Liverpool University Hospitals
NHS Foundation Trust

Planning for your future care (Advance Care Planning)

A guide to help you prepare and share your wishes ahead of time

Contents

Introduction

One way of making people aware of your wishes and preferences is a process called Advance Care Planning (ACP) You may want to think about what living with serious illness might mean for you, your partner, or relatives, or you might just be the sort of person who likes to plan ahead in general.

You do not have to have an Advance Care Plan. It is an entirely voluntary process, but many people find that it gives them reassurance to know that they will be cared for in the way they would prefer if they became unable to make decisions or communicate their wishes. If you were to lose consciousness or the capacity to make decisions about your life today, what are the important things you would like those caring for you to know about you and what you would want to happen?

This booklet provides an explanation about ACP and explores different options available to you and includes information about some of the things you might want to consider, such as deciding where and how you want to be cared for or making a will. This can help you to feel more in control.

Note: The guidance in this leaflet applies to England, different guidance may apply to the rest of the UK.

Planning for your future care

It can be helpful to think about where you would like to be cared for now, and in the future. These may be different, and you might change your mind over time.

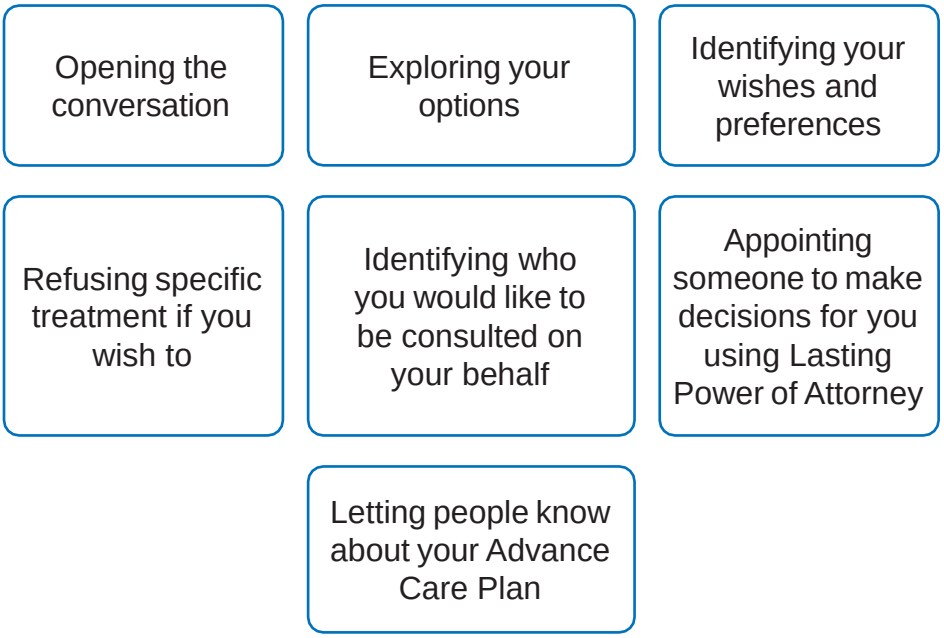
You may wish to consider things like how comfortable you will feel in various places and whether you will be able to get the personal and medical care you might require.

What is Advance Care Planning?

ACP is a process of discussion between you, your partner, your family or friends and the people who provide care for you such as doctors, nurses, social workers, or care home staff. It involves making decisions about your future care which can be followed if you are not able to make decisions or tell people what you want later. Even if you are not approaching the end of your life, it can still be helpful to plan ahead. ACP is centred around you.

ACP is an entirely voluntary process. It is not legally binding, not everyone will choose to engage with the process and that is okay. You can change your mind and the content of your ACP at any time. However, talking through your preferences and planning ahead means that your wishes are more likely to be known by others. This will help people who have to make decisions about your care if you cannot make decisions for yourself due to serious illness or lack of mental capacity. The useful information section signposts you to further guidance on ACP.

Aspects of Advance Care Planning?



Mental capacity and making decisions

Mental capacity is the ability to make decisions for yourself. People who cannot do this are said to 'lack capacity.' This might be due to illness, injury, a learning disability, or mental health problems that affect the way their brain works, but just because you have one of these conditions does not necessarily mean that you cannot make decisions.

