

Living well



Thinking and planning for
the end of your life

Acknowledgements

HSA and Lancashire County Council produced this guide, based on the work in Central Lancashire by a group of people who were supporting family members, or working with people in residential care at the end of their lives.

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We chose the dandelion to represent wishes and time passing - as children we called them dandelion clocks and as we blew their seeds we made a wish.

The guide is based on the person centred thinking tools developed by The Learning Community for Person Centred Practices. You can learn about person centred thinking tools from www.learningcommunity.us and www.helensandersonassociates.co.uk

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This book is part of a series of resources. There is a companion guide with examples, a person centred thinking and end of life minibook and courses and programmes available from HSA, www.helensandersonassociates.co.uk

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This guide is to help you think about and record what is important to you now, and what you want in the future (planning for the end of your life).

You could go through it step by step, or just fill in the sections that feel relevant to you and leave the others. You can fill this in by yourself but it is best to work through the guide with family, friends or staff. Some people prefer to do this with only one person and other people prefer using it in a small group.

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Living well



Name.....

Date started

What is my history...my important memories

You might want to spend some time thinking back over your life, and the memories that you have. Often people want to find a way to record this. You can simply create a list of important events in your life here, and leave it at that, or use that as the basis for more detailed or creative ways to record your life and history. Here are some ideas:

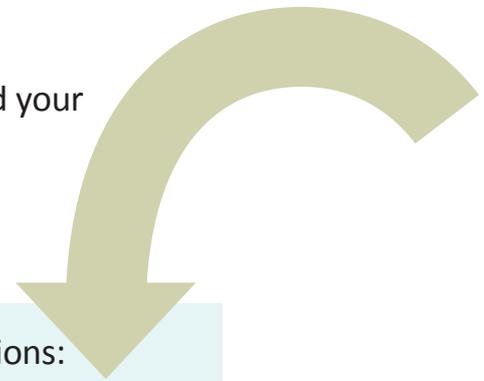
Creating an album or scrap book about your life with photos.

A journal with your memories written in it.

Letters to your family that talk about your past and your favourite memories with them.

A memory box of photos and memorabilia.

A video/DVD of you talking about your past.



Now that you have started this, here are some questions:

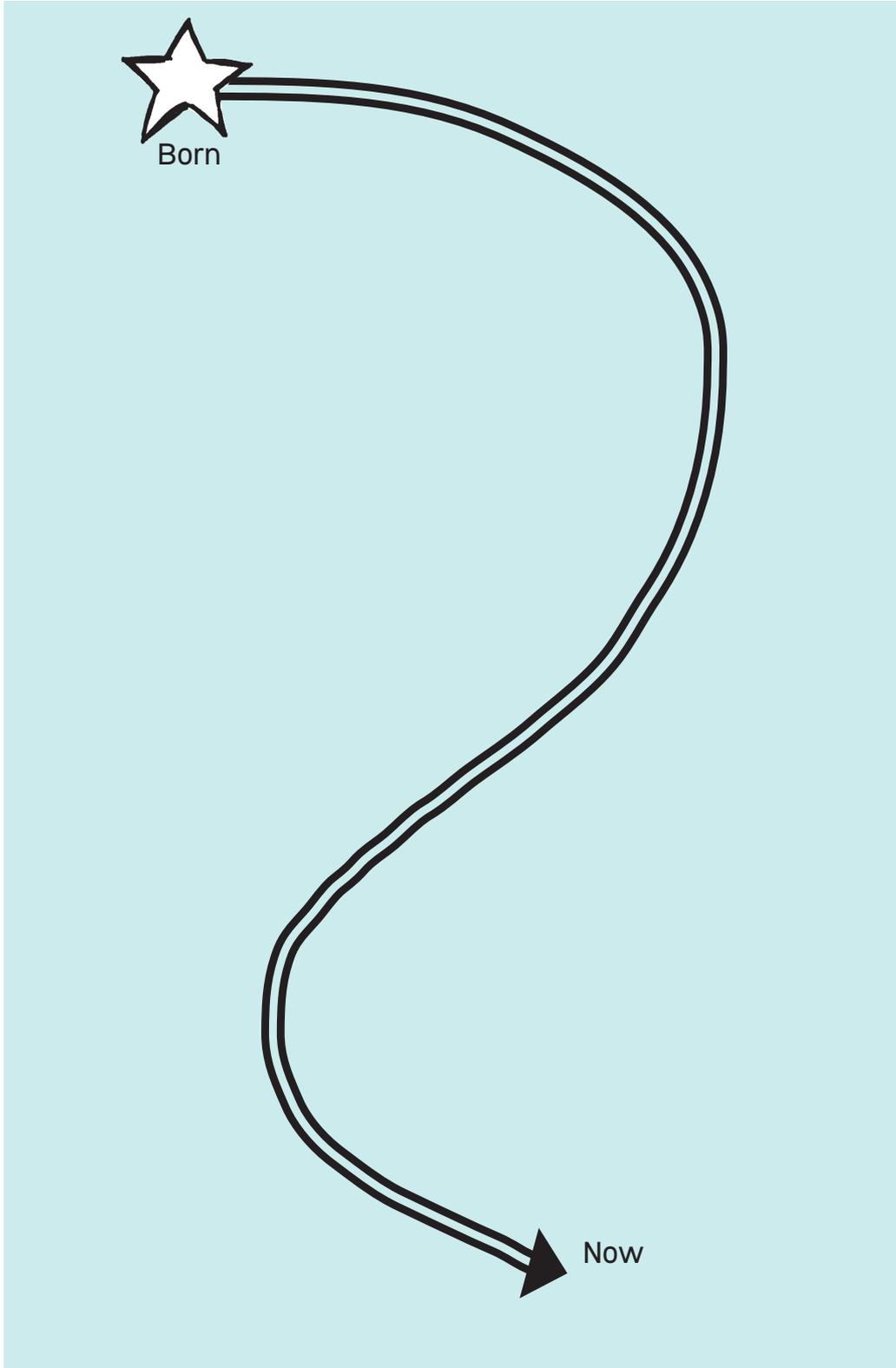
Is there anything else that you would like to do to record your history and precious memories? What do you need to do to get started? What would you like other people to do to help you?

How would you like this information to be stored or shared?

Please make some notes about what you want to do, or who could help you record your history and share this with others.

Notes for actions

What is my history...my important memories



Thinking about relationships

This is a way to map out the important people in your life. You can then think about whether there are people who you want to spend more time with, or simply get in touch with, or old friends you want to reconnect with.

Put your name in the middle. The next circle is for the people who are the closest to you. Write their names in that circle. The circle outside that one is for people who are also important to you, and you can write their names there. The outer circle is for people who are also in your life, who you care about, who may be acquaintances or relatives who you don't feel especially close to.

Now that you have filled this in, here are some questions:

Is there anyone who you want to see more of?

