POLICY AND GUIDELINES FOR HEALTH PROFESSIONALS ON ADVANCE STATEMENTS ABOUT MEDICAL TREATMENT

Last review date:	**October 2005**
Next Formal Review:	**March 2010 unless a change in legislation dictates otherwise**
Implementation Date:	**December 2007**
Author:	**Dr K Graham on behalf of the Clinical Governance Committee**

Approval Record	**Date**
Clinical Governance Co-ordinating Group	November 07 by email
Clinical Governance Committee	11th December 2007

Shetland NHS Board

Advance Statements about Medical Treatment – Policy

1. Introduction to the Policy

1.1. In April 1995 the British Medical Association (BMA) published a Code of Practice which provides advice to health professionals on advance statements. Further guidance is available from the General Medical Council (GMC) –1999, 'Seeking patients' consent: the ethical considerations'; British Medical Association (BMA) – 1995 'Advance Statements about Medical Treatment' and the Royal College of Nursing (RCN) – 1994 'Living Wills: Guidance for nurses'.

1.2. Some helpful definitions of terms used are attached as Appendix IV.

1.3. Shetland NHS Board believes that people should have the opportunity to plan for their future care if they so wish.

1.4. The policy is concerned not only with clear instructions regarding the refusal of some or all medical procedures (advance directives) 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 individuals behalf, about medical decisions.

1.5. Making decisions in advance may help to ensure that the care a person receives is what they would want in given circumstances but there are disadvantages. Preconceptions healthy people have about illness may be quite different from how they feel when it occurs and they are actually experiencing those circumstances.

1.6. It is also possible that a badly worded statement could be open to misinterpretation and implemented in a way the patient had not foreseen or wanted.

1.7. It is therefore essential that patients are aware of the advantages and disadvantages of making an advance directive before deciding to do so.

1.8. Courts have made it clear that patients can authorise or refuse treatment and advance directives are legally binding in certain circumstances. An advance statement cannot make a patient's request for specific treatment legally binding. Requests for euthanasia in all its forms, or assisted suicide, are not recognised by law and are, therefore, not legally binding. No advance statement may preclude the giving of basic care.

1.9. It is appreciated that this can be a difficult area of professional ethics. If clarification or discussion is required please contact the Medical Director.

2. Aims

2.1. The Board aims to achieve a balanced partnership between patients and health professionals and acknowledges that it is the right of every competent adult patient to determine whether or not to accept medical treatment.

3. Objectives

3.1. The objective of the policy document is to raise awareness of staff and patients in the following areas:

- the advantages and disadvantages of making an advance statement;
- the legal issues surrounding advance statements;
- how to write an advance statement, and
- caring for patients who refuse treatments.

4. Criteria for Use

4.1. 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 people a measure of control over end of life management, 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 of consent to medical treatment in defined circumstances.

It therefore provides them with an 'insurance' against the possibility of being unable to express their refusal to consent to medical treatment, either through inability to communicate or mental incapacity, at a future date.

4.2. What is an Advance Statement?

An advance statement is a statement made by a mentally competent person of 16 years or over which defines in advance their refusal of or preferences regarding medical treatment should he/she become mentally or physically incapable of making his/her wishes known[1]. An advance statement 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 who should be consulted on behalf of the patient. It is important to note, however, that consent or refusal to treatment by another on behalf of an adult who lacks capacity is not legally binding.
- A clear instruction refusing certain medical procedures or interventions (known as an advance directive).
- A clear instruction concerning medical procedures should the patient lapse into a persistent vegetative state.
- A combination of any of the above[1].

4.3. The current legal position of advance statements

An advance statement is legally valid 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 patient must be mentally able and over 16 when he or she makes the advance statement.
- The person has been fully informed about the nature and consequence of the advance statement at the time he/she made it.
- The person was not pressurised or influenced by anyone else when he/she made the decision to sign the statement.

