



Making decisions about future treatment

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Introduction

If you have dementia, it is likely that you will gradually become less able to make decisions for yourself. This means that you could be given medical treatment that you would not normally want, or other decisions could be taken that go against what you would like.

In this information sheet we talk about the best ways for you to say how you would and would not like to be treated when you are no longer able to decide for yourself. It can be

difficult to plan for the future when you don't know what the future holds. But by setting out your preferences you can help people to understand how you wish to be treated. Indeed, the process of thinking over how you would like to be treated may also help you to come to terms with your illness. The ways of planning for your future treatment are:

1. making a general advance statement for your physical care and for most of your dementia care
2. making an advance statement only concerning compulsory treatment for your dementia, if you need it in the future
3. appointing someone else to take over from you when you are unable to make decisions yourself (granting a welfare power of attorney)
4. making no plans, leaving it entirely to others to make the major decisions for you.

What is an advance statement?

Advance statements let you tell people how you would and would not like to be treated once you can no longer make these decisions for yourself. They allow doctors and other professionals to treat you as you would want to be treated.

There are two types of advance statements. The first is a general advance statement and the second is only for treatments if you became mentally unwell and need to receive compulsory treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003.

General advance statements

Some people use the term 'living will' or 'advance directive' to say what treatments you would *not* want in the future, but advance statements can be much wider than this.

What can I say in my advance statement?

Advance statements (except for if you have to be compulsorily treated for your dementia) can be made up of different sections. These sections are shown below. You could have just one section as your advance statement, or two, three, four or all five sections. We recommend that you include all five sections to give doctors the best idea of the treatment you would and would not like.

1. You can say which specific treatments you would not like to have. For example, you might not want to be resuscitated if your heart stops. This kind of advance statement is called an advance directive.
2. Instead of saying which specific treatments you would not want, you can say you would not want any life sustaining treatment if you were irreversibly ill and had no chance of getting better. For example, some people feel that if they had severe brain damage then they would not want to be kept alive.
3. You can request how you would like to be treated in the future. For example, you might want to receive all treatments your doctor thinks could help you.
4. You can write down what is important and meaningful in your life (called a 'statement of values'). This can be a list of statements or answers to questions (see page 8). The information you give shouldn't only be about medical care or treatment. The aim is to give enough information about your beliefs and values to help people making decisions for you understand what you would have wanted.

5. You can say who you would like to be consulted when a decision about your care and treatment needs to be made, if you can't make decisions for yourself. This will help your doctor know who to consult but doesn't give the person you list any power to make decisions on your behalf (that would require you to grant a welfare power of attorney – see page 5).

What can't I use an advance statement for?

Your advance statement can only be used when you can't make decisions for yourself. The doctor treating you has the responsibility of deciding if this has happened. You *can't* use your advance statement to:

1. say that you don't want basic care; for example, to be washed
2. insist on treatment that your doctor thinks is inappropriate
3. ask for your life to be ended (known as euthanasia). This is against the law in Britain.

Does the doctor have to do what I ask?

The law in Scotland says that doctors must look at your present and past wishes when deciding what treatment to give you. This is where the advance statement would be used. The doctor should also consult your main carer, family and welfare attorney (if you have one) where this is practical. If the doctor doesn't do what you have asked for, perhaps because he or she doesn't think it is in your best interests, he or she should write down why. A welfare attorney (or a welfare guardian appointed by the court) is the only person who can actually consent to treatment on your behalf.

What happens if I don't make an advance statement?

If you don't make an advance statement and you can't make decisions for yourself, the law says that doctors must ask your welfare attorney (if you have one), your nearest

relative and your main carer (if it's practical to do so) how they think you would like to be treated. In this case the doctor makes the final decision, but the people to be consulted have rights of appeal. This is all governed by the Adults with Incapacity (Scotland) Act 2000.

