

A guide to **PLANNING AHEAD**



Introduction

- This document is a guide to support people who wish to make plans for their future care.
- We have created a 'Useful Resources' section on our Planning Ahead web page to complement this document and help direct you to other organisations that may be able to support you as you go through this process.

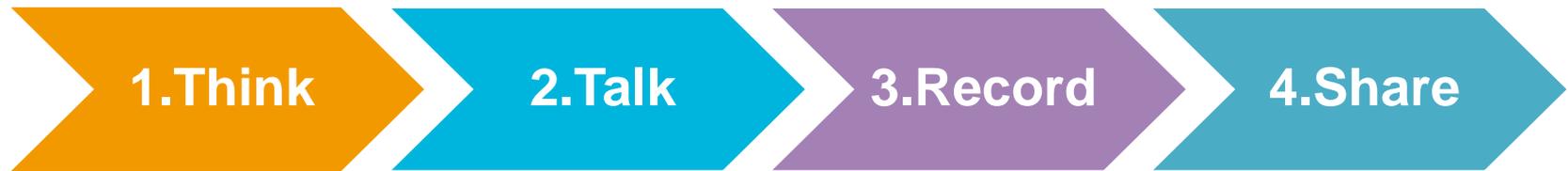


What is 'planning ahead'?

- The process of planning ahead is sometimes referred to as '**Advance Care Planning**' or ACP – this is a term you might have heard your GP or healthcare professionals use.
- The official definition of ACP is:
*'Advance care planning is a **voluntary** process of discussion and review to help an individual who **has capacity to anticipate** how their condition may affect them in the future and, if they wish, **set on record choices about their care and treatment**'*

How do I go about this?

1. THINK



- The first step is to think through your care options and work out what is important to you regarding your quality of life – what is acceptable to one person might be completely unacceptable to another.
- The following section gives you an idea of some of the things you might want to consider.



1. **THINK:** What do I need to think about?

ADVANCE CARE PLANNING

What do you want to happened?

Advance Statement – preferences and wishes

“I would prefer to stay at home for as long as possible and have carers to help me. I’ve written down all of the things I want them to know, like how I enjoy watching the garden from my window, and that I love to talk about sports.”

What do you not want to happen?

Advance Decision to Refuse Treatment
- decision to refuse a specific type of treatment at some time in the future

“I don’t wish to be kept alive if I can no longer breath independently. I don’t want my grandchildren to see me like that. I just want to die peacefully in as little pain as possible.”

Who will speak for you?

Lasting power of attorney – someone you trust to speak for you

“I want my son to make decisions for me once I’m no longer able. We’ve talked about what’s important to me and I trust him to follow out my wishes.”

1. THINK: What do you want to happen?

Creating an Advance Statement

This is a statement of anything that is important to you which can be used if you are unable to tell people how you wish to be cared for. It can cover:

- Things that are important in your life
 - Activities, people, interests, places to visit
- Things that are important to your identity
 - Independence, privacy and dignity
 - What you like to wear, how you like to present yourself
- Your values and religious/spiritual beliefs
 - How these might effect decisions around treatment and care
- Your lifestyle
 - What you like to eat and when, when you like to sleep

1. **THINK:** What do you want to happen?

Creating an Advance Statement

- An advance statement would also be a good place to record any wishes, preferences or arrangements you might have made regarding your funeral and will.
 - If you have appointed a solicitor then it would be sensible to record their details here so they are easy to find.
- Other things to consider might be:
 - Organ donation – if this is something you'd like to do it is important to let others know
 - Digital legacy – what will happen to any social media accounts, phone data etc. when you die? Once you've decided how you'd like your data to be dealt with, you must let someone know so they can carry out your wishes.

1. **THINK:** What do I not want to happen to me?

Advance Decision to Refuse Treatment

- An Advance Decision allows you to write down any medical treatments that you do not want to have in the future, in case you later become unable to make or communicate decisions for yourself.
- A common example of an advance decision that you may have heard of is a DNACPR which stands for Do Not Attempt Cardio Pulmonary Resuscitation, however there are a number of other treatments you can refuse that may be relevant if you have a specific diagnosis.

