guardian/Welfare Power of Attorney) and this should be clearly explained to staff.

3.4.3 To whom should the existence of a valid Advance Statement/Directive be communicated?

The existence of an advance statement/directive should be communicated to all relevant health care professionals including the consultant, nursing staff and any other involved health care staff and agencies.

3.4.4 Implementing the Advance Statement/Directive

If an individual makes staff aware of the existence of an advance statement/directive or has an advance statement/directive, then they should:

- Ascertain the existence and relevance to the patient's current healthcare needs, in the light of the age of the statement/directive, medical progress since the time it was made which might affect the patient's attitude, and the patient's current wishes and feelings, consulting with next of kin, general practitioner, advocate or friend.
- Ensure that all staff, in particular medical staff, are made aware of its existence and that an appropriate note is made and retained in a prominent position on the person's clinical file and records; and
- Declare any conscientious objections to carrying out the instructions of an advance statement/directive and arrange for an alternative carer.

3.5 Guidelines for staff dealing with a person who wishes to make an Advance Statement/Directive whilst receiving health care

3.5.1 Every individual has the legal right to make an advance statement/directive.

3.5.2 Health Care Professionals must appreciate that, as long as the person is competent, the reasons for any refusal of treatment may be rational, irrational or not stated.

3.5.3 Types of Advance Statement/Directive

Advance statements/directives may be:

- Made in writing by the person or on a signed printed card;
- Made orally by the person, preferably to a clinician, or as a last resort to a relative or friend; and
- A note of a discussion between the person and the clinician preferably signed by the person and witnessed or signed and witnessed by the clinician and clearly recorded and maintained in the person's clinical file.

3.5.4 The essential elements of a written Advance Statement/Directive are:

- Person's Full Name and Address;
- Date of Birth;
- Name and address of GP;
- Name, address and telephone number of any contact person nominated by the person;
- Details of statement/directive;
- Signature of person making the advance statement/directive in the presence of at least one witness;
- One of the witnesses should be a doctor. The second witness should not be a friend or relative of the patient who will benefit by the death of the patient; and
- Ideally all three parties should witness signatures.

3.5.5 An example of an End of Life Advance Statement/Directive is attached in Appendix 1 and further guidance for staff is available in Appendix 2.

3.6 Validation

There may be many kinds of advance statements/directives drawn up by individuals. Originals should be checked to see if they are relevant - having been made in good faith, properly documented and relevant to the presenting situation. Where possible, the statement/directive should be discussed with the person at the time of admission or referral. The person's lead Health Professional should be informed.

3.7 Disputes

In the event of a disagreement between health professionals or between health professionals and those closest to the person:

- The senior clinician managing this episode of the person's care must consider all the available evidence of the person's wishes

- Staff involved in the person's care must ensure that senior clinicians are aware of the person's stated wishes or written statements/directives
- If there is doubt or disagreement over the scope or relevance of an advance statement/directive, or refusal of treatment, emergency treatment should normally be given and legal advice sought if the issue cannot be clarified in any other way
- The opinion of all those who are familiar with the person should be sought. This should include all relevant health care professionals, carers and other relevant agencies. This will ensure those with the most contact with the person and those who are skilled at translating medical language into meaningful treatment options are involved in discussions where it is important to gain a particular insight into the person's views and those of their family.

Every effort must be made to seek agreement via case conferences, discussions etc. that should involve all of the aforementioned.

Ultimately, the senior clinician should take responsibility and may need to seek legal advice if either no agreement can be reached or the person's views/wishes are not clarified.

3.8 Conscientious Objection

If a health care professional who is involved in the management of care cannot for reasons of conscience accede to a person's request for the limitation of treatment, they should make it known to their manager immediately and be prepared to hand the care of the patient over to a colleague. Wherever possible, the views of the staff will be respected. The Nurse/Medical Director and the lead professional heads are happy to provide advice and support as required.

In an emergency, if delegation is impossible, the health professional should comply with an appropriate and valid advance statement/directive.

