

# Advance Care Planning Explained

## What is Advance Care Planning?

Advance Care Planning is a process rather than a form, a series of conversations not a one-off event and very much part of everyday life not just something associated in later life. An output of Advance Care Planning could be the creation of an Advance Care Plan and again there is no set way to do this, it will vary depending on where you live.

I have created an infographic called “Getting Your House in Order” to show the components of Advance Care Planning. The infographic shows Advance Care Planning as a house built firmly on foundation of What Matters Most to a person with four windows representing the different components of Advance Care Planning. Much of Advance Care Planning is part of normal life planning, however there are plans associated specifically with End of Life Care or care in the final years, months or days of life and these are within the window for End of Life Care. The sun and the cloud can be used to represent hoping for the best but preparing for the rest.



- What Matters Most to You
- What you do want
- What you don't want
- Who would speak for you
- Your legacy

# What Matters Most

## What Matters Most

- **What it is**
  - A series of conversations on which Advance Care Planning is built.
- **Why it matters**
  - What Matters Most conversations form the foundations of Advance Care Planning.
- **How to do it**
  - Listen. Listen to understand what matters most to the people you love and the people you care for. Using media in the form of reflecting on news and films can help to start conversations.
  - Check out resource at the annual [Dying Matters Awareness Week](#)
- **When to consider it**
  - What Matters Most conversations are life long and start at any age.
- **Resource**
  - [What Matters to You](#)
  - [Podcast: How Joy Lists can help Advance Care Planning with Andrew Saunderson](#)
  - [The Waiting Room Revolution with Dr. Hsien Seow and Dr. Samantha Winemaker](#)
  - [Advance Care Planning: Listening not box ticking with Professor Alison Leary](#)

## Advance Care Plan

- **What it is**
  - An Advance Care Plan is a generic term used for a plan that can be valuable for anyone to document different elements of Advance Care Planning. An Advance Care Plan is an output of Advance Care Planning.
  - It's not legally binding and includes things like where you would like to be looked after and what matters most to you.
- **Why it matters**
  - Having a plan helps you to decide ahead what matters to you and be in more control.
- **How to do it**
  - There isn't a national template, it's a good idea to ask your local hospice or palliative care team what template they use.
  - There are resources available for you to document your wishes.
- **When to consider it**
  - An Advance Care Plan is appropriate to start for anyone with a long term, chronic health condition or a person who might be in the last year of life.
- **Resource**
  - [NHS End of Life Care](#)
  - [My Future Care Handbook](#)
  - [Hospice UK planning Ahead Tool](#)
  - [Podcast: How to ensure your plans are heard with Clair Fisher](#)
  - [Podcast: My Care Matters with Zoe Harris](#)
  - [Universal Principles for Advance Care Planning](#)

# What You do Want

## Statement of wishes and Preferences

- **What it is**
  - A Statement of wishes and preferences provides a foundation for your Advance Care Planning. A Joy List can be part of this statement.
  - It explains why you make the decisions you do and what matters most to you.
- **Why it matters**
  - It can help guide treatment decisions and, if you are ever unable to make decisions for yourself, it can help people care for you.
- **How to do it**
  - There isn't a national template, it's a good idea to ask your local hospice or palliative care team what template they use.
- **When to consider it**
  - At any stage of life. If you are making an Advance Decision to Refuse Treatment or a Lasting Power of Attorney it's a good idea to consider doing a Statement of wishes and preferences.
- **Resource**
  - [NHS Advance statement about your wishes](#)
  - [NHS Advance statement about your wishes](#)
  - [What Matters Conversations](#)
  - [Podcast: How Joy Lists can help Advance Care Planning with Andrew Saunderson](#)



**“Grab a pen and paper and write your own advance statement.”**

# Who would Speak for You?

## Lasting Power of Attorney

- **What it is**

- A Lasting Power of Attorney (LPA) enables you to choose in advance someone to talk for you if you lose the capacity to make decisions for yourself.
- There are two types of LPA
  - Health and Welfare
  - Property and Finance

- **Why it matters**

- Your next of kin have no automatic right to speak for if you lose capacity through a sudden accident or a long-term disease, this can only be by consenting ahead through a Lasting Power of Attorney.
- Without a LPA your next of kin will be unable to manage a joint bank account or pay essential bills.

- **How to do it**

- There are three ways to make an LPA:
  - Using the GOV.UK site
  - Using an independent Lasting Power of Attorney Consultant
  - Using a solicitor

- **When to consider it**

- After the age of 18 and at any stage of life.
- Following diagnosis of a long-term health condition.

