

My Future Wishes Conversation Starter Pack

Tools to enable people with any long term health
condition to discuss and plan future wishes

West Yorkshire and Harrogate
Health and Care Partnership



About this pack

Enabling people with any long term health condition to discuss and record future care wishes can lead to reductions in non-essential hospital admissions, better experience for patients and families and improved care outcomes.

This is sometimes known as Advance Care Planning.

Getting Started: how to use this pack

Inside this pack you will find four topic cards covering essential topics to help you talk about planning for the future.

The contents of this pack have been co-produced by people affected by dementia and other long term conditions.

These cards are designed to enable any persons with long term health conditions to initiate conversations with all those involved in their care. This could be carers, family, friends and health and social care professionals.

The cards have been specifically designed to enable you to have conversations at your own pace and to break down the areas of planning into bite size chunks.

It is important to have discussions around your future wishes in a timely manner. With certain conditions **capacity** and the **ability to make decisions** may reduce or be lost as the condition progresses.

Each card contains: Conversation starters, a space to make your own notes and details of steps to take after you have had your conversations.

Whats important to me?

This topic card aims to get you thinking and talking about what makes you happy and what is most important to you.

This could include:

- Cultural, religious or spiritual needs
- Family and friends
- Diet, including favourite foods and drinks
- Where you live
- Hobbies and Interests: such as sports, music, films and pets

Talking about and recording what is important to you can help you live well, have greater control and help the people supporting you to understand you as a person.

Initiating these conversations earlier may help you consider the impact and implications on your wider social network.

“ I have real pride in my heritage..., this is important to discuss as part of future planning... ”

Conversation Starters

Who knows you best and understands what is important to you?

What are the most important things to you to have a good quality of life?

Tell me about your hobbies and interests?

What would you want somebody to know about you (routines)?

What or who makes you feel happy and secure?

Do you have a faith or belief that is important to you now and how would you like that to continue as you become less well?

How would I know if what is important to you has changed over time?

What plans do you need to make for anyone who is dependant on you - for example family, neighbours and pets?



TIPS:

*Allow a time and safe space to talk with no judgement
This does not need to be a formal conversation, "get a cuppa".*

*Everyone's preferences and choices can change with time
It's important to revisit the conversations regularly and
not to make assumptions.*

*Remember, diet, music, how a person chooses to dress
can all be heavily influenced by culture. Don't be afraid
to explore this further.*



It's brilliant that you have started a conversation about what is important to you.

The best way to ensure that professionals and other people involved in your care are aware of what is important to you is to record your wishes in an advance care plan.

My Future Wishes – Advance Care Plan is available by visiting:
<http://bit.ly/acpdementia>

Other helpful resources and websites to visit:
Planning for your Future Care – A Guide
www.england.nhs.uk/improvement-hub/Planning-for-your-future-care/

Lasting Powers of Attorney and Wills

This topic card aims to get you thinking and talking about some of the legal elements that are important and relevant when planning for the future.

A **Lasting Power of Attorney (LPA)** is a legal document that allows you to appoint someone to make decisions on your behalf when you are no longer able to.

There are two types of LPA; One relates to your **Property and Financial Affairs** and the other relates to decisions about **Health and Welfare**.

Both are legal documents once they have been submitted and registered with the Office of Public Guardian.

When someone no longer has **capacity** to make a LPA but needs a decision making on Property and Finance – you need to consider applying for a **Deputyship**. See Next Steps for further details and websites.

A **Will** is a legal document that says who should receive the things you own when you die, such as property, savings and valuables. It is also an opportunity to record your wishes for your **funeral**.

You don't have to ask a solicitor to help you make a LPA or a Will but it can be a good idea to ask advice on issues such as **capacity**.

Conversation Starters

Who would you trust to make decisions for you in your best interests?

Who are the key people in your life that know you best? (Prompt the person to be specific about those people who are important in their life and their care).

If at any point you need additional care- how would you like those needs to be met?

What would your ideal funeral look like? (What kind of casket, would you like music, which songs, what would you be dressed in?)



TIPS:

Be prepared this may be a series of evolving conversations over a period of time to suit the individual.

Recognise your own needs if you are having this conversation with a family member or friend.

Give yourself time out when you need it.

It may feel that you wish to put this conversation off, however, the earlier these conversations begin, the more chance there is for the person to think about, talk about and share their wishes.



“I’ve thought about doing a LPA – Health and Welfare... But I shelved it because I can’t face doing it alone.”





Next Steps

The Office of Public Guardian (www.direct.gov.uk) have designed the LPA forms to be simple as possible enabling people to self-complete. You can get in touch with them for one off advice.

You can enlist the support of other agencies to support with completing a LPA.

Whilst you don't have to enlist a solicitor to complete a LPA or Will it can be a good idea and some solicitors offer a free one off consultation. A number of charities offer a reduced cost Will Writing Service.

It is important to inform your GP, family and other professionals if you have a registered LPA and or Will in place.

Be aware that LPA's involve fees to register. LPA registration can take time but not as much time or cost when compared to applying for a Deputyship.

Other helpful resources and websites to visit:

www.sfe.legal

www.gov.uk/make-will

www.gov.uk/power-of-attorney

www.moneyadviceservice.org.uk

Medical Decisions

This topic card aims to get you thinking and talking about medical decisions.

