



DementiaUK

Helping families face dementia

Planning *NOW* for *your* FUTURE

Advance care planning

What is advance care planning?



There has been a lot of work over the past 15 years to help people in the UK to talk and think more openly about dying, death and bereavement, and also to make their own end of life plans.

The aim of advance care planning is to help you understand the range of different ways you can plan now for your future. We hope it will enable you to consider which plans might be useful to you and those close to you. There is an Advance Care Plan template (ACP) that accompanies this booklet.

Advance care planning is a process to help you plan and record your future wishes and priorities of care with those close to you. This means there is a record of your wishes when you may no longer be able to make or communicate such decisions.

This Advance Care Plan guide and the accompanying template have been designed in consultation with people with dementia and their carers and aims to help you to start making your own ACP with the help of those around you. It can initially seem like a difficult thing to think about, and many people do not know where to start. This advance care planning booklet tries to help you think about some of the things you may wish to talk about and consider writing down. You may already have thought of some of these things in the past and may have even talked about them with your family, friends and carers. It can help you to develop an **Advance Statement (AS)** that expresses some of the things you may or may not want in your future care.

“Advance care planning is not a one off conversation but something that is developed over time...”

The process of advance care planning is not designed to be carried out in a ‘one off’ conversation or meeting but is a process that takes place over time, perhaps with several discussions with those around you.

Some of the questions or things we suggest you think about may not be easy and may take time or consideration; you may wish to come back at another time and that is fine. Once it has been written down it does not mean it cannot be changed; it is expected that the contents are reviewed at times to ensure they are still valid – so including future review dates is encouraged.

The Advance Care Plan

The Advance Care Plan is designed to help to guide you in making your wishes and preferences known and make a record of these, if you want to. You do not have to complete all parts if you do not wish to. The first part allows you to record your own details. The main part of the Plan takes you and those close to you through a process to identify some of the things you value most; choices, preferences, things important in your life and that you would want to be considered at a time when you may not be able to express these. There is space for you to make notes which may help you to write an Advance Statement of your wishes and priorities and also in addition, if you wish to do so, make an Advance Decision to Refuse Treatment (ADRT).

The Plan may introduce some terms you are unfamiliar with so we have included a short explanation of these in the glossary (see page 6).

Lastly, and most importantly, when you have completed your Advance Care Plan (including your Advance Statement of wishes and/or Advance Decision to Refuse Treatment) it can be copied to others involved in your care.

Advance Statement

This section will help you to think about things that are important to you at a time when you may be unwell and need care or treatment. It will help those around you (family, friends and professionals) to have an understanding of those things that are important to you if for any reason you are unable to make your own wishes and preferences known at the time. You may wish to add some of this information to your **ACP** (see ACP template). While this section is **not legally binding** for health care it can still provide a useful guide as to what is important to you and will help facilitate future decisions on your behalf.

These are some examples of information which you could consider when developing your Advance Statement:

- If you are no longer able to care for yourself, where would you prefer to be cared for if possible?
- What important things do people who care for you or treat you need to know about you? For example, do you have any people or pets who are dependent on you?
- What are your thoughts and wishes about organ donation?
- What activities do you enjoy most in your life? Would you like help to continue these activities?

There are a list of questions in the accompanying ACP template that are aimed at helping you to start thinking about what is important to you and will help people understand more about you.

Advance Decisions to Refuse Treatment (ADRT)

An Advance Decision to Refuse Treatment (ADRT) is different from the Advance Statement that encourages you to record your future wishes and preferences. An ADRT, if completed properly, is a legally binding document that allows you to **refuse** certain treatments, that would not be acceptable to you, in the future. **You cannot request treatments this way.** For example, if you developed severe swallowing problems as part of another condition and if you felt that being fed by a tube was intolerable then you could develop an ADRT document to formally state this.

To properly develop an ADRT you should seek advice from someone who understands how to document your wishes in a formal way, e.g. GP or Solicitor. If it includes a refusal for life sustaining treatment it must be in writing, signed and witnessed and include the term 'even if my life is at risk'.

An ADRT will only be used if, at some time in the future, you lose the ability to make your own decisions about your medical treatment. This type of document can only be developed at a time when a person still has the mental capacity to do so. You can change your mind or alter your ADRT at any time; provided you still have the mental capacity to do so (you may wish to refer to the information on the Mental Capacity Act 2005 on page 7).

There are several examples of ADRT forms available which can be downloaded from the internet. You may ask your Admiral Nurse or other health professional for further guidance.

www.necn.nhs.uk/wp-content/uploads/2014/06/ADRT-NHS-Print-Form-v8-April-2013.pdf

www.compassionindying.org.uk/wp-content/uploads/2014/12/Large-Print-2014-Advance-Decision-Pack.pdf

My Will

Making a Will is probably the most commonly undertaken form of planning for end of life and can give you control over how your property and belongings are distributed after your death.