- **Resource**

- [Information about Lasting Power of Attorney](#)
- [Make, register or end a Lasting Power of Attorney](#)
- [Podcast: What can happen if you don't have an LPA in place & a story of systematic failure](#)
- [Blog: How much does it cost to make a Lasting Power of Attorney?](#)
- [Why you need a Lasting Power of Attorney](#)



For health  
and welfare



For property  
and finance



For complete  
piece of mind

# What you Don't Want

## Advance Decision to Refuse Treatment

- **What it is**
  - An Advance Decision to Refuse Treatment (ADRT) is a legally binding form that enables you to refuse specific treatments in the future if you lose capacity.
- **Why it matters**
  - An ADRT gives you peace of mind in knowing you will not receive a treatment in the future that you may wish to refuse.
  - For many people this can give a sense of control and peace of mind.
- **How to do it**
  - You can make an ADRT yourself; to ensure it is legal:
    - You must be over 18 and have capacity.
    - The Advance Decision to Refuse Treatment must be written down, signed and witnessed.
    - It must also have the following statement "I confirm the following refusal of treatment even if my life is at risk or may be shortened as a result".
- **When to consider it**
  - After the age of 18 and at any stage of life.
  - If you know there is a "hard line" or a treatment that you would not wish to have under any circumstance.
  - Following diagnosis of a long-term health condition.
- **Resource**
  - [Podcast: Advance Decision to Refuse Treatment with Celia Kitzinger](#)
  - [NHS: Advance Decision to Refuse Treatment](#)
  - [Compassion in Dying Living Will pack](#)

## Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

- **What it is**
  - A DNACPR is a form which protects people from receiving cardiopulmonary resuscitation (CPR) either when they have refused that specific medical treatment or when CPR would not be appropriate.
  - CPR was introduced as a treatment that can be given when you stop breathing or your heart stops beating. The purpose of CPR is to re-establish breathing and heartbeat.
- **Why it matters**
  - CPR is not a treatment for Ordinary Dying and without a DNACPR form some people might be at risk of receiving inappropriate treatment when they die.
- **How to do it**
  - A doctor and a healthcare professional with appropriate training can complete a DNACPR form.
  - The form is a guide and not legally binding.
  - You should always be involved with discussions and decisions about DNACPR.
- **When to consider it**
  - Following diagnosis of a long-term health condition.
  - If a person is approaching the end of life.
- **Resource**
  - [Hospice UK Planning Ahead Tool](#)

# What you Don't Want cont.

## ReSPECT

- **What it is**
  - The ReSPECT creates a personalised plan and recommendations for your clinical care and treatment in case of an emergency situation in which you are not able to make choices.
  - The recommendations are made through conversations between you, those important to you and your health care professionals to understand what matters most to them.
- **Why it matters**
  - Knowing and discussing what matters most to you, enables treatment to be given in line with your wishes.
  - The ReSPECT process includes discussion on CPR, but also includes other potential emergency situations.
  - Having a ReSPECT form in place can be a guide to medical teams who see you in an emergency situation.
- **How to do it**
  - A doctor and a healthcare professional with appropriate training can complete a ReSPECT form.
  - The form is a guide and not legally binding.
  - You should always be involved with discussions and decisions.
- **When to consider it**
  - Following diagnosis of a long-term health condition.
  - If a person is approaching the end of life.
  - If a person expresses a wish they do not want to receive CPR.
  - *This applies in areas that have adopted the ReSPECT process.*
- **Resource**
  - [ReSPECT](#)
  - [ReSPECT and Advance Care Planning with Dr Zoe Fritz](#)

“We have to invite people to start that conversation so we can really reflect on what matters most.”

# Legacy

## Memory making

- **What it is**
  - Memory making can take many different forms, from recording voice to writing letters. Hand casts, jewellery and sand jars are further examples.
- **Why it matters**
  - Memory making is deeply personal and can be an opportunity to create a tangible connection to a person who has died.
- **How to do it**
  - Memories can be as simple as creating a memory jar or hand print. Local hospice often have experts in memory making.
- **When to consider it**
  - At any stage of life that feels right.
- **Resource**
  - [The power of Memorial Jewellery with Ros Wood](#)
  - [Making Memories with Karen Pardoe](#)

## Digital Legacy

- **What it is**
  - “A digital legacy is the digital information that is available about someone following their death. Someone’s digital legacy is often shaped by interactions the person made and information that they created before they died. This might include their social media profiles, online conversations, photos, videos, gaming profiles and their website or blog.”  
- [The Digital Legacy Association](#)
- **Why it matters**
  - A Digital Legacy is increasingly recognised as part of our assets and something we may wish to consider management of when we die. Without planning ahead, precious pictures, information or work can be lost.
  - Leaving a Digital Legacy ensures that people know what to do with your digital assets when you die.
- **How to do it**
  - The [Digital Legacy Association](#) provide information on how to leave a [social media will](#) and manage your digital assets.
- **When to consider it**
  - Anyone who has digital assets can begin to think about how they would like them managed when they die.
- **Resource**
  - [The Digital Legacy Association](#)
  - [Podcast: How to start your Digital Legacy with James Norris](#)
  - [Following up Zoe’s pledge to sort out her Digital Legacy](#)

# Legacy cont.

## Organ Donation

- **What it is**
  - Now the law has changed (to the opt out system), it will be considered that you agree to become a potential organ donor when you die if:
    - You are 18 or older
    - You have not opted out
    - You are not in an excluded group
- **Why it matters**
  - Becoming an organ donor means you have the potential to save up to nine lives.
  - Anyone can register to become an organ donor, there is no age limit.
- **How to do it**
  - Register your decision on the NHS Organ Donor Register.
  - Have the conversation with your family and friends, tell them what you have decided.
- **When to consider it**
  - At any stage in life.
- **Resource**
  - [NHS Organ Donation](#)
  - [Organ Donation Law in England](#)
  - [Podcast: Organ Donation: hope and transition after an unexpected death with Vicki Caldwell, mother of organ donor Fi](#)

## Donating your body for medical education

- **What it is**
  - It is possible to donate your body for medical education, this needs to be set up in advance of your death.
- **Why it matters**
  - Many people express a wish to donate their body for medical education but are unaware of the process.
  - There is also an option to donate a specific body part, again this need planning and consent if this is your wish.
- **How to do it**
  - Contact the [London Anatomy Office](#) for advice.
- **When to consider it**
  - Anyone over the age of 17 can donate their body.
- **Resource**
  - [Title Donating Your Body for Medical Education with Kim Claridge](#)
  - [Sally and the Brain Bank](#)



# Legacy cont.

## Financial Planning

- **What it is**
  - The key things people could consider planning for:
    - How your estate is left
    - A financial plan for when you stop working
    - A plan for sickness or illness
    - Having an up to date will
    - Having a Lasting Power of Attorney
- **Why it matters**
  - Financial planning can ensure that you and your family are protected in the future and make the most effective use of your assets.
- **How to do it**
  - Some financial planning can be done independently, you may also have plans associated with your place of work.
  - A financial planner supports people to make good decisions with their finances.
- **When to consider it**
  - For anyone over the age of 18.
  - Life events such as starting a job, having a family or owning a home can be triggers to think about financial planning.
- **Resource**
  - [Why an Advance Care Plan should include your finances with Toby Freeman](#)

## Funeral planning

- **What it is**
  - Planning and or beginning finance for your funeral.
- **Why it matters**
  - If you die without sharing wishes regarding your funeral, this can add a burden to your family and may mean your wishes are not met.
- **How to do it**
  - Research your options.
- **When to consider it**
  - Anyone can plan a funeral, to consider a funeral payment plan you need to be over the age of 18.
- **Resource**
  - [Choice is meaningless unless you know all the options with Holly Lyon Hawke holistic funeral director](#)

# Legacy cont.

## Will

- **What it is**
  - A legal document detailing how you wish your assets to be left.
- **Why it matters**
  - Without a will you will die “intestate”. This means that any assets you have will be shared out by the rules of intestacy; this may not be your wishes.
- **How to do it**
  - Most people use a solicitor to make a will, but there are DIY versions available.
- **When to consider it**
  - There are key triggers in life for making a will, often this will be considered when buying a house or having a family. Any financial planning should include discussion about your will.
- **Resource**
  - [Intestacy - who inherits if someone dies without a will?](#)
  - [The Importance of having a will in place with Sara Sheppard](#)

“It isn’t just your will or your funeral, it’s your life, your narrative, people want that to live on and I’m sure families want that to live on.”

## Get in touch

Email: [clare@speakformelpa.co.uk](mailto:clare@speakformelpa.co.uk)

Website: <https://www.speakformelpa.co.uk>

Telephone: 07810 765552

Twitter: [@ClareFuller17](#)