



Planning for your future care

A GUIDE

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There may be times in your life when you think about the consequences of becoming seriously ill or disabled. This may be at a time of ill health or as a result of a life changing event. It may simply be because you are the sort of person who likes to plan ahead.

You may want to take the opportunity to think about what living with a serious illness might mean to you, your partner or your relatives, particularly if you become unable to make decisions for yourself. You may wish to record what your preferences and wishes for future care and treatment might be or you may simply choose to do nothing at all.

One way of making people aware of your wishes is by a process that is called advance care planning.

This booklet provides a simple explanation about advance care planning and the different options open to you. The booklet uses some of the terms contained within the framework of the Mental Capacity Act (2005), so some of the language used may be new to you.

What is Advance Care Planning?

Advance care planning is a process of discussion between you and those who provide care for you, for example your nurses, doctors, care home manager, social worker, family or friends.

During this discussion you may choose to express some views, preferences and wishes about your future care so that these can be taken into account if you were unable to make your own decisions at some point in the future. This process will enable you to communicate your wishes to all involved in your care.

Aspects of Advance Care Planning

Opening the conversation

Exploring your options

Identifying your wishes and preferences

Refusing specific treatment, if you wish to

Identifying who you would like to be consulted on your behalf

Appointing someone to make decisions for you using a Lasting Power of Attorney

Letting people know your wishes

These points will be explained in this booklet.

Advance care planning is an entirely voluntary process and no one is under any pressure to take any of the above steps.



Opening the conversation

Having an advance care planning conversation with someone may lead to one or more of the points mentioned in this booklet.

A conversation about advance care planning may be prompted by:

- The wish to make plans just in case something unexpected happens
- Planning for your future or for retirement
- Following the diagnosis of a serious or long term condition or being aware that you may have a limited time to live
- After the death of a spouse, partner or friend.

Not everyone will choose to engage in such a conversation and that is fine. However, talking and planning ahead means that your wishes are more likely to be known by others. This is important for those responsible for making decisions about your care if you lose capacity to make your own decisions because of serious illness.

Explore your options

Advance care planning can occur at any time you choose. Ask your care provider or someone close to you to have the discussion with you. You may want to plan an appropriate time and place for having an advance care planning conversation.

To explore what options are available to you, you and the person with whom you have the discussion may need to seek some support and advice.

You might have strong views about things that you would or would not like to happen. For example, some people may say they would always want to stay at home if they become ill. However this may not be a realistic choice in some circumstances.

An example about exploring options

Ella lives with her daughter, son-in-law and two young grandchildren. She knows she is approaching the end of her life and would like to remain in her home. But Ella also feels that she really must go into a nursing home to save her family any extra work or upset. The idea is causing her a great deal of worry.

Ella has not told her family her wishes so she does not know how they feel about the possibility of looking after her. She has not asked her doctor what support is locally available to help her stay in her own home or if there are any alternatives available to her other than a nursing home.

Discussing and finding out all of the options available might help Ella resolve some of her concerns and make her future plans together with her family.

Identify your wishes and preferences

The wishes you express during advance care planning are personal to you and can be about anything to do with your future care.

You may want to include your priorities and preferences for the future, for example:

- How you might want any religious or spiritual beliefs you hold to be reflected in your care
- The name of a person/people you wish to be consulted on your behalf at a later time; this could be a close family member but can be anyone you choose
- Your choice about where you would like to be cared for, for example at home, in a hospital, nursing home or a hospice
- Where you would like to be cared for at the end of your life and who you would like to be with you
- Your thoughts on different treatments or types of care that you might be offered
- How you like to do things, for example preferring a shower instead of a bath or sleeping with the light on
- Concerns or solutions about practical issues, for example who will look after your pet should you become ill.

If you become unable to make a decision yourself, this information will help those caring for you to identify what is in your best interests and make decisions on your behalf.

Refusing specific treatment

During an advance care planning discussion, you may decide to express a very specific view about a particular medical treatment which you do not want to have. This can be done by making an advance decision to refuse treatment.

An advance decision to refuse treatment (sometimes called a living will or advance directive) is a decision you can make to refuse a specific type of treatment at some time in the future. This is to be observed if you can't make your own decision at the time the treatment becomes relevant.

Sometimes you may want to refuse a treatment in some circumstances but not others. If so, you must specify all the circumstances in which you want to refuse this particular treatment.

There are rules if you wish to refuse treatment that is potentially life sustaining, for example, ventilation. An advance decision to refuse this type of treatment must be put in writing, signed and witnessed and include the statement 'even if life is at risk as a result'.

If you wish to make an advance decision to refuse treatment you are advised to discuss this with a health care professional who is fully aware of your medical history.

An advance decision to refuse treatment will only be used if at some time in the future you lose the ability to make your own decisions about your treatment.

Remember you can change your mind at any time.

Ask someone to speak for you

You may wish to name someone – or even more than one person – who should be asked about your care if you are not able to make decisions for yourself. This person may be a close family member, a friend or any other person you choose.

If in the future you are unable to make a decision for yourself, a health or social care professional would, if possible, consult with the person you named. Although this person cannot make decisions for you, they can provide information about your wishes, feelings and values. This will help the healthcare professionals act in your best interests.