Making decisions in advance about medical treatments can help to reduce hospital admissions and lessen the burden of decision making for loved ones. It can enable you to retain control about what medical treatments you would not want to receive in the future should **capacity or ability to communicate be lost**.

An **Advance Statement** is a written statement that sets out your preferences, wishes, beliefs and values regarding your future care. It provides a guide to anyone who might have to make decisions in your best interests. It's usually recorded as part of an 'Advance Care Plan' and kept on your GP record.

An **Advance Decision to Refuse Treatment** (sometimes known as a Living Will, Advance Directive or Advance Decision) is a legally binding document (dependant of certain requirements) which allows you to refuse specific medical treatments in the future, for example refusing artificial ventilation.

Some people choose to have a **Do Not Attempt Resuscitation (DNACPR)** form completed by their doctor, which communicates to professionals that resuscitation should not be attempted.

You may wish to consider whether people around you know of your thoughts on **Organ Donation** or research involvement after death.

Conversation Starters

Is there anything you worry about, or fear happening?

Is there anything you don't want to happen?

What are your thoughts on life prolonging treatments now and in the future?

Do you have any specific views or needs that are important to you that may affect the type of treatments you would want to refuse? (These could be for example, cultural or religious beliefs.)

What should happen to you in a medical emergency?



TIPS:

These conversations can be really sensitive for all involved so be mindful people may need additional support after the discussion.

You and your loved ones may have differing views about this area, give yourself emotional space and time but don't be afraid to make your views clear.

Recognise that this is the individual's decision.

Having these conversations now can help reduce feelings of guilt and pressure in times of medical crisis.

“Pick your time carefully and stop if it is causing distress” - try later.



Next steps:

Any medical decisions must be discussed with a clinical or healthcare professional, particularly if you would like to complete an Advance Decision to Refuse Treatment or a Do Not Attempt Resuscitation form.

It is important that any wishes you have around your future medical care are held on your medical records and with those who are important to you.

For more information on advance statements:

www.alzheimers.org.uk

www.ageuk.org.uk

For more information on Advance Decisions to Refuse treatment and Organ Donation.

www.nhs.uk/conditions/end-of-life-care

www.compassionindying.org.uk

www.organdonation.nhs.uk

For more information on DNACPR and emergency care planning:

www.resus.org.uk/respect

www.dyingmatters.org

Everyone is entitled to change their minds and it is important that these decisions and conversations are revisited regularly particularly if you have a hospital admission or a change in your health.

My Care Preferences

This topic card aims to get you thinking and talking about how and where you might want to be cared for if you needed additional support.

This could include:

- Your dignity and independence and how to personalise your care
- Who would you want to be involved in your personal care
- Important routines
- How you prefer to communicate
- Where would you like to be cared for
- Respite Care
- Choices around end of life care
- What would you like to happen after death

Talking about and recording your preferences for care can help you live well, have greater control and increase personalised care as your condition changes.

“ The end years are just as important as the early years of life. ”

“ We didn't talk about Palliative Care, I had to make best interest decisions...Big responsibilities... ”

Conversation Starters

If you were to receive personal care, what should the carer know about you?

How would you want a family member to support you with personal care (washing and dressing)? Are you all in agreement about this?

Tell me about your daily routine and what you would like support to continue to do?

Where would you like to be cared for if you are no longer able to remain at home? What are your wishes around end of life care?

Are there any religious or cultural practises that would be important to you around care of your body after death?

What specific funeral arrangements would you like? (What kind of casket, would you like music, which songs, who would you want at your funeral, what would you be dressed in?)



TIPS:

“Make it a conversation not an interview”

“Start this at home...when they have plenty of time and no other concerns...”

Recognise there may be challenging elements around these conversations, in particular, assumptions made about what family members should or shouldn't do.



Next steps:

Once you have had conversations around your care preferences you may wish to record this on the My Future Wishes – Advance Care Plan
<http://bit.ly/acpdementia>

Some of the decisions you have made may have been captured in other areas like **Lasting Power of Attorney (Health and Welfare)** but it is always important to inform those people important to you of your choices. If you have not completed a Lasting Power of Attorney (LPA)– please see the LPA Conversation card in this pack.

Include anything that is important to you no matter how trivial it seems. If it is important to you – it matters.

Everyone is entitled to change their minds and it is important that these decisions and conversations are revisited regularly to help keep you and those around you reassured of your choices.

Other helpful resources and websites to visit:

www.nhs.uk/conditions/social-care-and-support-guide/

www.alzheimers.org.uk

www.ageuk.org.uk

www.carersuk.org



This pack has been produced for West Yorkshire and Harrogate Health and Care Partnership in association with Alzheimer's Society.

The contents and structure of this pack have been co-produced with people affected by dementia and other long-term conditions alongside partnership organisations across West Yorkshire and Harrogate.

These aren't always easy conversations, but people affected by dementia and other long term health conditions tell us they are easier to have when approached earlier on with good time, space and even elements of humour.

Every person is different as are their needs and wants.

It is important that the person who is talking about their future wishes identifies the times they wish to do this and with the person(s) they wish to involve.

We hope the contents of this pack helps you to start meaningful conversations and enables you to make decisions and know where to record your plans for the future.