MND Factsheet 44
Advance Directives

Last Updated 27/10/11

Introduction

Living wills, advance decisions, advance directives and advanced medical directives are all names which are, or have been, applied to a document drawn up by someone which states what kinds of medical or surgical treatments or interventions are unacceptable to them in particular circumstances. These documents cannot be used to request particular treatments; to ask for your life to be ended; to force doctors to act against their professional judgement or to nominate someone else to decide about treatment on your behalf.

Differences Between a Directive and a Statement

An advance directive should not be confused with an "advance statement." An advance statement can set out which treatments you feel you would or wouldn't like to receive should you lose mental capacity in the future.

Advance statements aren't legally binding in Scotland, but health professionals should take them into account when deciding on a course of action. Family and friends can also use them as evidence of your wishes.

You could also make your views known verbally, for example, when discussing treatment with a health care professional, but having it written down may make things clearer for everyone.

An advance statement could include:

- treatment you would be happy to have, and in what circumstances.
- treatment you would want, no matter how ill you are.
- treatment you would prefer not to have, and in what circumstances.
- someone you would like to be consulted about your treatment at the time a decision needs to be made.

Include your name, address, date and signature in the advance statement. It's also advisable to say you understand what you're doing and are capable of making such decisions. You may want to get the statement signed by a witness who can say that you had "capacity" at the time, i.e. were in full possession of your mental faculties when you wrote and signed the document.

It's important that your advance statement is entered into your medical notes so that it is known and can be acted upon. Send a copy to your family doctor and to any hospital which is treating you. You should also provide a copy to your nearest relatives.

Advance directives

A written advance directive could form part of a general advance statement, but it is clearest if it sits under a distinct heading, such as, 'Advance decision' or 'Advance directive, refusing treatment'.

The intention of advance directives is solely to make the person's wishes regarding the withholding of treatments made known to the medical staff treating

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them if they themselves become unable to communicate their own wishes. This kind of situation could arise due to unconsciousness, coma, stroke, mental incapacity or similar events.

Raymond Voltz and colleagues carried out a survey of what patients and staff in the USA, Germany and Japan thought about advance directives. As a result of this survey they reached a number of conclusions:

- Most advance directives failed to have their desired effect as they were not specific enough to the disease the person was suffering from,
- Most patients with a terminal condition who would like to draft an advance directive expected their doctor to initiate this discussion. (Presumably since they thought the doctor's greater experience in dealing with the dying would let them know when the time is right for this kind of discussion.)
- About half of the doctors were uneasy in raising the subject of advance directives with their patients as they expected this discussion to be started by the patient.

If making an advance directive is of interest to you it is best to open the door to this discussion by asking your doctor when the time for this discussion would be appropriate. You can then explore with your physician when they consider the time would be right for such a discussion in their opinion and make your own views known to them. For those interested in making an advance directive you need to bear in mind that there is a small number of physicians who will object to them. If you get these kinds of signal you might consider discussing advance directives with someone else such as your MND Care Team Member or another professional.

Voltz and co-authors proposed a checklist, similar to the one below, for doctors who have patients with a terminal condition who are planning for end-of-life decisions.

What should be discussed?

1. Medical therapy decisions, such as:
    - Disease modifying treatments, when to stop them?
    - Cardio-pulmonary resuscitation
    - Respiratory support
    - Parenteral artificial nutrition
    - Enteral nutrition and hydration (for example through a PEG)
    - Anticoagulation treatments
    - Antibiotics
    - Specific emergency treatments, e.g. for pain or breathlessness.

2. Where the patient would prefer to be cared for?
    - Stay at home?
    - Admission to hospital?
        - Which hospital?
    - Hospice care?

3. What sources of support does the patient have?
    - e.g. family, friends, emergency phone numbers, physicians, nurses, social worker, other professionals, technical help, hospice, support group, a legal proxy.

4. Psychological coping?
    - Devices for communicating?
    - Does he or she want professional assistance when telling relatives?
    - Is "spiritual help" wanted?

5. Are there any areas of personal business where the patient may want help, e.g?
    - Financial matters?
    - Writing a will?

- Funeral planning?

6. Does the patient want to make an advance directive?
   - Does the patient have preferences for future decisions on any topic mentioned above?
   - Does the patient want information on how to set up a written advance directive?