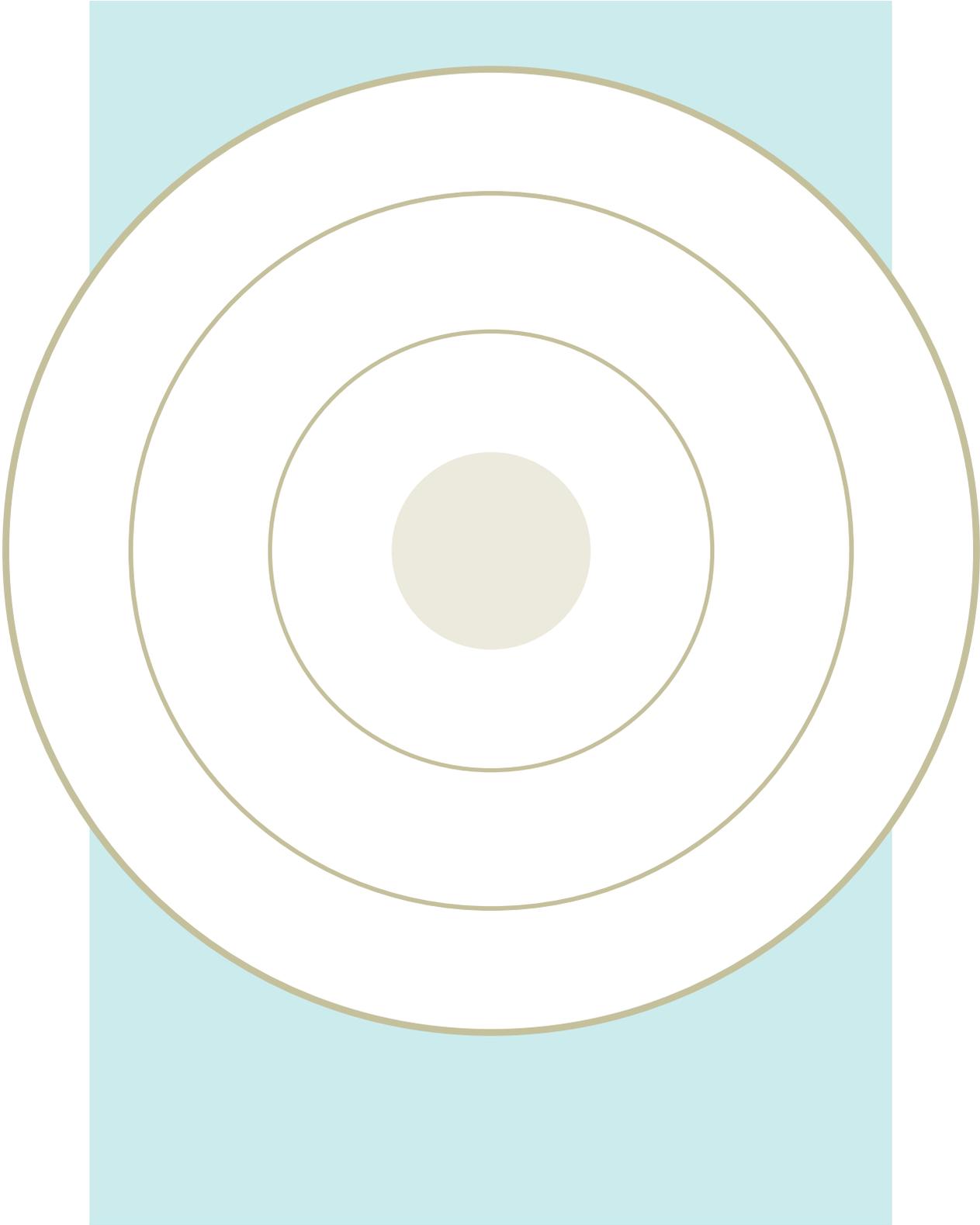
Is there anyone who you have not been in contact with for a while, who you want to reconnect with?

If yes, make some notes about what you want to do here.

Notes for actions



Thinking about relationships



What does a good day and a bad day look like for me?

All of us have good days and bad days. It can be helpful to think about what makes a really good day for you, and when bad days occur. You can then use this information to think about what it would take for you to have more good days.