- The advance statement covers specific medical conditions identified by the patient. Unless these relate specifically to the patient's current situation, the advance statement will not apply.
- The patient has not rescinded the advance statement either verbally or in writing since it was drawn up. Only reasonable and practicable steps are required to determine this, e.g. talking to friends and relatives; checking case records.
- The patient is now incapable of making any contemporaneous decision because they are unconscious or otherwise unable to communicate their wishes.

4.4. Other legal considerations

Only refusals of specified medical treatment are valid or potentially legally binding. A patient 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 patient is unable to communicate, they have no legal rights to either demand or refuse treatment on behalf of the patient. **The clinical responsibility rests with the doctor in charge.**

In Scotland, the Adults with Incapacity (Scotland) Act allows people over 16 to appoint a proxy decision maker ("Welfare Attorney") who has the power to give consent to medical treatment when the patient loses capacity. Unless to do so is unreasonable or impracticable, the proxy must be consulted about treatment decisions. Any demand by Proxy decision makers for treatment that is judged to be against the patient's interests will not be met. The Act also requires doctors to take account, so far as is reasonable and practicable, of the views of the patient's nearest relative and his or her primary carer.

The terms of the Mental Health Acts take precedence over the Adults with Incapacity Act and prevail regarding compulsory treatment for mental illness. A compulsorily detained adult can

make a legally valid advance refusal to treatment **not** covered by the mental health legislation.

4.5. Adult with Incapacity (Scotland) Act 2000

Provisions regarding withdrawal and termination of life supporting treatment and provisions regarding advance statements were included in the Scottish Law Commission's draft Incapable Adults Bill, but have since been omitted from the new Act.

Nothing in the Act authorises euthanasia and the Scottish Executive throughout the debates of this fact gave strong assurances that euthanasia is and will remain unlawful in our legal system.

The definition of medical treatment in terms of the Act has no reference to nutrition and hydration by artificial means and it emphasises the duty to safeguard and promote the adult's physical and mental health.

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.

4.6. Adult Support and Protection (Scotland) Act 2007

This policy will be reviewed in light of the Adult Support and Protection (Scotland) Act 2007 after the Code of Practice is published next year.

4.7. Restrictions on the use of Advance Statements

A patient cannot refuse basic care that is clearly appropriate in the circumstances and provided for all patients. This includes basic personal hygiene, effective relief of pain, the offer of being fed if the patient is capable of taking oral food and drink and relief of distressing symptoms such as breathlessness, vomiting and severe pain. Such basic/essential care does not encompass force-feeding or artificial nutrition/hydration.

5.0 Policy Dissemination and Communication

The Policy will be accessible to:

- All Departments (including Community Health Partnership services), and
- All staff.

The Policy will be made available via the IT System to ensure ease of access.

Through the usual information cascade process, managers will be responsible for communicating this Policy to all staff, in a manner appropriate to their area.

Advance Statement (Living Will) – Policy

1. Guidelines for Staff dealing with Advance Statements

1.1. Identifying the existence of an advance directive

- It is the patient's or their relatives' responsibility to let the hospital know that they have made an advance statement.
- A patient with an advance statement will be asked 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 patient's close relatives may be asked to provide a copy.
- As part of routine admission questions, where appropriate, a patient may be sensitively asked if they have an advance statement.
- To establish whether an unconscious, otherwise dysphasic or mentally incompetent patient has an advance statement, or has otherwise made their wishes known, relatives or close friends may be consulted.

1.2. Documentation and communication:

- The existence of an advance statement should be clearly documented in the patient's medical and nursing notes.
- If the patient is conscious, nursing and medical staff should be vigilant about documenting conversations which either confirm or retract the existence of a refusal of treatment.
- Relatives have no legal status in decision-making for an incapacitated patient and this should be clearly explained to staff.

1.3. To Whom Should the Existence of a Valid Advance Directive be Communicated?

- The existence of an advance statement should be communicated to all members of the team including the consultant, referring clinician, nursing staff and any other involved healthcare staff and agencies if relevant.

