The Leeds
Teaching Hospitals
NHS Trust

Planning for your future care

A guide for patients

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There may be times in your life when you wonder about what would happen if you were to become seriously ill. This may be as a result of a life changing event such as the diagnosis of a serious life limiting illness or simply because you are the type of person who likes to plan ahead. If you were to lose the ability to make important decisions about your life, what important things about you would those caring for you need to know?

One way of making people aware of what matters to you is by a process called advance care planning. Having an advance care plan is a bit like planning for a rainy day. You may wish to record what your preferences and wishes are for future care and treatment or you may prefer to trust those around you to make decisions in your best interests at the time.

This booklet provides a simple explanation about advance care planning and the different options available to you. Some of the terms used in the booklet are from the Mental Capacity Act (2005), ask your healthcare professional if you do not understand something.

What is advance care planning?

Advance care planning can be a series of discussions between you, your partner, family or friends and those who are involved in your care; for example: nurses, doctors, your GP, care home manager or social worker.

During these discussions you may decide to share 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 anyone involved in your care and these preferences can be updated at any time.

Aspects of advance care planning:

Advance care planning is an entirely voluntary process and no one is under any pressure to take any of the following steps. You can change your mind at any time.

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.
- The diagnosis of a serious or long term condition or being aware that you may have a limited time to live.
- The death of someone close to you.

Not everyone will choose to have a conversation like this and that is fine. However, talking and planning ahead means that your views are likely to be known by others. This is important for those responsible for decisions about your care if you become unable to make decisions because of serious illness.

Exploring 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. It is your choice who you wish to be involved in this conversation. You may want to plan the best time and place for having the discussion.

To explore what options are available to you, you and the person you have the discussion with 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 say they would always want to stay at home if they become seriously ill, but this isn’t always possible.

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 options 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.

Identifying your wishes and preferences

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

If you become unable to make a decision for yourself, knowing your preferences helps those involved in your care to put plans into place for you in order to make best interests decisions on your behalf.

Some of the things you may wish to consider for the future are:

- The name of a person / people you wish to be consulted on your behalf if you were to become more unwell. This could be a close family member but it can be anyone you choose.
- Where you would like to be cared for - for example: at home, in a hospital, in a hospice or a care home and who you would like to be with you.
- Concerns or solutions about practical issues, for example who will look after your pet should you become ill.
- Whether you have any religious or spiritual beliefs that you want to be reflected in your care?

Treatment

You may wish to discuss what medical treatment you would agree to if you were to become more unwell. For example; whether you would want cardiopulmonary resuscitation if your heart were to stop beating or any other hospital treatment.

It is important to discuss this with your doctor to establish what treatment options would be available to you and whether or not you would want these if they were offered to you in the future.

All of these preferences can be formally written on a document called ReSPECT. We look at this on page 8.

Other subjects you may want to talk about:

- Funeral arrangements
- Making a will
- Care of dependents e.g. children or parents
- Organ donation
- How you would like to be remembered
- Any concerns you may have about being ill or dying

Recording your wishes

On pages 10-12 there is space for you to write down your wishes and preferences. You may find it helpful to talk about these with your family and friends. Sometimes this can be difficult because it might be emotional or people might not agree.

As long as you have informed your healthcare professional, what you have written in here will be taken into account when planning your care. However, sometimes things can change quickly or resources may not be available to meet a specific need. You are encouraged to keep this document with you and you can choose to share it with anyone involved in your care and those closest to you.

If you would like your preferences to be documented more formally, in Leeds you can speak to a healthcare professional about completing a document called ReSPECT. This form is available electronically and on paper which can be printed for you to keep at home.

The ReSPECT form can record preferences and recommendations for potential future emergency events and will be accessible to all healthcare professionals involved in your care. This is particularly important for healthcare professionals if you are ever in a position where you are too unwell to express your own wishes. The form can be updated anytime if your situation changes.

I have a ReSPECT form: ☐ Yes ☐ No

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 healthcare professionals act in your best interests.

This is not the same as legally appointing somebody for you under a Lasting Power of Attorney. We look at that on page 14.

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 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 have always been, and discusses that with her solicitor.

Some people may find it helpful to talk about what they have achieved in their life and what they still want to achieve.

Below are sections to help you write things down if you feel this is right for you.

My name:

Three things I would like to do:

1) ....

2) ....

3) ....

Who I want to be involved in my care:

Name:	Relationship to you:	Contact details:

What is important to you?

Where would you like to be cared for in the future?