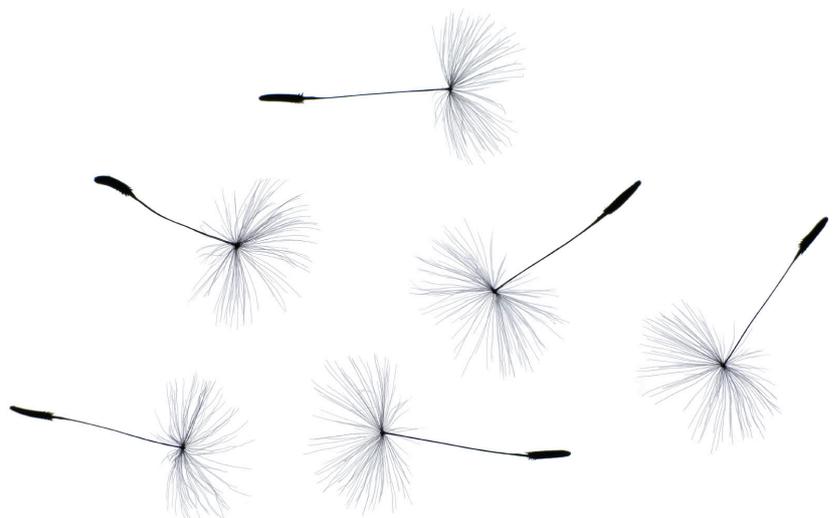
Now that you have filled this in, here are some questions:

Look first of all at what makes a good day for you. Is there anything you or others could do to have more of what is on your list, or for it to happen more often?

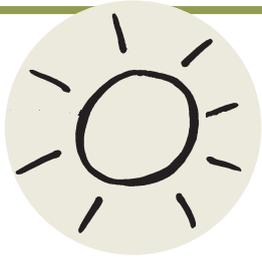
Now look at your bad day list. Is there anything that you or others could do to prevent some of those things happening, or make them happen less often?

Please make notes about what you want to do, or what others could help you with, so that you can have more good days and less bad days.

Notes for actions



What does a good day and a bad day look like for me?



What is important to me now, and how I want to be supported

Do you ever wish that some people in your life knew more about you as a person? Would it give you peace of mind if, in a few minutes, they could know a little about you and what they need to do to support you? If you have people who help you out, or are paid to support you, it is very helpful to give them a summary of what is important to you, and how you want to be supported.

What is important to you?

Think about your favourite things in life. How do you like to spend your time? What places do you like to go to? What are your hobbies and interests? Include in this what you don't like, what annoys you, or makes your miserable, what you don't want to happen. How do you celebrate your faith or culture? Think about what a great week or weekend would look like for you, and what makes it great. What about food and drink, what are your favourites, that are important to you. Are there routines that you must have in your life, for example, particular things about how you get up in the morning, or a TV programme that you never miss, or music that you always listen to if you are feeling down.

How do you want to be supported?

What do you really want people who help you, or staff, to know about how you like things done? This could include how you want to be supported around any treatments for illness that you might have.



Now that you have thought about what is important to you and how you want to be supported, let's think (in the next section) about how much of what matters is actually happening in your life, and whether you are bring supported in ways that work for you.

What is important to me now, and how I want to be supported

What is important to me...

How best to support me...

What is working and not working in my life and what do I want to change?

Think about what is going well or working in your life at the moment, and what is not working, and upsetting or frustrating you. Write that down.

Then look back over what you decided is important to you, and how you want to be supported. Look at each one and think about what is working or not working for you about that issue, and write it in the table. Be as specific as you can.

It can be really helpful to get other perspectives on what is working and not working for you. You might want to ask someone in your family or a close friend to add to this, and write what is working and not working about your life from their perspective.

Now that you have filled this in, here are some questions:

Look first at the 'what is working' list. We hope you feel good about the things that are going well. It is also worth thinking about whether you need to do anything to keep what is working for you happening. Is there anything you or others needs to do, to keep what is working happening?

