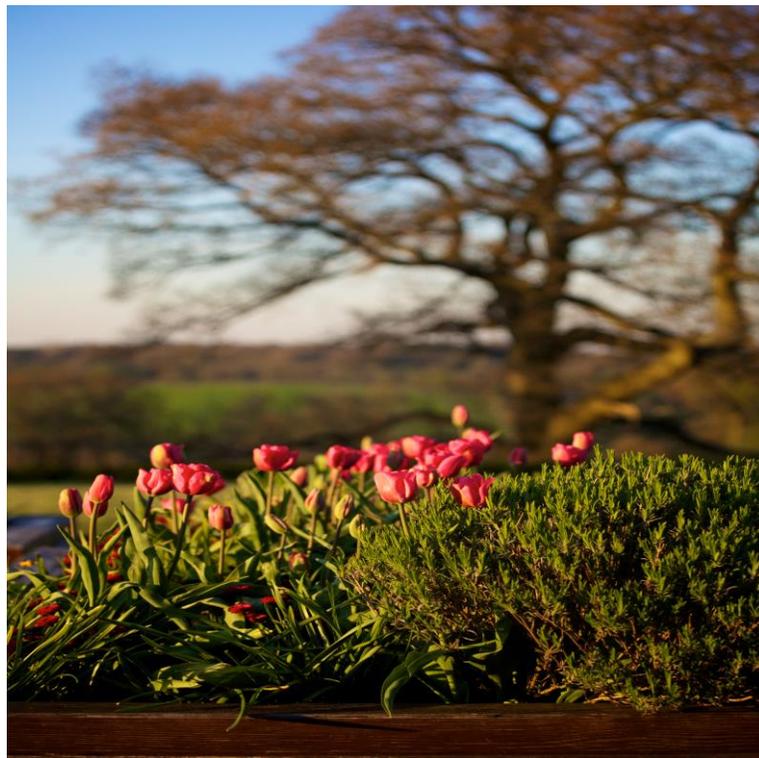




# Future Planning:

## Advance Care Planning Guide

For People and Those Who Are Important To Them



Information from the Hospice of St Francis / Isabel Hospice

## Introduction

Welcome to **Future Planning: Advance Care Planning Guide**. It is not easy to think or imagine a future without you or those you love in it.

However some people find it helpful to discuss and plan for their own end of life. As you discuss and plan for the future, you may wish to take your time and talk with those close to you. You might also find it helpful to discuss with your doctor, nurse, hospice, palliative care, hospital, health and social care teams. Please feel comfortable to do this.

This booklet is designed to give you and those who are important to you more information about **Advance Care Planning** and the documents that you might want to use.

### Advance Care Planning

- ✓ Is a way to discuss and record what is important to you about your care or medical treatment if one day you are unable to tell people yourself (e.g. if you are too unwell).
- ✓ Can help you prepare for the future and inform those important to you of your wishes and choices.
- ✓ By discussing and recording your wishes and decisions it will help your family, health and social care team and those who are important to you to take into account what matters to you about your care and treatment at the end of life.

We have included information for you about the process and documents used in **Advance Care Planning**.

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**1. What is Advance Care Planning?**

Advance care planning is the discussion and regular review to help you consider, discuss and decide about what matters to you care and treatment in the future.

You can write down and record your choices through an **Advance Care Plan**.

An **Advance Care Plan** is different to a Will. It is a way to tell others about what is important to you and how you would like to be cared for if you are unable to tell them yourself. Thinking, discussing and deciding in advance (**Advance Care Planning**) can really help to make sure people know what you want or don't want if sometime in the future you not able to tell them yourself.

Talking about these things can sometimes be emotional or tiring, so don't feel that you have to do it all at once. Advance care planning is an ongoing activity, so it sometimes takes time.

Talk to those who are important to you. Talk and discuss with your nurse, doctor, hospice, hospital, palliative care, health and social care teams. Give yourself time to have these conversations and talk with those close to you. The things that are important for you are more likely to happen if you share your ideas and thoughts.

**2. What does an Advance Care Plan include?**

An **Advance Care Plan** may include one or more of the following:

- a. An Advance Statement\*
- b. Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)
- c. A Lasting Power of Attorney\*
- d. An Advance Decision to Refuse Treatment\*

*\* In England and Wales we use these terms but you may sometimes hear the terms Living Will, Advance Directives and Enduring Power of Attorney which are terms used in other countries.*

- e. Practical issues such as your Will or plans you have for your funeral

Advance Care Planning (The activity)		Leading to the Advance Care Plan (The plan)	
Advance Statement	DNACPR	Advance Decision to Refuse Treatment	Lasting Power of Attorney
Will, Funeral Plan and Anything else important to you <i>Remember that you can always make changes to your Advance Care Plan. What is important to you may change so don't forget to look again at your Advance Care Plan and make sure it is still what you want.</i>			



## 2a. An Advance Statement (sometimes called A Statement of Wishes and Preferences)

This is a way for you to write down and tell those who are important to you, health and social care teams what you know about your illness and what is important to you about your care and treatment. If at any time in the future you cannot tell them yourself, then the **Advance Statement** can be used to help those who are important to you, health and social care team make the decisions for your care based upon what you have already told them.

### ***It is only used if you cannot say yourself what matters to you***

You may want to include things like:

- ✓ If there are any treatments that you do not want, for example resuscitation (restarting your heart if it should stop) or other medical treatments. A more formal way to do this is by doing an **Advance Decision to Refuse Treatment** which we discuss later.
- ✓ If you became too ill to care for yourself, where you would prefer to be cared for or where you would like to die (e.g. at home, in hospice, hospital, in a care home or with a family member). Sometimes people also like to say where they do not want to die or be cared for.
- ✓ If your condition worsened, how much information you would like about your condition or how much or who you would want to be involved in decision making.
- ✓ Is there anyone that those who are important to you or health and social care teams should be consulting with if you can't say yourself what you want. A more formal way to do this is for you to appoint a **Lasting Power of Attorney** which we discuss later.
- ✓ What are your thoughts about organ or tissue donation, as you may need to make sure people are aware of your wishes
- ✓ How you would like to be cared for (e.g. music you like, who you would want to visit you, any religious or spiritual care)
- ✓ Your thoughts about anyone depending on you (e.g. pets, children or relatives)
- ✓ Anything else that matters to you.

When you have completed your **Advance Statement** it is important to let those who are important to you, hospice, hospital, health and social care teams know about it, so that they can use it in the future.

***Please see our example of an Advance Statement which you may wish to use.***



## 2b. Do NOT Attempt Cardio Pulmonary Resuscitation (DNACPR)

CPR is an emergency treatment which tries to restart a person's heart or breathing when these have suddenly stopped. Sometime the media present CPR as being very successful. In fact when people have a serious illness only about 1 in 100 who receive CPR will recover enough to leave hospital. <http://www.stchristophers.org.uk/wp-content/uploads/2015/09/STCH-Advance-Care-Plan-web-version-1112.pdf>

This can be a very emotive subject but you may feel that in the event of a cardiac arrest you would not want to be resuscitated. If you feel strongly about this subject and would like to discuss it further please liaise with your Oncologist, GP or Nurse Specialist who will be able to give you more information.

## 2c. A Lasting Power of Attorney (LPA)

A **Lasting Power of Attorney (LPA)** enables you to give another person the right to make decisions about your property and/or personal health and welfare if you are unable to tell anyone yourself.

It only comes into force if you lose the ability to tell those who are important to you, health and social care teams your preferences and wishes.

You have to be over the age of 18 years to make a **LPA**.

There are two types of Lasting Power of Attorney:

1. **Health and Welfare Lasting Power of Attorney:** This allows you to choose one or more people to make decisions for things such as your daily routine (e.g. eating and what to wear), medical care, moving into a care home or life-sustaining treatment. This type of lasting power of attorney can only be used when you're unable to make your own decisions
2. **Property and Financial Affairs Lasting Power of Attorney:** This lets you choose one person or more to make decisions about money and property for you, e.g.: paying bills, collecting benefits, selling your home. This type of lasting power of attorney can be used as soon as it's registered, with your permission.

There are special rules about appointing someone as your **LPA** and you must complete and register the forms with the Office of the Public Guardian available from <https://www.gov.uk/power-of-attorney/overview> . It can take up to 10 weeks to register a LPA.

*(Above information correct as of 17.06.15).*



## 2d. An Advance Decision to Refuse Treatment Document (ADRT)

This is a document for you to write down and inform those who are important to you, health and social care teams **in advance** any treatments you wish to **refuse** in the future. It is used if you cannot say your wishes yourself. The Mental Capacity Act (2005) outlines the legal nature of **ADRT's** and your **ADRT** must comply with these specifications. We recommend that you should not complete an ADRT without consulting your Consultant, GP or Nurse Specialist for advice. They will also be able to advise on who you can ask to witness this document.

### What an ADRT **is not**:

- ✗ A document requesting to have *your life ended*
- ✗ A document to *demand* medical treatments.
- ✗ A document to *refuse the offer of basic care* that gives you comfort such as assistance with personal hygiene or the offer of food and water.

### What an ADRT **is**:

- ✓ A formal document used to **refuse in advance** specific medical treatments in specific circumstances.
- ✓ It should be discussed with your health care team (e.g. doctor or senior nurse) so that you have the opportunity to talk through what you wish to refuse.
- ✓ It is advisable to inform those who are important to you, health and social care teams of your **ADRT**, so that they know it exists and can act upon it if you cannot tell them your wishes yourself.
- ✓ If you change your mind about the **ADRT**, you should let everyone know.
- ✓ The **ADRT** only comes into force if you are unable to tell everyone your wishes yourself. Whilst you are still able you still tell others about your wishes and choices.

Examples of treatments that you may want to refuse in advance in your **ADRT** might include:

- ✗ Resuscitation or restarting your heart if it should stop
- ✗ Feeding you through artificial tubes if e.g. if you had a severe stroke and could not swallow
- ✗ Going back into hospital to have antibiotics for specific types of infections or specific surgery when you have decided that you do not want it anymore.

**An example of an Advance Decision to Refuse Treatment can be obtained from your hospice team.**



### 3. Discussing with those who are important to you about Advance Care Planning

It is not always easy to think and discuss with those who are important to you your thoughts and choices and about what is important to you for the future. You may be worried about upsetting each other or just not want to see a future without you in it. What helps?

1. Sit down together to discuss things.

- ✓ *'can we talk about if things get worse'*
- ✓ *'let's sit down together and talk about what might happen in the future'*
- ✓ *'well since you mention it, I am a bit worried about what would happen if I went back into hospital again, let's talk about it'*
- ✓ *'I have been wondering about what would happen if...'*
- ✓ *'I know it is not easy to talk about these things...or we have never talked about these things before but....'*

2. Share your worries, thoughts and concerns – about yourself and them

3. Be prepared that you both may feel emotional during conversations

4. Agree a time to make any decisions or choices

5. Think about what other family and friends might need to know about your conversation and decisions – they may be able to help or have ideas and suggestions as well

6. Share your advance care planning documentation and use it as a way to discuss your thoughts and feelings with your family, friends and health and social care team. Don't be afraid to ask your doctor, nurse or carer for advice.

There are also useful resources available from a variety of websites that you could use to discuss and share such as:

<http://www.dyingmatters.org/overview/resources>

<http://www.macmillan.org.uk/Cancerinformation/Endoflife/Endoflife.aspx>

<http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers>

[Advance decisions and advance statements - Alzheimer's Society](#)

<http://www.mndassociation.org/forprofessionals/mndmanagement/palliative-and-end-of-life-care/planning-ahead-for-end-of-life/>

#### 4. My Advance Care Planning Reminders

*(Note to hospice, hospital, health and social care professional – please photocopy this sheet for your records with my permission)*

**My Name and Date of Birth:**

**My Address:**

I have completed:	Yes	No	Date Completed	I have agreed who can be made aware of these documents	
				Yes	No
My Advance Statement					
My Advance Decision to Refuse Treatment (ADRT)					
My Lasting Power of Attorney <ul style="list-style-type: none"> <li>○ Health and Welfare and/or</li> <li>○ Property and Affairs</li> </ul>					
My Will					
My Funeral Plan					
Do Not Attempt Cardio Pulmonary Resuscitation?					

**Other Useful Information about me**