7. Does the patient want to appoint a legal proxy (attorney)?
   - Is there an informal or culturally implicit appointment?
   - Does the patient want information on how to make a legally correct appointment?

How to proceed if the patient wishes to express their preferences in advance.

Any expression of preferences should be the result of an intensive and longstanding communication between patients, healthcare professionals and relatives.

1. Advance directives
   - Note orally expressed ADs in the medical record.
   - Before offering help in a written AD:
     - The physician should know the patient well.
     - The patient should be fully informed of the diagnosis, prognosis and options available.
     - The patient must be mentally clear (capax). The attending physician should certify this.
     - The AD should be as specific to the disease and the individual as possible, rather than a general list of refused treatments unlikely to be offered for that condition or its complications.
     - The AD should be reviewed regularly, e.g. monthly.
     - Avoid influencing the wording of the AD, but give all the necessary information.
   - The patient must know that the AD can be changed or revoked at any time.
   - Witnesses should be present when the AD is signed and should also sign.

2. Appointing a proxy;
   - Is there an obvious, or culturally appropriate, candidate?
   - Does the patient need help in meeting the legal requirements to appoint a proxy? (See Factsheet 24 Powers of Attorney.)
     - The proxy (attorney) must be trustworthy, fully informed, reliable and present.
     - Try to avoid obvious conflicts of interests
     - Schedule regular revision and discussion of the AD.
   - A witness should be present and sign when the power of attorney is signed.
   - It is in everyone's interest to register any power of attorney with the Office of the Public Guardian. (See Factsheet 24 Powers of Attorney.)

3. Compliance with national laws and conventions.
   - Signed statements indicating acceptance and understanding of AD by all parties, including relatives.

In Scotland, Advance Directives are not legally enforceable under the Adults with Incapacity (Scotland) Act 2000, but one of the general principles of the Act states that the wishes of the adult should be taken into consideration when acting or making a decision on their behalf. As a

result some legal authorities think it is arguable that a medical practitioner who ignores the wishes of a patient, properly expressed in an advance directive, could be guilty of assault in the same way as if he or she had continued treatment immediately following refusal of that treatment by a fully competent, fully informed adult.

Normally English case-law would have no immediate direct bearing on Scots law, with the exception of where an appeal under Scots law, passes through all our courts and is referred to the House of Lords as the last court of appeal in the UK. When considering an appeal the Lords can take account of judgements made in similar cases brought within other UK jurisdictions to guide their deliberations. It was ruled by Mr Justice Thorpe, in a case brought in England under English law in 1998, that an advance written declaration refusing treatment, granted when the patient had full mental capacity, would survive supervening incapacity; even where the refusal might lead to the patient's death. (In other words, if you write it down before you become senile; your wishes *should* still be observed later.)

There have been several similar rulings under English law which have resulted in the validation of "advance decisions," subject to certain tests and safeguards, by sections 24 to 26 of Westminster's Mental Capacity Act 2005, applicable to England and Wales. No such recognition is given in Scot's law.

Although the Lords is the highest court of appeal under domestic law, article 8 of the European Convention on Human Rights states, "Everyone has the right to respect for his private and family life, his home and his correspondence." Some legal minds think it could be argued that observance of a properly made advance directive is nothing more than observance of that human right. This opinion has still to be tested in court at the time of writing.

It is likely that future legislation or guidelines, formalising best practice, will draw the provisions of the two legal systems closer together as there appears to be no appreciable difference between the wishes of the people of Scotland and the rest of the UK population regarding advance directives.

Further Information

Factsheet 8	Care Planning and End of Life Issues
Factsheet 14	Making a Will and Leaving a Legacy
Factsheet 24	Powers of Attorney
Factsheet 38	Financial and Legal Issues
Factsheet 43	Useful Organisations

Scientific Paper: End of Life Decisions and Advance Directives in Palliative Care, Voltz et al, J. of Pain and Sympt. Management, 1998, Vol 16 pp 153-162

NB: The available UK internet resources on Advance Directives are largely influenced by the English legal system and make little reference to the differing situation in Scotland.

