

Friends at the End
Promoting end of life choices



Advance Directives/ Decisions

Version: November 2017

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Introduction

There are many different templates available for the documents that were previously known as Living Wills and are now called Advance Directives in Scotland and Advance Decisions in England and Wales. For convenience, we will refer to these documents as ADs. There are also examples of ADs available from the charity Advance Decisions Assistance (see 'Resources' section at the end of this leaflet).

An AD is a formal document which enables you to refuse life-prolonging medical treatments/interventions in the event of a situation arising in which you cannot refuse them at the time (eg because you are unconscious — perhaps in a coma — following a stroke, heart attack or car crash).

Many people are sure they would not want to be kept alive in a long-term coma-like state. According to a recent YouGov poll, 82% of people have strong views about their end-of-life treatment but very few (only about 4%) have made an AD.

One of the reasons for this is that many people wrongly believe that family members would be able to make health care decisions on their behalf if they were unable to do so themselves. In fact, such decisions are made by your medical team, and must be done in your 'best interests' (a legal term), unless you have written an AD (or appointed an Attorney to act on your behalf). The medical decision-making process should include, but is not limited to, what you would want — and recent legal cases have shown that 'sanctity of life' can take priority over what the person might have wanted.

Writing an Advance Directive/Decision

Anyone over 16 (18 in England) who has the mental capacity to understand, retain and weigh the information relevant to their decisions can write an AD. They are binding in common law in Scotland and Northern Ireland and legally-binding under the Mental Capacity Act 2005 in England and Wales.

As long as an AD is valid and applicable, it has effect as if the person had made the decision contemporaneously. It needs to be witnessed and dated.

You don't need a solicitor or a special form to write an AD — FATE has however produced one and there are others freely available from charities that can help you think through the issues. Charities such as the Alzheimer's Society or the Motor Neurone Disease Association offer disease-specific ones (see their websites for details).

An AD can be as simple as a paragraph that says:

I refuse all medical treatment or procedures/interventions (including but not limited to clinically assisted nutrition or hydration) aimed at prolonging or artificially sustaining my life if I am persistently unconscious and have been so for at least four weeks and there is little prospect of recovery in the opinion of two appropriately qualified doctors. I maintain this request even if my life is at risk.

This is valid if signed and witnessed, and it would become applicable as soon as you have been unconscious for four weeks.

You should specify what you mean by 'recovery': for one person it might mean the ability to return to work; for another it may simply mean the ability to recognise and communicate with loved ones.

Other points to consider

- Make sure that you are refusing what you want to refuse. For example you may have refused life-prolonging treatments if you are 'unconscious', but would you also wish to refuse them if you were 'minimally conscious' ie conscious in only a very fragmentary or fleeting way?
- Include a 'statement of capacity' – available from your GP - if there is any possible doubt about your capacity when you are making the AD (eg if you are, or have recently been depressed, or have had a dementia diagnosis).
- Review and re-sign your AD annually — more often if your medical, or other, circumstances change; and review it before elective surgery, ensuring the hospital has the updated copy. Consider including the statement:

I intend this AD to be valid indefinitely unless it is specifically revoked.

- If you already have an AD, or a pre-2005 'living will', it may no longer be valid — eg if it is not signed and witnessed; and does not include the statement "I maintain this request even if my life is at risk". (If you are not sure whether your AD is valid, you can get advice about this from Advance Decisions Assistance – contact details at the end of this leaflet.)
- If you have completed a 'Do Not Resuscitate' form (available from your GP) you should attach a copy to your AD.

Consider adding a Values Statement

This provides the opportunity to say what you value about life, what degree of 'recovery' would be acceptable to you, what you fear, and what really matters to you. Describe your values, wishes and beliefs, explaining the reasons underpinning the decisions you have made as this could be persuasive if there is any doubt on the part of the medical professionals.