1. **THINK:** What do I not want to happen to me?

Advance Decision to Refuse Treatment

- It is important that you talk to your GP/Healthcare professional if this is something you want to consider putting in place.
- You may want to refuse a treatment in some situations, but not others. Your GP can help you understand this and ensure documents are clear about all the circumstances in which you want to refuse this treatment.

1. **THINK:** What do I not want to happen to me?

Advance Decision to Refuse Treatment

- An advance decision is legally binding as long as it:
 - complies with the Mental Capacity Act*
 - is valid
 - applies to the situation
- For more information about creating an Advance Decision please visit the NHS website:
<https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/>

*The Mental Capacity Act (MCA) is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment.

1. THINK: Who will speak for you?

Lasting Power of Attorney

- Think about who would be the best person to represent your views and ensure they understand their responsibilities and are aware of your wishes.
- There are 2 types of LPA:
 - health and welfare: this only applies when capacity* is lost
 - property and financial affairs: capacity doesn't have to be lost, you can nominate your LPA to do something e.g. manage bank account, out of preference

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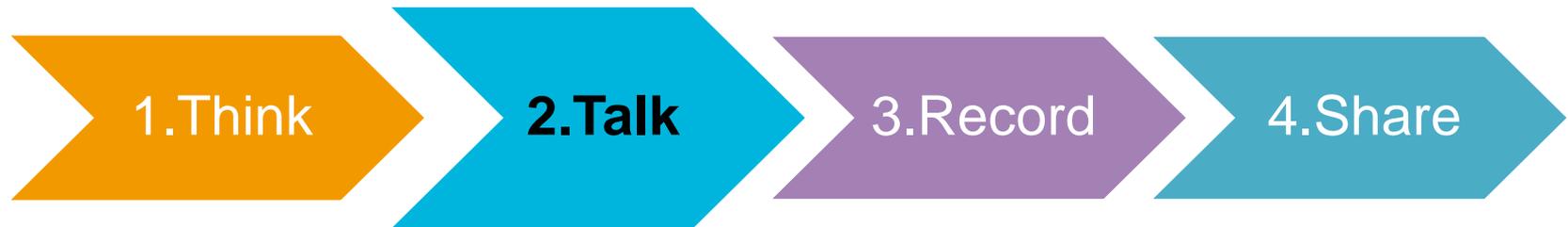
1. THINK: Who will speak for you?

Lasting Power of Attorney

- LPAs must be registered with the Office of the Public Guardian and you don't need a solicitor to do this.
- It costs £82 to register an LPA unless you get a reduction or exemption.
- For more information on how to make, register or end Lasting Power of Attorney visit the Government website here:

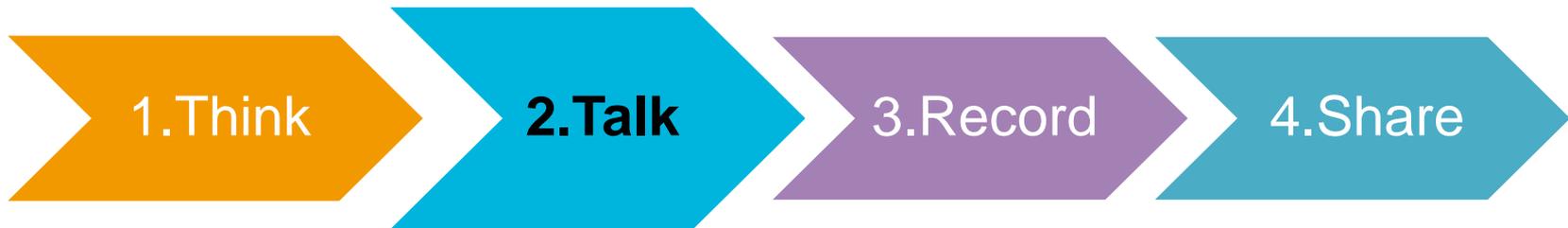
<https://www.gov.uk/power-of-attorney>

2. TALK: Involving friends, family and healthcare professionals



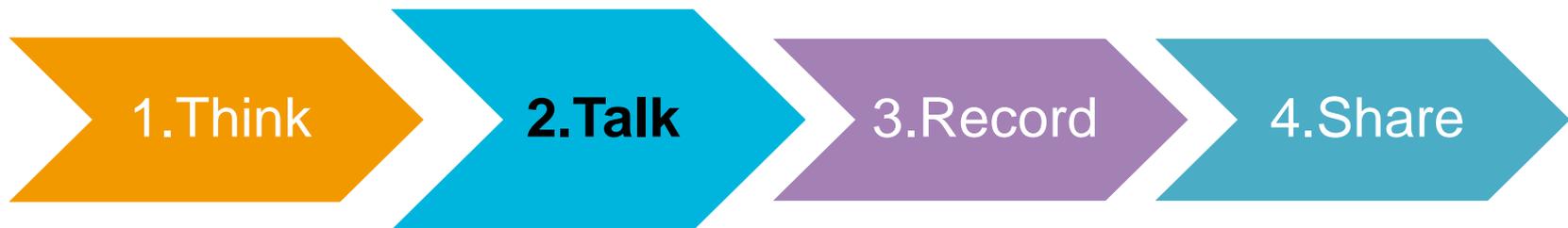
- Next you need to talk with all the people involved in your care. This may include your GP and other professionals involved in your care, but should definitely include any friends or family who need to be made aware of your wishes and possibly represent your view point in the future.

2. TALK: Starting difficult conversations



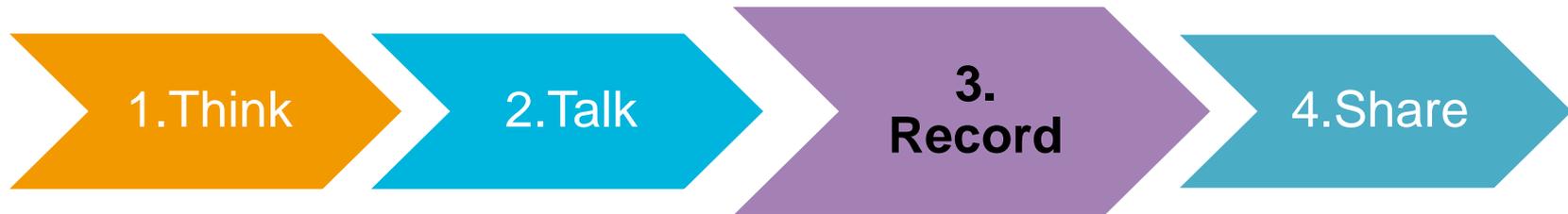
- We know it can be difficult to start these conversations with people you are close to. You may not wish to upset them or you may find it upsetting yourself. You may be concerned that they will not be supportive or disagree with your wishes.
- There is no wrong way or right way to have these conversations but it is important to involve people in your decision making process.
- The 'Useful Resources' section on our Planning Ahead web page has links to leaflets/guides for starting difficult conversations which you may find useful.

2. TALK: Considering what is practical and realistic



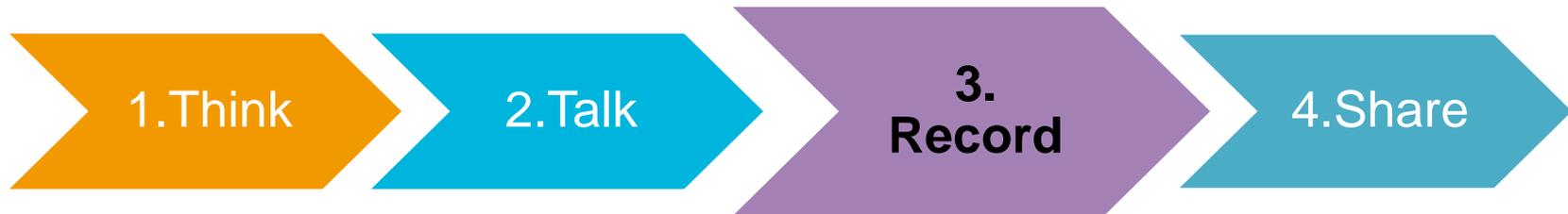
- It is important to remember, although these are your preferences and wishes for your future care, you must also consider what is practical and realistic.
- For example if you wish to be cared for at home, you might talk through:
 - who will look after you? Are they aware of this and happy to do this?
 - Any modifications that might need to be made to the environment e.g. stair lifts, downstairs bathroom.
 - What is the financial cost of this? Can you afford this?