Advance Directive to Refuse Treatment

Personal Details	Details of people you would like consulted in the event of incapacity:	
Name:	Name:	Name
Date of Birth:		
Address:	Address:	Address
Phone Number:	Phone Number:	Phone Number:
Mobile Number:	Mobile Number:	Mobile Number
E-Mail	Have you granted this person a welfare power of attorney? Yes ❒ No ❒	Yes ❒ No ❒
Preferred Method of Communication	Have you granted this person a continuing power of attorney? Yes ❒ No ❒	Yes ❒ No ❒
CHI (Hospital) Number:	Relationship to you (if any)	

General Practitioner Details	Neurological Consultant Details	Attending Physician Details	
Name:	Name:	Date	Name
Practice Address:	Contact Address		
Phone Number:	Switchboard		
Mobile Number:	Direct line Pager/mobile/e-mail as preferred		
E-Mail			

Patient's Initials Date

Doctor's Initials Date

Advance Directive to Refuse Treatment

The following sections should be only completed in consultation with the doctor currently responsible for your care.

Under what conditions would you want any current treatments to be stopped? (Please list each treatment you are currently receiving that you would want stopped and state the conditions for this.)
Is there a completed DNACPR (do not attempt cardio-pulmonary resuscitation) order? Yes ❒ No ❒
For some patients respiratory support can improve quality of life and give an extension to life. If, in the opinion of your Doctor, you might benefit from this, would you want respiratory support? Yes ❒ No ❒
Under which circumstances would you want respiratory support (if supplied) to be discontinued?

Patient's Initials Date

Doctor's Initials Date

Advance Directive to Refuse Treatment

Are there any specific treatments not listed below, including possible emergency treatments, you would not wish to take place.

Where would you prefer to be cared for? Home ❒ Hospice ❒ Hospital ❒ Care Home ❒

What is/are the name/address(es) of your preferred place(s) of care?

In case of incapacity or prolonged unconsciousness list here any people you would wish notified in addition to the persons on page 1, these could include carers, other professionals involved with you or clerical or spiritual advisors.

Patient's Initials Date

Doctor's Initials Date

Advance Directive to Refuse Treatment

Many people with MND can benefit from nutrients and fluids supplied either through a vein (parenteral) or direct to the stomach or intestines (enteral) through a tube which enters either through the wall of the abdomen (PEG or RIG) or via the nose or mouth.

Under which conditions or circumstances would you not want parenteral hydration (fluid supply) to be started?	Under which conditions or circumstances would you want parenteral hydration (fluid supply) to be discontinued?
Would you accept parenteral hydration for symptom relief, e.g. thirst, if you are unable to swallow and there is no other way to give liquid?	
Under which conditions or circumstances would you not want to have a feeding tube such as a PEG or RIG fitted?	
Under which conditions or circumstances would you not want enteral feeding to be started?	Under which conditions or circumstances would you want enteral feeding to be discontinued?
Under which conditions or circumstances would you not want enteral hydration (fluid supply) to be started?	Under which conditions or circumstances would you want enteral hydration (fluid supply) to be discontinued?

Patient's Initials Date

Doctor's Initials Date

Advance Directive to Refuse Treatment

Many people with MND develop respiratory infections which can be helped by antibiotic drugs.

Under which circumstances would you not wish to begin treatment with antibiotics for a respiratory infection?

Under which circumstances would you wish antibiotics for a respiratory infection to be discontinued?

Are there any other circumstances under which you would not want to be prescribed antibiotic drugs or have them discontinued?

Patient's Initials Date

Doctor's Initials Date

Advance Directive to Refuse Treatment

The above is written confirmation of my advance decision to refuse treatment. I understand that I can revise and change this directive at any time should my opinions or circumstances change and that I should review this document regularly.

I give/do not give (delete as appropriate) consent for this information to be shared with out of hours, hospital and primary care services.

Signature of person refusing treatment (or proxy)..... Date.....

I have discussed the implications of this document with my patient and confirm that he or she fully understands the meaning of an advance directive to refuse treatment and the circumstances in which it may or may not be followed.

Name or Physician (please print) ..... Post Held.....

Address, if not already given on page 1

Copy sent to GP ☐ **ePCS completed** ☐ **Emergency Care Summary completed** ☐

Signature of Physician..... Date.....

Witnessed by (Print Name)..... Signature.....Date.....

Record of Review

Date	Signature	Date	Signature
.....	.....	.....	.....
.....	.....	.....	.....
.....	.....	.....	.....
.....	.....	.....	.....
.....	.....		