

# **ADVANCED CARE PLANNING**

This leaflet gives information for patients, families and carers on what to consider around end of life care.



# My doctor has suggested I think about Advanced Care Planning, what is this?

A discussion between you, your family (if you wish) and the professionals who look after you. The discussion allows you to express your views, preferences and wishes about the way you should be cared for in the future.

#### What is an Advanced Care Plan?

A document which summarises your wishes about the future care in a way that can be shared with others, such as family, friends and health professionals.

# What does advanced care planning at the end of life mean?

"End of life" is a phrase used to refer to the last years, months, weeks or days of your life, especially if you have an illness which cannot be cured.

Thinking about your care during this time involves taking the opportunity to think about what living with a serious illness might mean to you and your loved ones and documenting your wishes.

Your wishes will then be known to everyone even if you are no longer able to communicate them.

## What sorts of things are in an Advanced Care Plan?

This should be an individualised document but the kinds of things you may wish to consider are:

- · Where you want to be cared for
- Whether you would want to go to hospital in different circumstances
- When you feel you would want active treatment to stop and emphasis to be put on keeping you comfortable
- Where you would wish to be when you died

- Who you want to be with you at the end of your life
- Your spiritual values and beliefs and how you would like these to be honoured

# Who should be involved in discussing my Advanced Care Plan?

Your health care team, such as GPs, district nurses, and Macmillan nurses can help you to develop your plan. They

"Let our advanced worrying become advanced training and planning"

Winston Churchill

are used to helping people think about these issues.

It can be difficult to talk to the people close to you about your wishes around end of life care. Sometimes they may not want to acknowledge that you will die or they may disagree with some of your decisions. However, if you feel able to, it is important to involve those closest to you in these discussions because it can help them to understand what you want, what is likely to happen to you, and to be realistic about what is possible. Your health care team can help you with these discussions too.

# My family think differently from me about my Advance Care Plan, what should I do?

Sometimes we don't all think alike, and it can be a shock for your family if you start to talk about these things.

Take your time talking and thinking about things together. Try and find out why they think differently and if there are



specific things they are worried about. Explain to them why you think the ACP is important and why you have the views you do.

It may be helpful to involve your health care team to advise and, if you consent, speak to your family on your behalf. If some family members have differing views, it may be worthwhile looking at Lasting Power of Attorney for health and care.

# Is an Advanced Care Plan the same as Lasting Power of Attorney?

No, and advanced care plan is simply a record of your conversations and wishes. It is not legally enforceable and sometimes the things you would like to happen are not possible due to circumstances.

It can, however, help the professionals looking after you to understand what is important to you.

Lasting Power of Attorney is a legal document which allows other people to

"For human beings, life is meaningful because it is a story, and in stories, endings matter"

Atul Gawande

make decisions on your behalf if you are unable to do so. More information can be found at:

https://www.gov.uk/power-of-attorney

#### Why is advanced care planning helpful?

There are lots of reasons why it may be helpful to think about your wishes and preferences; many of these will relate to the individual themselves and their circumstances.

Some people find it helpful to discuss these issues with their family and friends, it can be reassuring both to you and for them that they know your wishes and feelings.

Research studies have also shown that taking part in advanced care planning increases the likelihood of you having the end of life care that you would like.

## Who should have a copy of my Advanced Care Plan?

You can share your plan with as many people as you wish.

It is helpful to share it with family and friends so that they know what is important to you.

It is important that your GP has a copy so that it can be kept with your medical notes.

Consider also how the following people can access it:

- Community nurses
- Out of hours services
- Ambulance service
- Hospital team
- Hospice
- Palliative care team
- Professional carers

# Where should I keep my Advanced Care Plan?

Ask you care team if they can keep an electronic copy attached to your medical notes. This makes it easier to share with all of the teams involved in your care. You should keep the original document in an easily accessible place in your home and make sure that your family, friends and carers know where it is.

# Can I change the information on my Advanced Care Plan?

Yes, you can change any aspect of your plan. In fact it is a good idea to review it at regular intervals to make sure that it standrewshospice.com



still reflects your wishes and choices. You can either start a new form or just make changes to the existing one, making sure you sign and date it again. When you have updated it, take care to let your family and health professionals know, and give them a copy of the updated plan.

## Where can I get an Advanced Care Plan to fill in?

In NE Lincolnshire we use a document called "My future Care Plan." Your health care team will be able to give you a copy of this.

Other organisations have useful templates, e.g.

http://advancecareplan.org.uk/advance-care-plan-passport/

# Do I have to make an Advanced Care Plan?

No, no one is obliged to have an ACP. It may be helpful to you and your loved ones but you should not feel under pressure to complete it if you don't want to.

Keep in mind, though, that you can complete it at any time. So if now isn't the right time, it may be that you feel ready to do it at some point in the future.

#### **Comments or suggestions**

If you have any comments or suggestions regarding this leaflet or you would like the information in a different format or language, please contact us.

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