The Mental Capacity Act 2005 (MCA) protects and empowers people who may lack the mental capacity to make their own decisions about their care and treatment. People can lack capacity to make some decisions but have capacity to make others. Mental capacity can also fluctuate with time – someone may lack capacity at one point in time but may be able to make the same decision at another time.

Before deciding that a person lacks capacity every step will be taken to help them to try to make a decision themselves by, for example, giving them information in an easier to understand format such as pictures, ensuring they are at ease and feel comfortable, or waiting until they may be better able to make that decision. If, despite support, it is felt that a person is not able to make decisions for themselves then a Mental Capacity Assessment will be conducted, usually by the person responsible for their care. A mental capacity assessment is specific to the decision that needs to be made at that moment in time.

Best interest decisions

Once a person has been assessed as lacking capacity, to make whatever decisions are needed, the MCA states that these must be made in their best interests. Best interest decisions are made the people responsible for a person's care (e.g., their doctor) after consulting with those involved in the person's care, e.g., nurses, personal carers or care home staff, people with Lasting Power of Attorney for Health and Social Care, and after speaking to friends, family or colleagues who know them well.

For more information on Mental Capacity see the useful information section.

Process of Advance Care Planning

Opening the conversation

You might start thinking about ACP when you are planning for your future or retirement, if you have received a serious diagnosis of a long-term or life-limiting health condition, following the death of a partner, relative or friend. Whatever it is that prompts you to think about your future care you can talk with your family, friends, health and social carers or someone from chaplaincy or your faith community. Speaking to someone about your wishes can also allow others to provide emotional support to you.

You do not have to write your wishes down but by doing so you can share your ACP with the people involved in your care which can make it easier for people to know what your wishes are. Your GP or nurse might be able to create an electronic record of care that could be accessed by hospital staff, called a Summary Care Record (in England). These services can vary depending on locality.

Exploring your options

Planning for your future care can take place at any time you choose, and while you may be happy to make your own decisions about your future care, many people find it helpful to discuss their options with the people responsible for their care as well as with friends and relatives who are important to them.

It can be helpful to plan an appropriate time and place to discuss your plans, and it might take several discussions before you feel ready to record your wishes.

Identifying your wishes and preferences

These will be very personal to you and could be anything to do with your future care, but they may include things like:

- How and where you would like to be cared for if you become ill?
- Where would you prefer to spend your final days before death (although clinical circumstances may influence how a decision is made)?
- Who you would most like to spend time with at the end of your life?
- Who would you want doctors and nurses to talk to about your wishes if you become unable to make decisions?
- How do you like to do things? What matters to you?
- Do you want to appoint someone to make decisions on your behalf if you are unable to make decisions (a Lasting Power of Attorney)?
- Do you have any spiritual or religious beliefs that you wish to be reflected in your care?
- Who will look after your pet if you are unable to?
- Have you got any specific wishes you would like to be followed after death?

Resources and templates to complete an ACP are available from several organisations. Recording your wishes is sometimes known as an advance statement – of wishes and preferences. Please see the useful information section at the end of this book.

Refusing specific treatment

You are entitled to say whether there are specific treatments that you do not want to have. This is called an **'advance decision to refuse treatment' (ADRT)** (also sometimes referred to as an 'advance directive' or a 'living will')

In an ADRT you can refuse a treatment in some circumstances but not others. For example, you might refuse treatment that could potentially keep you alive, such as artificial ventilation to help you to breathe, but you cannot refuse care to make you comfortable, nor request help to end your life.

If you wish to make an ADRT you are advised to discuss this with a healthcare professional who is fully aware of your medical history and can tell you the implications of refusing specific treatments.

If you do complete an ADRT it has to be written down, worded specifically, dated, and signed by you, and signed by a witness if you want to refuse life-sustaining treatment.

You will need to share your ADRT with health and social care professionals so that they know what treatments you do not want to receive. It can also help to share it with the people close to you.

In England and Wales an ADRT **is legally binding** but will only be used if you lose the ability to make your own decisions about your treatment.

You can amend your ADRT at any time. Remember that any changes you wish to make must be communicated and recorded correctly to be valid. For more information on ADRT see the useful information section.

Identifying who you would like to be consulted on your behalf

You can name anyone (or more than one person) who you would prefer to be consulted about your care if you later became unable to decide by yourself. That could be your partner, a friend, a relative or anyone you choose. This person will not be able to make decisions for you, but they can provide information about your wishes, preferences and values which will help those caring for you to act in your best interests.