1.4. Implementing the Advance Statement

If a patient makes staff aware of the existence of an advance statement or has an advance statement, then staff should:

- Acknowledge the existence of the advance statement.
- Check its validity with the patient where possible or, if not, their next of kin, general practitioner, advocate or friend. (If no such option is available, the advance statement should be regarded as valid and acted upon).
- If appropriate and possible, ask the patient to sign the additional disclaimer form (Appendix II), as this may be one method of ascertaining its validity. The signing of this form is **NOT** essential. If the patient is not willing or is unable to sign the form, then the advance statement should nevertheless be considered valid unless explicitly refuted by the patient.
- 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 patient's clinical file and records.
- Declare any conscientious objections to carrying out the instructions of an advance statement and arrange for an alternative carer.

2. Guidelines for staff dealing with a patient who wishes to write an advance statement and/or refuses treatment

2.1. The patient's consultant and referring doctor should be informed.

2.2. Medical staff must determine the reason for refusal. The decision making process should incorporate consideration of:

- the patient's understanding of the consequences of refusal;
- the patient's competence, i.e. mental capacity;
- whether he/she is exercising his/her own free will, i.e. that he/she is not under any undue influence, and
- whether the patient has received sufficient relevant information about the purpose and implications of any treatment, which allows him/her to make informed choices.

2.3. Health professionals must appreciate that, as long as the patient is competent, the reasons for the refusal may be rational, irrational or not stated.

2.4. The matter should be fully discussed in the presence of a witness, contemporaneous notes of the matters discussed must be made and a copy retained in the patient's record/care plan. The Board must retain the original note securely. The note should be legible, unambiguous and not contain any abbreviations. The note should be clearly signed by the author and witnessed. It should be dated and a note made of the time of the discussion and circumstances wherever possible.

3. Drafting an Advance Statement

3.1. The following are the ideal elements to be included in an advance statement (a helpful template is attached as Appendix I)**.**

- Full name of patient.
- Date of birth of patient.
- Address of patient.
- Name and address of patient's GP.
- Name, address and telephone number of any contact person nominated by the patient.
- Details of patient's statement.
- Signature of patient ideally in the presence of two witnesses.
- 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 that patient. There is no obligation on anyone who objects to being a witness.
- Ideally all three parties should witness signatures.
- When accepting a patient's advance statements, a health professional **MUST** complete and sign the staff form (Appendix III) which should always include a second witness statement as indicated. These forms should be included in the patient's medical records.

4. Validation

There may be many varied advance statements drawn up by individuals. They should be checked to see if they are valid and, where possible, revisited with the patient at the time of admission or referral.

4.1. Types of Advance Statement

Advance statements may be:

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

4.2. The Patient must:

- understand in broad terms and simple language what the medical treatment is, its purpose and nature and why it is or will be proposed for them;
- understand its principal benefits, risks and alternatives;
- understand in broad terms what will be the consequences of not receiving the proposed treatment;
- make a free choice (i.e. free from undue pressure);
- retain the information long enough to make an effective decision, and
- be aged at least 16 years.

4.3. The Advance Statement must:

- have anticipated the particular circumstances that in fact arise;
- be signed by the patient, ideally in the presence of two witnesses (please see Section 3.1 above);
- be clear in meaning - if the statement is not clear then the Courts are likely to declare it invalid;

- any refusal of treatment must have been clearly understood at the time the statement was made;
- not require a doctor to act unlawfully nor preclude the giving of basic care, and
- be legally valid, i.e. unambiguous and informed - refusal of medical treatment may have serious consequences and, ideally, should be preceded by discussion with clinicians.