Sometimes a court may need to appoint someone to take decisions on your behalf. This may happen if there is no-one able to take an interest in your welfare, or if those caring for you do not agree. The court could appoint a welfare guardian or intervener to make formal decisions about your care and treatment.

How to write an advance statement

Here are some important points.

- It is very important that when you write your advance statement you can make decisions for yourself and understand the consequences of your decisions. So you should write it early on in your dementia – don't put it off too long.
- It is best to write your statement down, but you can also speak to your doctor about your future wishes. He or she will write your wishes in your notes. This can be used as an advance statement.
- You should speak to your doctor or another health professional you feel comfortable with when you are writing your advance statement. He or she will be able to give you advice on how your illness might progress and the types of treatment you might be offered in the future. You can also discuss the circumstances that might arise in the course of your illness where your advance statement would be useful.
- You should tell your family and friends your wishes because they will be asked how you would like to be treated, if you can't make the decision for yourself.

Your advance statement should include the following things.

- Your full name.

- Your full address.
- The name and address of your GP.
- Whether you spoke to your doctor about your advance statement.
- Your signature.
- The date that you signed the advance statement.
- It is a good idea to get a witness to sign and date your advance statement.

We have produced a template of an advance statement that you can use (it's on page 7). You might also want to carry a note with you at all times; for example, in your purse or wallet, to let people know that you have an advance statement. There is one you can cut out and use on page 9.

Once you write your advance statement, you should keep a copy for yourself and give a copy to:

- your GP
- your consultant at the hospital, if you have one
- your welfare attorney, if you have one (we talk about this on page 5)
- your nearest relative or the person who would be your main carer.

Write down all the people you have given a copy to so that if you need to change your statement, you will know who has a copy.

It is a good idea to review your advance statement frequently, perhaps once a year, to make sure it is up to date. If you have reviewed it but not made any changes, you should sign and date it again saying that you have done this. This is so that if doctors need to use it, they know that you still agreed with what you originally wrote.

If you need to make changes to your advance statement, you should write a new one. Make sure that if you write a new one, you destroy all copies of the old advance statement. This means you will have to contact everyone you gave a copy to. Ask them to destroy the old copy and replace it with the new one.

Advance statements under the Mental Health Act

There is a special type of advance statement you can make where you can say the treatments you would like and would not like for your dementia (or other mental illness). It **only** applies if you are being treated compulsorily under the Mental Health (Care and Treatment) (Scotland) Act 2003.

Most people with dementia will probably never need to be treated under the Mental Health Act. But the Act sets out how someone may be detained in hospital or treated in the community, against their will, if that is necessary.

Consider making this kind of advance statement if you have concerns, such as which treatments you might be given if you needed to be compulsorily treated or detained.

It is best if you can give reasons for your opinions. For example, if you don't want to get a particular type of tranquilliser you could say *"I would not want to have this type of tranquilliser because it takes me a long time to feel better after taking it"*.

This type of advance statement is different from general advance statements because it is specially recognised by the law, and it must be signed by a witness.

If a doctor makes a decision that goes against what you say in your advance statement under the Mental Health Act, he or she has to write down the reasons and give it to you, your welfare attorney or guardian if you have one (see page 5), put it in your medical records and also give a copy to your 'named person'. A named person can help to protect your interests if you have to be given compulsory care or treatment. The named person will have to be told and consulted about aspects of your care, and can make certain applications; for example, if a person with dementia has to be treated compulsorily, the named person can apply to the Tribunal for a review of this.

A named person can be your carer, husband or wife, son or daughter or anyone else you would like to ask that agrees to be the named person. It can also be your welfare attorney, but the named person has a different role from a welfare attorney: the named person can only do things which relate to being detained or treated under the Mental Health Act, whereas a welfare attorney has broader responsibilities. You may find the booklet called *'The New Mental Health Act: A Guide to Named Persons'* useful. You can get a free copy from Blackwell's Bookshop (0131 622 8283 or 0131 622 8258) and you can see it on this website

www.scotland.gov.uk/Resource/Doc/26350/0012825.pdf

How do I make an advance statement under the Mental Health Act?