This is different from legally appointing someone to make decisions for you under a Lasting Power of Attorney.

Appointing a Lasting Power of Attorney

When you have a long-term or life-limiting illness you might want to give someone legal authority to make decisions on your behalf in the future. This is called a Lasting Power of Attorney (LPA). An LPA can be anyone you trust to act in your best interests such as a relative, friend or solicitor. There are two types of LPA:

LPA for Health and Welfare: Use this LPA to give an attorney the power to make decisions about things like:

- your daily routine, for example washing, dressing, eating
- medical care
- moving into a care home
- life-sustaining treatment

This type of LPA can only be used when you are unable to make your own decisions, i.e., if you lack the capacity to make those decisions yourself. An LPA for Health and Welfare must be registered with the Office of the Public Guardian (see useful information section)

LPA for Property and Financial Affairs: An LPA for Property and Financial Affairs has the authority to make decisions about money and property for you, for example when:

- managing a bank or building society account
- paying bills
- collecting benefits or a pension
- selling your home.

With your permission, this type of LPA can be used as soon as it is registered.

Information about appointing an LPA can be found on the government website: https://www.gov.uk/power-of-attorney or from the Citizens Advice Bureau: https://www.citizensadvice.org.uk/family/looking-after-people/managing-affairs-for-someone-else/

Anticipatory Clinical Management Planning

Anticipatory Clinical Management Planning is a proactive plan prepared in advance for a clinical situation that may that is thought likely to occur, to allow conversation and preparation for the future.

Conversations and documentation could include decisions about limiting treatment but also could be used to support people to express their views about treatments and approaches to care.

This type of plan forms part of future care planning but is not Advance Care Planning if it is not a personal plan made by you. However, an Advance Care Plan and Anticipatory Clinical Management Plan can work in conjunction with end of life care planning by identifying the person's preferences for and goals of care in the event of a future emergency or life changing event.

Anticipatory Clinical management plans may include discussions about ceilings of care and Cardiopulmonary Resuscitation (CPR), this should be documented on the patient's health record and the outcome shared with health professionals and/or organisation involved in the patient's care with the consent of the patient or nominated person.

Dementia, Disabilities and Advance Care Planning

Having a diagnosis of dementia, or a disability, whether that be physical, learning, or both should not be a barrier from letting your preferences and wishes be known, you might require support to help you with this and to record what you want to happen to you in the future.

Easy read templates are available to help guide you, someone who knows you well, might be the best person to help you with this. See the useful information section for further support.

Cultural beliefs

ACP is unique to everyone. It should be about what is important to you, such as your personal beliefs, values, faith, and culture. There may be specific rituals that you wish to be followed and this should be respected. You are under no obligation to share any information that you do not want to disclose but expressing your wishes could help others to support your preferences, particularly if they are not familiar with certain cultural practices.

Sexual orientation and gender identity

If you are LGBTQ+ you may have specific concerns or questions about future planning. It is your choice whether you tell people that you are LGBTQ+. You should do what feels comfortable for you. It is okay to correct someone if they have made assumptions about your sexual orientation or have not used the correct pronouns or name.

If you are on hormone therapy you might have questions about how this might affect certain treatments or about what alternatives are available if you become ill or have difficulty swallowing, if your doctor or nurse does not have experience with this, they can speak to a gender identity specialist.

You might have specific preferences about care at the end of life, or what name and gender should be on a death certificate. There are certain processes to follow for this. See the useful information section for further support.

Choosing a place of care

It might be helpful thinking about where you would like to be cared for now, and in the future. These may be different, and you might change your mind over time. Things to consider may include things like how comfortable you feel in various places and whether you will be able to get the personal and medical care you might require.

It might be helpful to talk with your doctor or nurse about the care you might need in the future, which will help to guide you about what level of care, or setting, may be right for you.

Care at Home

Many people prefer to be cared for at home in familiar surroundings and surrounded by their family and friends. Your GP or Community Nurse can tell you about what care and support is available, including palliative care. It is important to consider what care and support family, or friends are able and willing to provide. See the useful information section for local carer support services via the carers trust.

Hospice Care

Hospices provide specialist palliative and end of life care. This includes medical and nursing care as well as emotional and spiritual support. They are usually, small, short stay units.

Some people stay in a hospice if they need a lot of care or have particularly complex needs. Others may go in for symptom control or visit for a specific appointment or treatment.

Sometimes hospice care can be provided in people's homes. Your GP or Community Nurse will be able to advise you on this.

Hospital Care

If you become unwell or need tests or treatment you may need to go into hospital. Sometimes people are referred to hospital care by their doctor or nurse. Other people need to go into hospital in an emergency. Liverpool Hospitals have Specialist Palliative Care Support Services across all sites.

Care Homes and Nursing Homes (residential care)

If you can no longer manage in your own home you may choose to be cared for in a care home or nursing home, either for short or long-term care.

In a care home, staff will look after you, provide your food and can assist with your personal care needs. A nursing home has trained registered nurses who can provide nursing care and administer medicines etc. If your health means you need nursing care on a frequent basis this type of care provider may be more appropriate for you.

Paying for care

NHS nursing and medical care is free if you are resident in the UK; this includes any NHS funded hospital or hospice stay.

You may have to pay for, or contribute towards, the cost of your personal or social care, including residential care provided in a care or nursing home, or personal care provided at home. This can depend on where you live and your income and/or savings. You can contact your local council about what care is available in your area or speak to your nurse or doctor who will be able to advise you.

Making a will

A will lets you decide what happens to your money, property, and possessions after your death. You can also use a Will to decide who should look after any children under 18.

You can write your will yourself, but you should get advice if your will is not straightforward. You need to get your will formally witnessed and signed to make it legally valid.

If you have not made a will, or your will is invalid, your money, property and possessions will be shared out according to law. You might want to make a will so that you can make these decisions yourself. You could contact a solicitor or independent financial adviser for advice.

Many charities also offer will-writing services and in some cases, they may provide this service free of charge. Search for free will writing online or contact your local will writing service.

Managing your social media and online accounts

Many people have social media and online accounts, these are sometimes referred to as **digital assets**. It can be helpful to think about what you want to happen to these accounts after you have died.

You can put plans in place to make things easier for your family and friends to carry out your wishes.

Accounts to consider include:

- Music and other media subscriptions (Spotify and Netflix etc.)
- Social media (Facebook, Instagram, Twitter, WhatsApp etc.)
- Professional sites (Google Apps, LinkedIn)
- Email (including Hotmail, Gmail)
- Cloud storage (Apple iCloud, Dropbox)
- Smartphone or tablet apps
- Online accounts for utility or mobile network providers

Deciding what to do with each account:

Companies have different rules about what happens to your account when you die and whether someone else can have access. It might be helpful to look at your options for each account and decide what you want to do with it. You might be able to:

- Memorialise a social media account, so that friends can see your pictures and timeline, but no one can make changes to it
- Download your data (photos, videos, and messages) and keep them in a secure place
- Deactivate an account so that it is not publicly available, but the information is stored with the company in case someone needs to access it in the future

- Delete an account so that it is not publicly available, and all the information is deleted
- Assign someone you trust to have access to some or parts of your account after you die.

Guidance is available from the Digital Legacy Association and the 'MyWishes' organisation (see useful information section).

Funeral planning

Some people want to plan their own funeral in detail while others are happy to leave those decisions to relatives or friends. If you have any specific wishes such as burial or cremation, where the funeral will be held, where you would like your ashes to be scattered, your choice of music or poems, religious preferences etc. it might help to write them down and discuss them with friends and family or with a funeral director.

You might have already identified the funds to cover the cost of your funeral, if so, it could be helpful to share that information with your friends and relatives, as well as with your bank or building society so that funds can be released if necessary. Some undertakers offer pre-paid funeral plans. Financial help is sometimes available for funeral costs, for more information visit: https://www.gov.uk/funeral-payments

Rehoming a pet

A pet can be a wonderful companion, but you may be worried about who will care for them if you become too ill, move into long term care or after you have died.

You may be able to make arrangements with a friend or relative but if not, there are some organisations that may be able to help you. These include the cinnamon trust and the blue cross charity. (See the useful information section).

Letting people know about your Advance Care Plan

An ACP does not always have to be written down unless you are making an Advance Decision to Refuse Treatment (ADRT – see page 7). However, by sharing your ACP with those caring for you, as well as with your partner, close relatives, and friends, it is more likely that your wishes will be followed.

Remember:

- ACP is not compulsory
- If you do decide to write a plan it is a good idea to sign and date it so that the people caring for your always have the most up to date version
- You can change your mind about your ACP at any time – but remember to share any changes with the people involved in your care and those close to you.

Local Palliative Care Services

IMPaCT is the Integrated Mersey Palliative Care Team, a partnership between Marie Curie, Mersey Care NHS Foundation Trust, Liverpool University Hospitals NHS Foundation Trust, and Woodlands Hospice. It is a multi-professional service offering a single point of access and referral to palliative care. If you have a life limiting condition, the team can help you get support with your health to maintain your quality of life and plan your future care. IMPaCT operates from two hubs:

Marie Curie Hospice Liverpool – for patients registered with a central or South Liverpool GP

Woodlands Hospice – for patients registered with a North Liverpool or South Sefton GP.

IMPaCT can support patients and their carers with:

- Expert advice about managing their condition – including difficult symptoms.
- making sure their quality of life is as good as it can be.
- Planning for future healthcare needs.
- For more information and to contact the IMPaCT Team visit the website (see useful information section) or by telephone: 0300 100 1002

Useful information and organisations

Advance Care Planning

Information and resources to help with planning for your future care.

Website: www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/end-of-life-resources/dying-matters/

Anticipatory Clinical Management Planning

Information on what an Anticipatory Clinical Management Plan is and how this differs to an Advance Care Plan.

Website: https://www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/for-professionals/north-west-anticipatory-clinical-management-planning/

Advance Decision to refuse treatment

Information to guide you with Advance Decisions to refuse treatment and signposting to support

Website: www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/

Blue Cross Animal Charity

The Pet Peace of Mind Service can ensure that your pet is cared for after your death.

Website: https://www.bluecross.org.uk/pet-peace-of-mind

Cardiopulmonary decisions

Website: https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/

Carer's Trust

The Carers Trust is a charity for, with and about carers. They work to improve support, services, and recognition for anyone living with the challenges of unpaid caring for a family member or friend

Website: https://carers.org/help-and-info/carer-services-near-you/115-liverpool-carers-centre

Cinnamon Trust

A National Charity for older people, the terminally ill and their pets, The Cinnamon Trust can provide support for pets whose owners have made arrangements with the trust in advance.

Citizens Advice

The Citizens Advice website provides 24/7 access to information on your rights, including benefits, housing, and employment, and on debt, consumer, and legal issues.

Website: www.citizensadvice.org.uk

Telephone: advice line on 0800 144 8848

Court of Protection (England and Wales)

The Court of Protection makes decisions on issues affecting people who lack mental capacity.

Website: www.gov.uk/court-of-protection

Telephone: 0300 456 4600

Dementia UK

A specialist dementia nursing charity that provides support and guidance to people diagnosed with dementia and those important to them. Includes ACP guidance and templates.

Website: https://www.dementiauk.org/get-support/legal-and-financial-information/advance-care-planning/

Telephone: 0800 888 6678

Digital Legacy Association

Provides resources for healthcare professionals and the public. Helps people to make plans for their digital legacy

Website: www.digitallegacyassociation.org

Gender Identity Clinic

Your nearest gender identity clinic can provide advice and support for issues related to gender and provide specialist support for professionals around end-of-life care. Search online or speak to your GP for your nearest clinic. Gov.UK also provide information on how to get a Gender Recognition Certificate.

GOV.UK (including Lasting Power of Attorney)

The Gov.UK website gives links to a wide range of government services and information including appointing a Lasting Power of Attorney.

Website: www.gov.uk

LGBT foundation

The LGBT foundation is a national charity that provides guidance and support to the LGBTQ+ community, including advice on end of life care

Website: www.lgbt.foundation/prideinageing/end-of-life-care

Hospice UK

A directory of hospice and palliative care, plus other information and signposting to Dying Matters, an annual campaign aimed at creating an open culture in which we are comfortable talking about death, dying and grief.

Website: www.hospiceuk.org

Telephone: 020 7520 8200

Mental Capacity Act

Information about the Mental Capacity Act and the supporting code of practice

Website: www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/

My Wishes

Information and resources for sorting out your digital legacy, including tutorials for people who want to put plans in place for their online accounts at the end of life

Website: www.mywishes.co.uk

NHS

Provides information about health and social care including conditions, treatment, and service information in England.

Website: www.nhs.uk

NHS England

Universal Principles of Advance Care Planning. Information about ACP which includes an easy read format.

Website: www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/

Office of Public Guardian

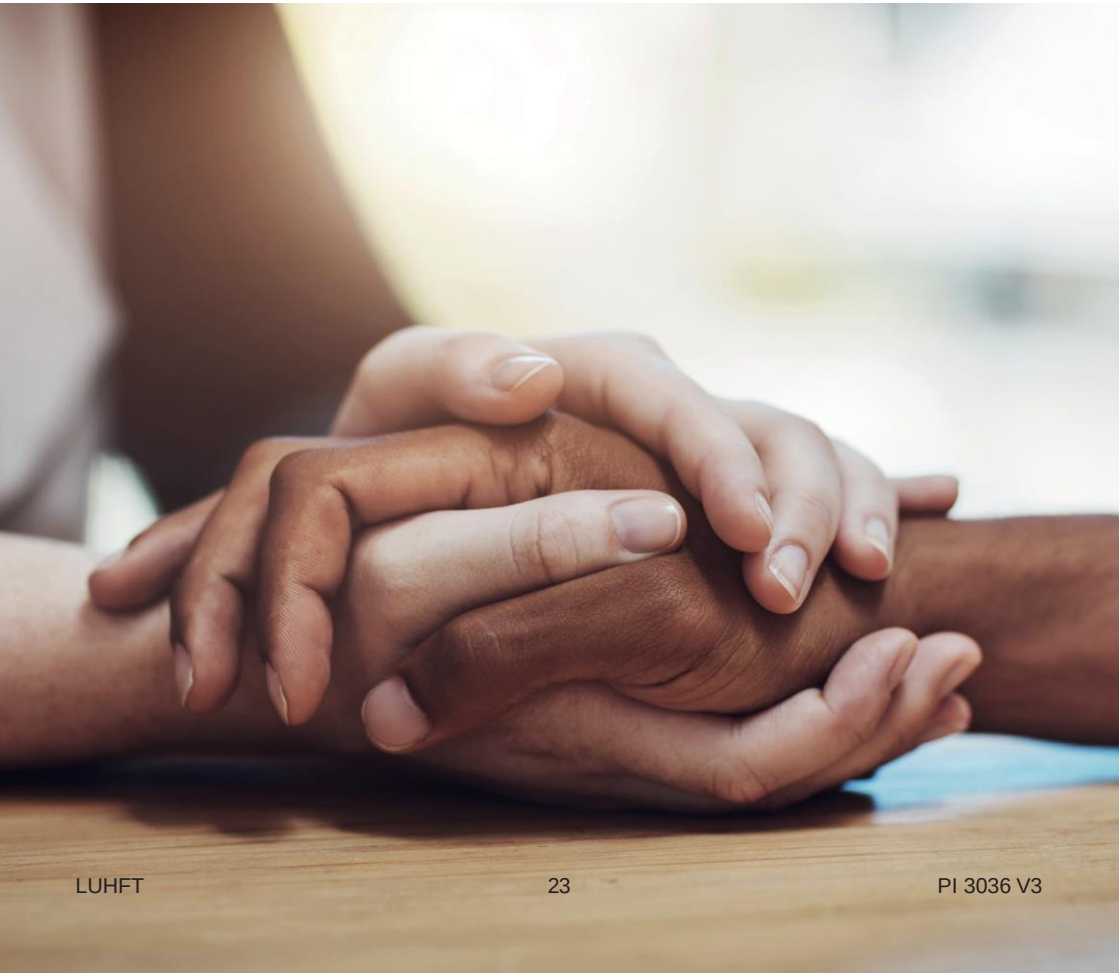
The Office of Public Guardian is there to protect people who lack capacity. Forms and guidance on appointing a Lasting Power of Attorney are available.

Website: www.publicguardian.gov.uk

Palliative Care of People with Learning Disabilities (PCPLD)

The PCPLD Network brings together service providers, people with a learning disability and carers working for the benefit of individuals with learning disabilities who have palliative care needs. Several easy read resources are available to support with future care planning.

Website: https://www.pcpld.org/



Your notes

Author: Palliative Care
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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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