3. RECORD: Documents and online resources



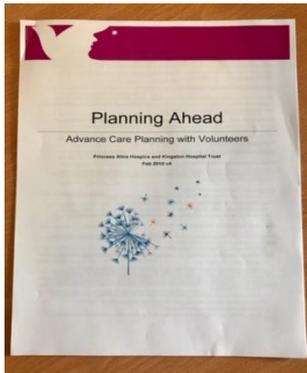
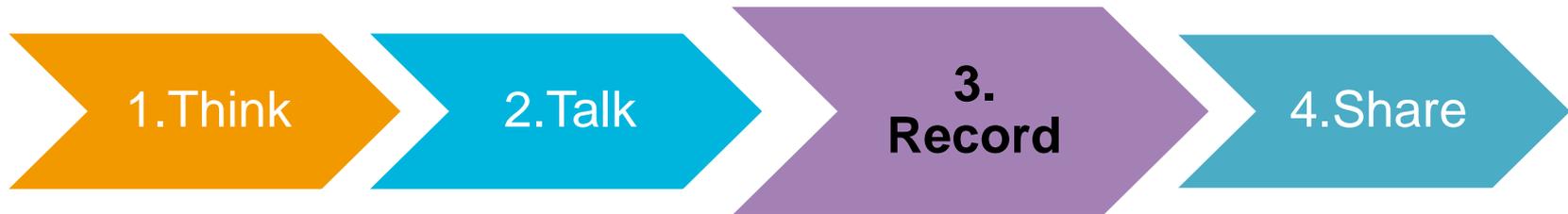
- Once you have spoken with friends, family and healthcare professionals, it is useful to create a record of your wishes.
- There are a number of documents available online from different organisations that are useful for recording your wishes. Princess Alice has created one which is available on our website.
 - In addition to these ‘Planning Ahead’ documents you may also need to complete additional documents depending on whether or not you wish to have any Advance Decisions in place. Please ask you healthcare professionals about this.

3. RECORD: Documents and online resources



- Those living in London are able to access an online NHS clinical service call MyCMC to record their wishes (see the ‘Useful Resources’ section of the web page for more details on this).
- For people living outside London, in Surrey, there is a form known as ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) that is used by healthcare professionals to record patients’ urgent care plans (see the ‘Useful Resources’ section of the web page for more details on this).

3. RECORD: Documents and online resources



The Princess Alice Hospice Planning Ahead document
www.pah.org.uk/planningahead/



<https://www.coordinatemycare.co.uk/mycmc/>



<https://www.respectprocess.org.uk>



4: SHARE AND REVIEW



- Once you have made a record of your wishes, it is important to share them with everyone involved in your care.
- If you have created a paper document you may want to make copies to give to people, or scan it to create an electronic version that can be emailed.
- It would also be advisable to keep any legal documents such as LPAs and DNACPRs in an easily accessible place and tell someone where they are kept.



4: SHARE AND REVIEW



- If you live in London and have created a MyCMC record online, you will need to speak with your GP or Nurse so they can input your clinical information. They will then make your record available to healthcare services such as London Ambulance, out of hours GPs, NHS 111 Line and Emergency Departments.
- It is important to remember that the record you have created **can be reviewed and changed at any time** to reflect a change in your wishes, but you must also remember to share any updates with relevant people.



How can we help?

- Princess Alice has a team of trained volunteers happy to support you through this process if you feel you need it.
- They will:
 - Speak with you at a time convenient to you – with a partner/relative/friend also present if you wish
 - Help you think through your options and record your wishes
 - Give guidance to other resources to support you in arranging Wills, LPAs, MyCMC etc.
- If you are interesting in talking to one of our Planning Ahead volunteers please email our Volunteer Coordinator, Jo Bolton - jobolton@pah.org.uk