5. Disputes

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

- the senior clinician managing this episode of the patient's care must consider all the available evidence of the patient's wishes;
- staff involved in the patients care must ensure that senior clinicians are aware of the patients oral wishes or written statements;
- if there is doubt or disagreement over the scope or validity of an advance statement or refusal, emergency treatment should normally be given and legal advice sought if the issue can not be clarified in any other way;
- the opinions of all those who are familiar with the patient should be sought. This may include nurses involved in a patient's care who should have the opportunity of expressing their views, for example, concerning the patient's previously expressed wishes, because:
    - nurses are often the professionals who have the most contact with the patient, and
    - nurses are often skilled in translating medical language into meaningful treatment options and they often gain particular insight into a patient's views and those of the patient's family.

Every effort must be made to seek agreement, for example through case conferences and discussions.

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

6. Conscientious Objection

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

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

APPENDIX I
Advance Statement (LIVING WILL)

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:

1 I suffer from one or more of the conditions mentioned in the schedule; and
2 I have become unable to participate effectively in decisions about my medical care; and
3 two independent doctors (one a consultant) are of the opinion 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:

1 that I am not to be subjected to any medical intervention or treatment aimed at prolonging or sustaining my life;
2 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 situation.

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…….

SCHEDULE

A Advanced disseminated malignant disease (e.g. widespread lung cancer).

B Severe immune deficiency (e.g. AIDS)

C Advanced degenerative disease of the nervous system (e.g. motor neurone disease).

D Severe and lasting brain damage due to injury, stroke, disease or other cause.

E Senile or pre-senile dementia (e.g. Alzheimer's disease).

F Any other condition of comparable gravity.

APPENDIX II

ACKNOWLEDGEMENT OF ADVANCE STATEMENT (LIVING WILL)

I, ……
(Name in full)

of ……..
(Address)

Acknowledge as follows:

1. That I have been advised by:
   (Insert name of doctor) ……

   That I may require the following treatment:

   ……

   ……

   ……

2. That my refusal to agree to have this treatment may cause my death or otherwise impair my health.

3. That nevertheless I am unwilling to consent to the treatment under any circumstances.

4. That I have made this decision of my own free will.

5. That I agree to absolve Shetland NHS Board, its servants and agents, from the consequences of not providing the treatment, which has been recommended to me.

Signed:…… Date:…… Time: ……
(Patient aged 16 or over and otherwise competent to refuse treatment)

Signature of responsible Consultant: ……
(in the presence of the patient signing this form)

Name (in full) ……

Title (position held) ……

Signature of Witness present at interview: ……

Name (in full) ……

Status/relationship: ……

Address:
……

……

APPENDIX III

STAFF FORM TO ACCOMPANY ACCEPTANCE OF AN ADVANCE STATEMENT (LIVING WILL)

Name: …… Position: ……...

Patient's Name: ……

Address: ……

To the best of my ability I consider that: ……
(Name of patient)

is capable of:	Tick box ✓		Tick box ✓
Understanding and retaining information	☐	Weighing that information in the balance	☐
Believing that information to be true	☐	Arriving at a choice of their own free will	☐

Believing that *(Name of patient)*…… understands the implication, I have explained the advantages and disadvantage of taking such a step.

I have checked that they wish:	Tick box ✓		
All treatment to stop/no further treatment to commence	☐	No intravenous infusions	☐
No resuscitation	☐	No tracheotomy	☐
No medication to be given except (list any exceptions)	☐	No tube feeding	☐

Basic Care:

The patient will be made aware that the following **WILL** continue to be provided[1]:

1. Warmth
2. Shelter
3. Basic pain relief
4. Hygiene – management of incontinence etc
5. Relief of distressing symptoms, e.g.
    - Vomiting
    - Breathlessness

Signature of Patient: ……..…… Date: …… Time: ……

Signature of Staff Member completing form: ……. Date: …… Time: ……

Signature of Witness: …….. Date: …… Time: ……

APPENDIX IV

Definitions:

Nominated Person:	➢ Someone who knows the patient'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 a patient. No competent adult patient can nominate another to make a legally binding decision as regards their treatment. The views of a "nominated person" may be indicative of the patient's wishes but are of no binding force.
Legally competent:	➢ The patient can understand and retain the information relevant to the decision in question, can believe it and weigh it before arriving at a choice[2].
Basic Care (BMA Definitions) including the following[1]:	➢ Warmth ➢ Shelter ➢ Pain relief ➢ Hygiene measures (for example the management of incontinence) ➢ Relief of distressing symptoms (for example vomiting) ➢ Relief of breathlessness
Basic Care does **NOT NORMALLY** include:	➢ Nutrition ➢ Hydration ➢ Feeding by tube ➢ Intravenous infusions ➢ Tracheotomy

REFERENCES

1. British Medical Association. *Advance Statements about Medical Treatment*. London: BMJ, 1995.

2. RE C (Adult: Refusal of Medical Treatment) [1994] 1 WLR 290.

1. Rapid Impact Checklist **Policy and Guidelines for Health Professionals on Advance Statements About Medical Treatment**

Appendix V

<table>
<tr><td colspan="2">Which groups of the population do you think will be affected by this proposal?
• minority ethnic people (incl. gypsy/travellers, refugees & asylum seekers) ✔
• women and men ✔
• people in religious/faith groups ✔
• disabled people ✔
• older people, children and young people ✔
• lesbian, gay, bisexual and transgender people ✔
Other groups:
• people of low income ✔
• people with mental health problems ✔
• homeless people ✔
• people involved in criminal justice system ✔
• staff ✔</td></tr>
<tr><td>N.B. The word proposal is used below as shorthand for any policy, procedure, strategy or proposal that might be assessed.</td><td>What positive and negative impacts do you think there may be?
Which groups will be affected by these impacts?</td></tr>
<tr><td>What impact will the proposal have on lifestyles? For example, will the changes affect:

• Diet and nutrition?
• Exercise and physical activity?
• Substance use: tobacco, alcohol or drugs?
• Risk taking behaviour?
• Education and learning, or skills?</td><td>No impact</td></tr>
<tr><td>Will the proposal have any impact on the social environment? Things that might be affected include

• Social status
• Employment (paid or unpaid)
• Social/family support
• Stress
• Income</td><td>Positive Impact - Social / family support Stress

A well planned and understood advance statement and supporting policy can reduce the stress and anxiety around decision making for end of life care for patients, relatives and staff and reduce the possibility of coercion of vulnerable adults by relatives.

Negative Impact – vulnerable adults

Possibility of coercion of vulnerable adults by relatives.</td></tr>
</table>

Will the proposal have any impact on • Discrimination? • Equality of opportunity? • Relations between groups?	**Possible negative impact** if policy is not clearly understood by those for whom English is not their first language.
Will the proposal have an impact on the physical environment? For example, will there be impacts on: • Living conditions? • Working conditions? • Pollution or climate change? • Accidental injuries or public safety? • Transmission of infectious disease?	No impact
Will the proposal affect access to and experience of services? For example, • Health care • Transport • Social services • Housing services • Education	No impact

Rapid Impact Checklist: Summary Sheet	
Positive Impacts (Note the groups affected) **All groups** A well planned and understood advance statement and supporting policy can reduce the stress and anxiety around decision making for end of life care for patients, relatives and staff and reduce the possibility of coercion of vulnerable adults by relatives	**Negative Impacts (Note the groups affected)** **Possible negative impact** If policy is not clearly understood e.g. by those for whom English is not their first language, they could be disadvantaged. Possibility of coercion of vulnerable adults by relatives.
Additional Information and Evidence Required	

Recommendations

1. Circulate CGCG members for comment by email.
2. CGC on 11th December 2007 for approval.

From the outcome of the RIC, have negative impacts been identified for race or other equality groups?
Yes.

Has a full EQIA process been recommended?
No

If not, why not?

No unresolved negative impacts identified.

Manager's Signature: Date: