

**Advance Care  
Planning  
FAQs**

**Thinking about the  
future, planning  
ahead and starting  
the conversation**

# What do we mean by Advance Care Planning (ACP)?

Living with a serious illness, or becoming frail as we age, can bring about challenges for our future health and care and most of us prefer to avoid thinking about it. While all of us will die one day, this is something we rarely discuss in society and for some it is considered a 'taboo' subject. However, not talking about it can make people feel alone and scared about the future.

At the same time many of us fear losing control around decisions relating to our health, including what treatments we will receive, what care we will need and how and where we will die.

ACP is a voluntary process, with you at the centre, and involves discussing your preferences and priorities for your future care with your healthcare team. The process of ACP usually involves a number of conversations over time, with whoever you wish to involve. Most people like to include those closest to them in these conversations as well.

## What are the benefits of ACP?

When Advance Care Planning is done well, people feel they have had the opportunity to plan for their future care. They feel more confident that their care and treatment will be focused on what matters most to them in a personalised, holistic way that helps them to achieve the best quality of life possible.

Thinking ahead and writing down what matters to you can be a daunting process. However, if no one else knows what is important to you, it makes it hard to ensure your preferences and choices are taken into consideration if you become less well and can't speak up for yourself.

It may be difficult to talk together as a family, you may worry about upsetting them, but having these conversations in advance will help your family and health care professionals make the right decisions for you if you are ever too unwell to make your wishes known.

These conversations may help reduce your family's distress if they know they are supporting what you want.

## **If my healthcare team start talking about ACP, does it mean they think I will die soon?**

No. ACP discussions can take place at any time. They may take place when you and your health practitioner have noticed that your condition is beginning to change or progress, however these discussions can also happen whenever you start to think about what care you might need in the future or what treatments you may or may not wish to receive.

## **Can I request any treatment that I want?**

No. The final decision regarding what treatments will benefit you lies with the senior clinician looking after you. For example, you cannot request that cardiopulmonary resuscitation be attempted when your heart stops if the clinical team feel that this will not work or may harm you.

## **Where can I write down my preferences?**

We have included a form at the end of this leaflet which you can fill in to express your preferences. This can be copied into your electronic notes and the original form should be kept by you and your family.

We also recommend that we record your views and wishes electronically on the NHS Universal Care Plan. This is a digital record which is shared and can be viewed by doctors, nurses, social care and emergency services to help them to understand the choices you have made about your care. Emergency services include the ambulance service, NHS 111 telephone service and the out of hours GP service.

## **Can I change my mind once I have written down my wishes?**

Yes. Recording your preferences in this way creates an 'advance statement' which is not legally binding, but it will be a helpful document to guide your family and clinical teams should you not be able to communicate your wishes. You should review it regularly with those important to you and your healthcare team and you can change your mind at any time.

# What is an Advance Decision to Refuse Treatment (ADRT)?

An Advance Decision to Refuse Treatment (ADRT) is a legally binding document normally discussed and written with your clinical team, which details specific treatments or interventions that you do not want to receive. For example, receiving ventilation, artificial (tube) feeding or intravenous antibiotics.

It is important that an ADRT is put in writing, signed and witnessed and that it includes a statement that ensures the decision stands 'even if life is at risk'.

<https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Advance-Decisions-to-Refuse-Treatment-Guide.pdf>

## Can I make legal arrangements for someone to make decisions for me in the future?

Yes. A Lasting Power of Attorney (LPA) is a legal document that lets you appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf.

There are two types of LPA: Health and Welfare, and Property and Financial Affairs. The process involves choosing your attorney (you can have more than one), filling in the online forms to appoint them as an attorney, registering your LPA with the Office of the Public Guardian (this can take up to 20 weeks).

Visit the government website for a step by step guide and to find out how much it costs to register an LPA, unless you get a reduction or exemption.

You can cancel your LPA if you no longer need it or want to make a new one.

<https://www.gov.uk/power-of-attorney>

# Who can I talk to if I want further help about anything in this leaflet?

Any member of the St Raphael's Hospice Team will be pleased to talk to you about anything relating to ACP. You can contact them by telephoning 020 8099 7777. Or, if you prefer, you can speak to your own GP, District Nurse or Hospital Team.

Thinking about the future may have raised questions or fears about what might happen, please talk to us about anything that is on your mind. We know these conversations can bring up all sorts of emotions and we want to support you in every way we can.

This leaflet has been written with reference to NHS England's Universal Principles for ACP (see below table). If you have any concerns that these are not being followed please speak with a member of the Hospice Team or your GP.

## Universal Principles for Advance Care Planning

1. The person is central to developing and agreeing their advance care plan including deciding who else should be involved in the process.
2. The person has personalised conversations about their future care focused on what matters to them and their needs.
3. The person agrees the outcomes of their advance care planning conversation through a shared decision making process in partnership with relevant professionals.
4. The person has a shareable advance care plan which records what matters to them, and their preferences and decisions about future care and treatment.
5. The person has the opportunity, and is encouraged, to review and revise their advance care plan.
6. Anyone involved in advance care planning is able to speak up if they feel that these universal principles are not being followed.

This form is for you to fill in to express your preferences. This can be copied into your electronic notes and the original form should be kept by you and your family.

## Thinking about the future, my thoughts and preferences

Name: ..... Date:...../...../.....

The following examples may help you to start thinking about your preferences and what matters most to you.

### About me

Being able to.....  
.....  
.....is the most important thing to me.

For me, a life worth living is where I .....  
.....

### About Life

What does a good day look like to me?.....  
.....

What's on my bucket or wish list?.....  
.....

What do I value most in life?.....  
.....

What do I fear most / wish to avoid:.....  
.....

### About Choices

I would want.....to help my clinical team to make medical decisions on my behalf if I was unable to.

If.....happened to me, I would want.....

I was thinking about what happened to .....  
.....and it made me  
realise that .....

This next section details specific preferences regarding future care and treatment. This part of the form may feel quite difficult to consider, take your time and talk to your loved ones and your clinical team for support.

## Decisions related to your health and treatment preferences should you become less well.

My main focus is on:

*(please circle)*    **Living as long as possible**        **Quality of life and comfort**

Would you wish to be transferred to hospital if you have a reversible condition which may respond to treatment or if an admission to hospital may improve your symptoms e.g. for Intravenous antibiotics?

*(Please circle Yes or No)*

**Yes**, I would like to be admitted to hospital

**No**, I would not wish to be admitted to hospital even if interventions may prolong my life. I would prefer to focus on quality of life and symptom control interventions that can be given at home / nursing home / hospice.

Comments .....

There are rare occasions where the clinical team may recommend hospital as the only place to safely care for you, for example in the rare event of a fractured bone, hospital admission is advised for orthopaedic team review and to ensure comfort and pain control or if being in hospital will keep you safe from harm.

If your heart and breathing stops, has your clinical team discussed with you, and those important to you, what should happen? *(Please circle)*

**Yes**        **No**

I have a Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decision in place *(Please circle)* **Yes No**

Some people may respond to cardiopulmonary resuscitation (chest compressions, defibrillation and ventilation) when their heart and breathing stops however for most people with a life limiting illness this is rarely beneficial and may prolong the natural dying process. Please note that this is a decision made by the clinical team looking after you. If you would like to discuss this please talk to us, we also have written information that may help you think about this further.

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Where would you like to be cared for if you are less well and need help looking after yourself (home with care, a friend or relative's home, nursing home)?

**First preference:** .....

**Second preference:** .....

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Where would you prefer to be cared for when you are reaching the last weeks of your life (home, a friend or relative's home, nursing home, hospital, hospice)? *Some of these preferences will depend on your specific circumstances, how you and those important to you are feeling and the availability of a bed at the time.*

**First preference:** .....

**Second preference:** .....

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## Organ donation

If it were possible, would you wish to donate any of your organs or tissues to help others after you have died? (please circle)      **Yes**      **No**

Many people think they will be unable to be a donor due to their disease, however one of the tissues that can often be donated is the cornea of the eye.

If yes, please ensure that your next of kin and those important to you are aware. <https://www.organdonation.nhs.uk/register-your-decision/donate/>

## Legal documents, managing your affairs

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### Advance Decision to Refuse Treatment (ADRT)

Do you have an ADRT? (please circle)      **Yes**      **No**

If **YES**, where is it held? .....

If **NO**, Is this something you would like some support with? .....

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## Lasting Power of Attorney (LPA)

Do you have a LPA for health and welfare? *(please circle)*      **Yes**      **No**

Do you have a LPA for property and financial affairs: *(please circle)*

**Yes**      **No**

If **YES**, please give contact details:

Name .....

Telephone ..... Mobile .....

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## Your Will

Have you made a Will? *(please circle)*      **Yes**      **No**

If **YES**, where is it held? .....

If **NO**, Is this something you would like some support with? .....

The Hospice Team are unable to witness legal documents, such as Wills, we are sorry for any inconvenience this may cause.

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## Funeral arrangements

Have you considered what funeral arrangements you might wish for and whether you want to be buried or cremated?

Are there any specific spiritual or religious beliefs you would like taken into account?

Do you have arrangements in place? *(please circle)*      **Yes**      **No**

If yes, who is your chosen funeral director? .....

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## Memory Making

Some people like to consider making a memory box for their loved ones to keep after they have died. These may include letters, photos, videos, pictures or sentimental items.

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## Your Digital Legacy

It may also be worth considering the digital legacy you leave such as your email accounts and social media platforms such as Facebook. Some people choose to share important passwords with their next of kin in case these are needed later.

**Is there anything else you would like to include  
in your Advance Care Plan?**

.....  
.....  
.....  
.....

Name of patient .....

Signature ..... Date: ..../...../.....

Name of healthcare professional:.....

Signature ..... Date: ..../...../.....

Designation:.....

Telephone:.....

**Contact us**

If you would like more advice or support, please contact  
St Raphael's Hospice on **020 8099 7777**

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**[www.straphaels.org.uk](http://www.straphaels.org.uk)**

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