If you die without making a Will, your money and belongings will be divided according to legal rules and sorting out your affairs often becomes time consuming and costly.

How to make a Will

A solicitor can help you to draw up a Will for a fee. You will need to have the mental capacity to make a Will, and it will need to be signed and witnessed by two people. It is best to seek advice from a solicitor as they will ensure your Will is legally 'water tight'. You can find a solicitor via the Law Society website [solicitors.lawsociety.org.uk](https://www.lawsociety.org.uk) (England & Wales), www.lawscot.org.uk/find-a-solicitor (Scotland), www.lawsoc-ni.org/solicitors (Northern Ireland).

Or you could have your Will drawn up by a professional via the Institute of Professional Will writers www.ipw.org.uk

Before speaking to a solicitor, or Will writer, it would be helpful to think about a few things:

- Decide who will be named as your executors – the people who will make sure your wishes are fulfilled
- Calculate the value of your assets; make note of your possessions from small items, such as jewellery, to larger assets including property, savings and investments
- Choose the family and friends you would like to remember in your Will. After them, consider whether you would like to leave a gift to charity

Changes to your Will

Family circumstances can often change, such as the death of a partner or through divorce, which may cause you to change what you leave, and to who. If you already have a Will then contact the solicitor who originally helped you to draw it up or you may wish to seek a new solicitor (refer to the Law Society details above). Information from the Citizens Advice Bureau may also be useful. www.citizensadvice.org.uk/family/death-and-wills



Small and simple changes or additions to a Will can be made with a supplement called a Codicil. This needs to be signed and witnessed, like your original Will, but the witnesses needn't be the same people. There is no limit to the number of Codicils that can be added to your Will, but for any major changes, a new Will should be drawn up.

For further information on Wills or if you would like to leave a gift to Dementia UK, visit: www.dementiauk.org/giftsinwills or call **020 7697 4322**

Further Information

1. *Good Decision Making: What you need to know about the Mental Capacity Act and end of life* is a book you can purchase from www.ncpc.org.uk/news/new-edition-good-decision-making-best-guide-mental-capacity-act-and-end-life-care
2. Information booklets about the Mental Capacity Act 2005
www.gov.uk/government/collections/mental-capacity-act-making-decisions
3. Forms and information about Lasting Power of Attorney (LPA).
The Office of Public Guardian www.gov.uk/power-of-attorney
4. If you have any questions or concerns, our specialist Admiral Nurses provide practical and emotional support.
Admiral Nurse Dementia Helpline 0800 888 6678 helpline@dementiauk.org

Glossary of Terms

A glossary of terms used:

Advance Care Plan (ACP)

An Advance Care Plan is a term used to describe the discussion between an individual, their care providers, and those close to them, about future care. Even if a person does not wish to write anything down, these discussions are still useful.

Advance Statement

An Advance Statement is a written record of general beliefs and aspects of life a person values; wishes and preferences for future care. This is not legally binding.

Advance Decision to Refuse Treatment (ADRT)

An Advance Decision to Refuse Treatment is a specific refusal of treatment(s) in a predefined potential future situation and when worded and registered correctly, is legally binding.

Lasting Power of Attorney (LPA) - Property and Financial Affairs

This allows you to choose someone to make decisions about how to spend your money and manage your property and affairs when you no longer have the capacity to do so for yourself.

Lasting Power of Attorney (LPA) – Health and Welfare

This allows you to choose someone to make decisions about your health care and welfare. This includes decisions to consent to or refuse treatment on your behalf, including deciding where you live when you no longer have the capacity to do so for yourself. All LPAs are only valid when registered with the Office of Public Guardian www.publicguardian.gov.uk

The Mental Capacity Act 2005 (MCA)

Capacity is the ability to make a decision for yourself. The MCA states a person has capacity to make decisions for themselves unless proved otherwise. It is important when making ACPs that a person can demonstrate they have understood the decisions they are making. Those supporting them in making these decisions must also be aware of the MCA www.gov.uk/government/collections/mental-capacity-act-making-decisions

Best Interest Decision

This is when a decision is made on your behalf when you are no longer able to do so. It will take into account many factors and views. This can include an Advance Statement (if you have made one) as well as the opinions and views of others i.e. family, friends and professional carers who know you well. If your Admiral Nurse, or another health care professional, is helping you to complete this document then please ask if you need more information on this.

Living Will

Living Will is now an outdated term that is used to describe, what we now call, an Advance Care Plan which includes many of the aspects talked about in this booklet. Some people may have developed a Living Will many years ago and these may still be useful to guide your care at the end of life.



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info@dementiauk.org • www.dementiauk.org

Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).