The most important thing is that you write the advance statement when you are able to make these decisions. We recommend that you get help in writing your advance statement from anyone who knows you well; for example, your doctor or your support worker.

There is a booklet called *'The New Mental Health Act: A Guide to Advance Statements'* that will give you more detail. It includes an advance statement form that you can fill in. You can get it from this website www.scotland.gov.uk/Resource/Doc/26350/0012826.pdf or call Blackwell's Bookshop (0131 622 8283 or 0131 622 8258) for a free copy.

If you don't want to use the form, you must include the following things in your advance statement.

- Your full name.
- Your full address.
- The full name and address of the witness and why they are allowed to be a witness. They must be a clinical psychologist, a doctor, an occupational therapist, a person working in or managing a care service, a nurse, a social worker or a solicitor. Some of these people might charge you for

signing your certificate, so make sure you check with them first.

- The witness must write that you were able to make these decisions when you wrote the advance statement.

It is good if you can also include the name and address of the following people, if you have them.

- Your named person.
- Your carer.
- Your GP.
- Your guardian or welfare attorney. A guardian is someone who can make decisions for you if you can't make them for yourself and have no welfare attorney (we talk about this on page 5).

What is a personal statement?

If you write an advance statement covering treatment for your dementia, it is also advisable to write a personal statement. In this you can explain important things other than treatment for your dementia. For example, you can say who you want to look after your pet if you are ill or if you have a special diet. You don't need to get a witness to sign this.

Who should I tell that I have made an advance statement under the Mental Health Act?

You should give a copy of your advance statement to the following people.

- Your named person.
- Your carer.
- Your family.
- Your GP and nurse.
- Your guardian or welfare attorney (if you have one).
- Your mental health officer (if you have one).
- Your solicitor.
- Anyone else close to you.

Some parts of Scotland differ in where you should send your advance statement. You should check with your GP, social worker or

Community Psychiatric Nurse (if you have one) whether the advance statement has to be stored in your medical records.

Should I review my statement?

You should review your statement about every six months to make sure your views are the same. If you change your mind about your advance statement, you can withdraw it and make a new one. If you withdraw it you need a witness to sign it. If you change your personal statement you don't need to get a witness to sign it.

Allowing someone else to make decisions for you

In Scotland, you can appoint someone to make decisions about your welfare, when you can't make decisions for yourself. You do this by writing a legal document called a welfare power of attorney. You could choose your husband, wife, child or a friend to be your welfare attorney. Doctors must speak to your welfare attorney when making decisions about your treatment, if you can no longer make decisions yourself. Your welfare attorney is the only person who can give consent for care or treatment on your behalf. If you want more information about how to make a welfare power of attorney, please read *Dementia: Money and Legal Matters*. You can get it from this website www.alzscot.org/pages/info/mandleg.htm or call the Dementia Helpline for a copy (0808 808 3000).

Alzheimer Scotland's recommendations

We recommend that you do the following things as early on in your illness as you can.

1. Make a general advance statement.
You can use our template on page 7.
2. Carry a note to say that you have made an advance statement. You can cut out and use the one on page 9.
3. Make an advance statement under the Mental Health Act (see page 4).
4. Appoint a welfare attorney (see page 5).

If you do all of these things, it will make sure that your wishes about your treatment will be

fully considered when you can longer express them.

Further information

If you live in England, Wales or Northern Ireland, the law is different so you should contact the Alzheimer's Society on 0845 300 0336.

For further information or support, or a copy of *Dementia: Money & Legal Matters*, please call Alzheimer Scotland's freephone 24 hour Dementia Helpline on 0808 808 3000, or visit our website at www.alzscot.org

General advance statement template

You can get a copy with more space from the Dementia Helpline (0808 808 3000) or from our website www.alzscot.org/pages/info/advancestatementtemplate.htm

This is my advance statement. When I wrote this, I could make decisions for myself and understand the consequences of my decisions.