It is not always easy for medical professionals to withhold or withdraw treatment and your statement may help them. Research also shows that healthcare teams appreciate an acknowledgement that complying with your wishes may be difficult for them, and thanks for doing so.

Consider including a sentence like:

I offer the healthcare team my heartfelt thanks for respecting my sincerely held wishes, as expressed here.

None of this is legally required: it simply increases your chances of having your AD respected.

Copies of your Advance Directive/Decision

We suggest that you make a copy for yourself, and additional copies for your:

- **Welfare Attorney (Scotland)/Lasting Power of Attorney for Health & Welfare (England & Wales) – if you have appointed one**

These are your legally-appointed representatives.

- **Family members and significant others**

A great benefit of making an AD is the opportunity to discuss these vitally important matters with your family and others. (Note that if they disagree, or won't talk about these matters, your AD is still legally binding.)

- **General Practitioner and any other medical specialists involved in your care**

Discuss your AD with your GP and/or other relevant medical specialists. They may be able to help strengthen it by including things you that have not occurred to you — and they obviously also need to know what you want and do not want. Most crucially, having discussed your AD, make sure your GP puts it – prominently - on your medical records.

If your doctor objects to your Advance Directive/Decision on grounds of conscience, you should consider changing to another doctor. Remember that an Advance Directive is binding under common law in Scotland and Northern Ireland, and an Advance Decision is legally-binding under the Mental Capacity Act 2005 in England and Wales.

- **Hospital**

You should ensure that your AD is known to the Medical Records Department and its existence features prominently on any computerised records. Remember that most of the decisions regarding implementation of an AD will be made in hospital.

- **Lawyer** (if appropriate).

Note, however, that you should not simply put your AD with your will – it is of no use after your death!

Maximising effectiveness

As there is no central register for lodging an AD, here are some ways of trying to ensure that it is available when needed:

- Give copies to the people indicated above – especially your GP.
- Wear indicative jewellery — MedicAlert or SOS Talisman.
- Use the Lions ‘message in a bottle’ scheme.
- Check you are on your local Ambulance Service’s end-of-life register (if it has one) if you do not want to be resuscitated.
- (If available) register with an advance care planning scheme — such as London’s ‘Co-ordinate My Care’ — this includes the possibility of logging an AD. Some areas of Scotland use Palliative Care Summaries or ePCS where your AD can be recorded.

Resources

You can obtain a simple AD template from FATE.

You can obtain help in writing an Advance Directive/Decision from the charity Advance Decisions Assistance (ADA).

Website: <http://ADassistance.org.uk>

Email: info@ADassistance.org.uk

Telephone (answerphone): 01757 289453

You might also be interested in the following articles:

Kitzinger, Celia. 2014. Advance Decisions: Do they work in practice? *Elder Law Journal* 4(2): 123-238. Available (under "Publications") at <http://cdoc.org.uk>

Kitzinger, Celia and Wilkinson, Sue. 2015. A matter of life and death. *The Psychologist* 28(12): 972-974. Available from ADA website (as above, under "Resources").

And you might also like to read other publications from FATE:

Introduction: *Purposes and membership*

Why we support assisted dying

Dying well: *Possible directions to your carers when you are terminally ill*

A journey to Switzerland: *Is someone close to you considering assisted dying?*

The last kindness: *Experiences of a veterinary surgeon and thoughts on assisted dying*

Death of my father: *From a member of Friends at the End*

Welfare Power of Attorney (Scotland)

Lasting Power of Attorney (England)

Do Not Attempt Resuscitation

UK Guide to Dignitas (Available to FATE Members only)

One way to die: *Voluntary refusal of food and fluids* (Available to FATE Members only)

Acknowledgement

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Why not join us?

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Office 7, Unit 2, Kirkhill Office Park, Broom Road East,
Newton Mearns, Glasgow, G77 5LL

0141 356 4222

www.friends-at-the-end.org.uk

info@friends-at-the-end.org.uk