# PLANNING

## FOR YOUR FUTURE CARE

## A Guide

## Planning for your future care - a guide

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 of advance care planning.

This booklet provides a simple explanation about **advance care planning** and the different **options** open 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 or family members. During this discussion you may choose to express some views, preferences and wishes about your future care.

### Aspects of Advance Care Planning

- Opening the conversation
- Explore your options
- Identify your wishes and preferences
- Refusing specific treatment, if you wish to
- Ask someone to speak for you
- Appoint someone to make decisions for you using a Lasting Power of Attorney
- Let 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 the future or for retirement
- Following the diagnosis of a serious or long term condition
- After the death of a spouse, partner or friend.

Not everyone will want to engage in such a conversation and that is fine.

## 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.

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

Mrs Smith 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. Mrs Smith 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.

Mrs Smith 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 may help Mrs Smith make her plans and put her mind at rest.

## 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 act on your behalf at a later time
- Your choice about where you would like to be cared for, for example at home, in a hospital, nursing home or a hospice
- 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 dog should you become ill.

If you become unable to make a decision yourself, this information will help those caring for you to 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 (previously known as 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.

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.

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

## 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

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

As Mrs Jones gets older she starts to think about what will happen to her if for any reason her health fails. Mrs Jones knows Jenny so well 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.

Mrs Jones is happy that her financial affairs continue to be managed by her solicitor just as they always have been.

## Making a Lasting Power of Attorney

You may want to give another person legal authority to make decisions on your behalf.

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 can only be used when you lack the ability to make specific 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).

## An example of appointing a Lasting Power of Attorney

Mr Brown suffers from a heart condition and he has started to think about what might happen in the future if his illness gets worse.

Mr Brown has always handled the finances and affairs for both himself and his wife. Mr Brown is concerned that should anything happen to him, his wife would not be able 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 son William. They both discuss with William their thoughts about any possible future decisions which may arise around money, property or healthcare. By doing so their son understands their wishes and preferences and can act for them in the way they would choose should the need ever arise.

William will only make decisions for his parents if 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 wishes and preferences are in writing. 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 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 and witnessed
- If you have named someone to speak for you or have a Lasting Power of Attorney remember to write down their name
- If your wishes are in writing or if you have a Lasting Power of Attorney keep a copy of the record safe
- Provide copies to those who need to know your wishes eg 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 or healthcare worker, your library or at a hospital information centre.

### Making Decisions - a guide

Information booklets about the Mental Capacity Act.
www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet01.pdf
Tel. 02380 878038

### The Mental Capacity Act Code of Practice

The code provides guidance and information about how the Mental Capacity Act works.
www.dca.gov.uk/menincap/legis.htm#codeofpractice

### Office of Public Guardian

The Office of Public Guardian is there to protect people who lack capacity.
www.publicguardian.gov.uk
Tel. 0845 3302900

### Preferred Priorities for Care

A document which can be used to help write down preferences and wishes for the future.
www.endoflifecareforadults.nhs.uk/eolc/files/F2110-Preferred_Priorities_for_Care_V2_Dec2007.pdf

### The Mental Capacity Act in Practice:

*Guidance for End of Life Care* (2008) - The National Council for Palliative Care.
www.ncpc.org.uk
Tel. 0207 6971520

### Advance Decisions to Refuse Treatment website

A training website for professionals which contains a patient section.
www.adrtnhs.co.uk

### 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

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

The University of Nottingham

NHS

National End of Life Care Programme

*Improving end of life care*

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