EXAMPLE

END OF LIFE - ADVANCE STATEMENT/DIRECTIVE

TO MY FAMILY, MY DOCTOR AND ALL OTHER PERSONS CONCERNED

THIS STATEMENT is made by me (full name in capitals)

.....

of

(address).....

.....

.....

Name and address of my GP

.....

.....

Name, address and telephone number of my nominee

.....

.....

at a time when I am of sound mind and after careful consideration. **I DECLARE** that if at any time the following circumstances exist, namely:

- I suffer from one or more of the conditions mentioned in the attached schedule; and
- I have become unable to participate effectively in decisions about my medical care; and
- Consensus medical opinion is that I am unlikely to recover from illness or impairment involving severe distress or incapacity for rational existence,

THEN AND IN THOSE CIRCUMSTANCES my directions are as follows:

That I am not to be subjected to any medical intervention or treatment aimed at prolonging or sustaining my life. That any distressing symptoms (including any caused by lack of food or fluid) are to be fully controlled by appropriate analgesic or other treatment, even though that treatment may shorten my life.

- I consent to anything proposed to be done or omitted in compliance with the directions expressed above and absolve my medical attendants from any civil liability arising out of such acts or omissions
- I wish it to be understood that I fear degeneration and indignity far more than I fear death
- I ask my medical attendants and any person consulted by them to bear this statement in mind when considering what my intentions would be in any uncertain situations

I RESERVE the right to revoke this STATEMENT at any time, but unless I do so it should be taken to represent my continuing directions.

Signature Date

Witness Signatures

(one of which should be a doctor)

Name.....Designation.....Date

Name.....Designation.....Date.....

Schedule for End of Life Advance Directives/Statements
Advance disseminated malignant disease (e.g. widespread cancer)
Severe immune deficiency (e.g. AIDS)
Advanced degenerative disease of the nervous system (e.g. Motor Neurone Disease)
Severe Dementia (e.g. Alzheimer's Disease or Vascular Dementia)
Any other condition of comparable gravity such as severe and irrecoverable Cardiac or Respiratory Disease
Severe and lasting brain damage

APPENDIX 2
STAFF FORM TO ACCOMPANY ACCEPTANCE OF AN
ADVANCE STATEMENT/DIRECTIVE WRITTEN WHILST RECEIVING
HEALTH CARE

When accepting a person's Advance Statement/Directive, which has been written during this episode of healthcare, the health professional should consider the following issues.

That the person is capable of: -

- Understanding and retaining information;
- Believes that information to be true;
- Weighing that information in the balance; and
- Arriving at a choice of their own free will.

The following should be discussed and confirmed: -

- All treatment to stop/no further treatment to commence
- No attempt at cardio pulmonary resuscitation
- No tube feeding
- No intravenous infusions
- No tracheotomy
- No medication to be given except (list any exceptions)

.....
.....
Any other treatments not mentioned please specify
.....
.....

Fundamental Healthcare Procedures:

The patient should be made aware that the following **WILL** continue to be provided (BMA 1995)

- Warmth
- Shelter
- Basic Pain Relief
- Hygiene - Management of Incontinence
- Relief of distressing systems e.g. Vomiting and Breathlessness
- Offer of nutrition and hydration by cup, bowl, spoon etc

Basic Care does **NOT NORMALLY** include

- Artificial Nutrition
- Artificial Hydration
- Feeding by Tube
- Intravenous Infusions
- Tracheotomy

DEFINITIONS

Nominated Person

A nominated person is someone who knows the person's wishes and who should be consulted on the individual's behalf about medical decisions.

There is no legal requirement to consult another person concerning the wishes of the individual. The views of a "nominated person" may be indicative of the individual's wishes but are of no binding force unless Court appointed via 'Adults with Incapacity' or otherwise.

Legally Competent/Has Legal Capacity

The individual can understand and retain the information relevant to the decision in question, can believe it and weigh it before arriving at a choice (Re C 1994).

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