My name is:

My date of birth is:

My address is:

When I wrote this, I spoke to these people:

My GP is called Dr

My GPs address is:

I do/do not have a welfare attorney. His/her name is:

My welfare attorney's address is:

The treatments I would like to receive are:

If I can't make decisions on my treatment, I would like you to consult this person:

I would not like to receive the following treatments under the following circumstances:

I do not want to receive any treatment to keep me alive if the following happens to me:

Here is my signature:

Here is the signature of my witness:

This advance statement was witnessed on (date):

Advance statement review

I reviewed this advance statement on (date):

Here is my signature:

Statement of values

If you choose to, you can also include a statement of what is important to you in your advance statement. Here is a list of things you might want to include (created by Alzheimer Europe).

1. Preferences

Here is a list of some preferences in my life that are important to me - for example, about what I wear, what I eat or drink, my personal habits and lifestyle, about company, about music or other entertainment, hobbies or pastimes, special interests, what things I have around me etc. Knowing about these will help those who care for me to ensure my comfort and well-being.

2. My spiritual and philosophical beliefs

Here I put down the spiritual or philosophical beliefs or principles that are important to me in my life. Here I also put down what, if any, religion I belong to, and what importance religion has in my life generally.

3. What makes life worth living

Here are some of the things that give special meaning to my life, including things about my health and welfare, relationships, work, leisure, art, sport and recreations. These are the things that make me the sort of person I am.

4. Dislikes

Here is a list of some of my important personal dislikes – for example, about things I do not like doing or being involved with, or things that I dislike others around me doing, or about my environment. Knowing about these will help those who care for me avoid causing me unnecessary distress or discomfort.

5. What I fear most

Here are some of the things that might take away the pleasure from my life, or make me feel that my life had lost its meaning or quality. They include things that would make me fearful, anxious or distressed.

6. Attitudes to making decisions

Here I put down my thoughts about how I like to make decisions – how independent-minded I am, and/or how much I tend to depend on the advice of others.

7. People who matter

This is a list of the most important people in my life, and how I would like them to be involved if I am not capable of making certain decisions about my health or welfare. Here I also list particular people that I would not wish to be involved if I were not capable of making certain decisions about my health or welfare.

8. My attitudes to professionals who are treating me and caring for me

Here I put down any particular views I have about my relationships with doctors, nurses or others in the other caring professions, especially the degree to which I tend to rely on their judgements.

9. Attitudes to illness and disability

Here I put down my views about how I might cope with illness or disability, including pain and discomfort, loss of my mental powers or loss of my physical abilities.

10. Attitudes to death and dying

Here I put down any beliefs or principles that should influence the decisions people make on my behalf when there is a possibility of my imminent death. This includes my views about the sanctity of life, and about maintaining life artificially. Here I also put down any particular beliefs or views I hold about giving treatment to relieve pain or suffering, and about artificial methods of feeding, where giving or withholding these might either hasten or delay my death. Here are my wishes about the circumstances of my death, understanding that, for a variety of reasons, these wishes may be difficult to achieve. These include where I would like to be and whom I would like to have around me.

11. After my death

Here are some wishes about what should happen in the time after my death; for example, about who should be informed, my funeral etc.

12. Other values

Here I put down any other values, principles or beliefs that I have not mentioned before, but which are important to me.

Note to tell people you have made an advance statement

Here is a note to tell people that you have an advance statement. The person you name on the note could be your carer, your welfare attorney or nearest relative. You can cut it out and carry it with you all the time; for example, you could put it in your purse or wallet.

Medical treatment information
My name is: _____
I have made an advance statement about the care and treatment I want. If I can't make the decision for myself, please contact this person.
Name: _____
Phone number: _____
My GP is called Dr: _____
My GP's phone number is: _____