This is not the same as legally appointing somebody to make decisions for you under a lasting power of attorney. We look at that on page 10.

An example of naming someone to speak for you

Sheelagh lives alone and has no living relative. She has always received help and support from her lifelong friend and neighbour Jenny.

As Sheelagh gets older she starts to think about what will happen to her if for any reason her health fails. She knows and trusts Jenny well and she decides to ask her to be the person she would like to be consulted and speak on her behalf, should the need ever arise.

Sheelagh is happy that her financial affairs continue to be managed by her solicitor just as they always have been, and discusses that with her solicitor.



Making a Lasting Power of Attorney

You may choose to give another person legal authority (making them an 'attorney') to make decisions on your behalf if a time comes that you are not able to make your own decisions. This can be a relative, a friend or a solicitor.

A Lasting Power of Attorney (LPA) enables you to give another person the right to make decisions about your property and affairs and/or your personal welfare.

Decisions about care and treatment can be covered by a personal welfare LPA. An LPA covering your personal welfare (sometimes called health and welfare) will only be used when you lack the ability to make specific health and welfare decisions for yourself.

There are special rules about appointing an LPA. You can get a special form from the Office of the Public Guardian (OPG) or stationery shops that provide legal packs. The form will explain what to do. Your LPA will need to be registered with the Office of Public Guardians before it can be used (see details on page 14).

LPA has replaced Enduring Power of Attorney.





An example of appointing a Lasting Power of Attorney

Kamal lives with a heart condition and has limited mobility; he has started to think about what might happen in the future if his illness gets worse.

Kamal has always handled the finances and affairs for both himself and his wife. They are both concerned that should anything happen to him, his wife would find it hard to cope with any major decisions or he may become too ill to make decisions about his own care.

To give him and his wife peace of mind they both decide to give Lasting Power of Attorney to their daughter. They both discuss with Farah their thoughts about any possible future decisions which may arise around money, property or healthcare. By doing so their daughter understands their wishes and preferences and can act for them in the way they would choose should the need ever arise.

Farah will only make decisions for her parents if a time comes that they are unable to make decisions for themselves.

Let people know

Advance care planning does not always need to be in writing unless you are making an advance decision to refuse life sustaining treatment. However the professionals involved in your care and members of your family may find it helpful if your wishes and preferences are in writing, signed and dated. It is a good idea to give a copy of your wishes to everyone who needs to know. Remember to keep your own copy safe.

By letting people know about your wishes you may have an opportunity to discuss your views with those close to you.

If you have made an advance decision to refuse specific treatment you must be sure that the people involved in your care know this. Ask your nurse or doctor to help you do this.



Key points about advance care planning

- No one is obliged to carry out advance care planning
- You may wish to discuss your wishes with your carers, partner or relatives
- Include anything that is important to you no matter how trivial it seems
- If you wish to refuse a specific treatment, consider making an advance decision to refuse treatment
- It is recommended that anything you have written down should be signed and dated
- It is recommended you seek the advice of an experienced healthcare professional if making an advance decision to refuse treatment
- If you make an advance decision that refuses treatment that is life sustaining it must be in writing, signed, dated and witnessed and use a specific form of words
- If you have named someone to speak for you or have a Lasting Power of Attorney, remember to write down their name in your advance care planning documents
- If your wishes are in writing or if you have a Lasting Power of Attorney, keep a copy of the documentation safe and provide copies to those who need to know your wishes e.g. nurse, doctor carer or family member.

Remember you can change your mind at any time.

Where to find further information

The following information is found on websites. You may be able to get help to access these through your GP, health or social care worker, your library or at a hospital information centre.

Dying Matters

10 leaflets focusing on having discussions and planning ahead can be found at www.dyingmatters.org/overview/resources

Mental Capacity Act

Information about the Mental Capacity Act and the supporting Code of Practice.

www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act

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.

www.publicguardian.gov.uk

Tel. 0300 4560300

Preferred Priorities for Care

A document which can be used to help write down preferences and wishes for the future.

www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare

The Mental Capacity Act in Practice

Guidance for End of Life Care (2008) – The National Council for Palliative Care.

www.ncpc.org.uk

Tel. 020 7697 1520

Good Decision Making – The Mental Capacity Act and End of Life Care

A summary guidance to introduce people to the MCA and its contents and to explain the importance for End of Life Care decision making.

www.ncpc.org.uk

Advance Decisions to Refuse Treatment website

A training website for professionals which contains a patient section.

www.adrt.nhs.uk

NHS Choices

A website providing information on conditions, treatments, living well and support for carers.

www.nhs.uk

Age UK LifeBook

The LifeBook is a free booklet to document important and useful information about your life, from who insures your car to where you put the TV licence.

www.ageuk.org.uk/home-and-care/home-safety-and-security/lifebook/

Tel. 0845 685 1061 quoting reference ALL 721

Healthtalkonline

A website detailing people's experiences of dying and bereavement, including sections on caring for someone with a terminal illness.

www.healthtalkonline.org/Dying_and_bereavement/

www.endoflifecareforadults.nhs.uk

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