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Any other wishes or questions?

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Refusing specific treatment

During an advance care planning discussion, you may want to tell people about a very strong view you have about a particular medical treatment that you do not want to have. This can be done by making an **advance decision to refuse treatment (ADRT).**

An ADRT (sometimes referred to informally as ‘living wills’ or ‘advance directives’) is a decision you can make to decline 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 decline a treatment in some circumstances but not others. If so, you need to let people know all the circumstances in which you do not want this particular treatment.

There are rules if you wish to decline treatment that will potentially keep you alive, for example, artificial ventilation or hydration. An advance decision to decline 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’. This must clearly describe the exact circumstance this wish applies to.

If you wish to make an ADRT, you are advised to discuss this with a health care professional who is fully aware of your medical history. At the Leeds Teaching Hospitals NHS Trust, we have an ADRT procedure, containing an ADRT template, guidance for patients and staff on making an ADRT, and storing it in your hospital record.

An ADRT 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.

I have an ADRT: ☐ Yes ☐ No

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 form from stationary shops that provide legal packs or from the Office of the Public Guardian (OPG). The form can be completed on-line and can be found in the links section on page 18. The form will explain what to do. Your LPA will need to be registered with the Office of the Public Guardian before it can be used.

Old versions such as Enduring Power of Attorney or General Powers of Attorney may still be valid but need to be registered with OPG. NB: these old forms of Attorney only give powers relating to property/money.

Name of Lasting Power of Attorney and contact details (if applicable):

An example of appointing a Lasting Power of Attorney

George 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.

George 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 Farah. They both discuss with Farah their thoughts about any possible future decisions which may arise around money, property or healthcare. By doing so Farah understands their wishes and preferences and can act for them in the way they would choose should the need ever arise.

Farah is granted two separate LPA's - one allows her to make decisions about health and welfare, the other allows her to make decisions about property and affairs. She 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, however the professionals involved in your care and members of your family may find it helpful if your preferences are in writing, signed and dated. It is a good idea to give a copy of this to everyone who needs to know. Remember to keep your own copy safe and let those who need to know of any changes you make.

In Leeds the best place to store this information is on a ReSPECT form as discussed previously on pages 7 & 8.

If you have made an advance decision to refuse specific treatment you must be sure that the people involved in your care know this. You can ask any healthcare professionals involved in your care to help you with this.

Key points about advance care planning

- You don't have to carry out Advance Care Planning
- Discuss your wishes with your carers, partner or relatives
- You can include anything that is important to you no matter how unimportant it may seem to others
- If you want to decline a specific treatment, consider making an advance decision to refuse treatment
- It's a good idea to sign and date anything you have written down
- 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 may keep you alive, 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 documents safe and give copies to those who need to know your wishes e.g. nurse, doctor, carer or family member
- **The best way to document your preferences is on a ReSPECT form.**

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 surgery, health or social care worker or your local library.

ReSPECT

For further information on the ReSPECT form

Web: www.resus.org.uk/respect/respect-patients-and-carers

Dying Matters

Dying Matters aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. The website contains leaflets, films and other resources which will help people have conversations and make plans about their future care. Furthermore you will find guidance here on decisions about cardiopulmonary resuscitation (CPR).

Web: www.dyingmatters.org

Mental Capacity Act

Information about the Mental Capacity Act Code of Practice

Web: www.gov.uk/government/publications/mental-capacity-act-code-of-practice

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

Web: www.gov.uk/government/organisations/office-of-the-public-guardian

Tel: 0300 4560 300

NHS Choices

The website has information on advance care planning

Web: 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 your TV licence.

Web: www.ageuk.org.uk/information-advice/money-legal/end-of-life-planning/lifebook/

Tel: 0800 678 1602

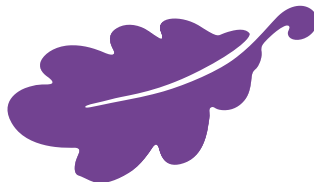
Marie Curie

Web: www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/advance-care-planning#whatisadvancecareplanning

Macmillan

Get information about ways to plan ahead and make choices about your future care

Web: www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/advance-care-planning/planning-ahead



If you would like this information leaflet in another language, please visit:

https://www.leedsth.nhs.uk/patients-visitors/patient-and-visitor-information/patient-information-leaflets/palliative-care

and select the **BrowseAloudTM** icon.

What did you think of your care?

Scan the QR code or visit **bit.ly/nhsleedsfft**

Your views matter

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