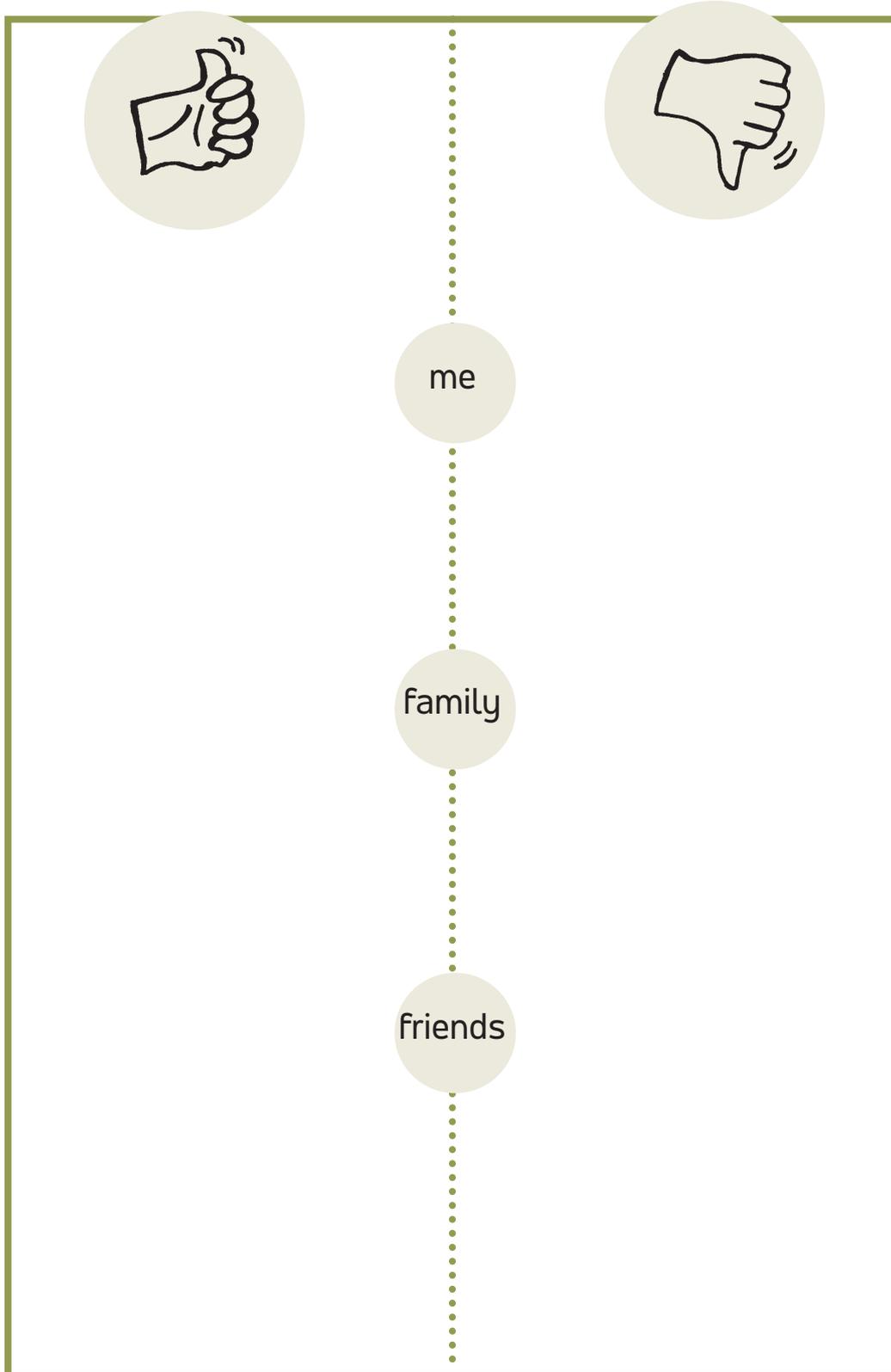
Now look at your 'what is not working' list. Is there anything that you or others could do to change what is not working for you?

If someone else gave you their perspective on what is working and not working, are there any differences that you want to talk to them about, and see if there is a way forward if there is disagreement?

Please make notes about what you want to do, or what others could help you with, so that what is working for you keeps happening, and you can change what is not working.

Notes for actions

What is working and not working in my life and what do I want to change?



If I could, I would...

This is a place for you to think about what you would like to do before you die. There are books called '1000 Places To See Before You Die' or '1000 Things To Do Before You Die'. What is on your list? What would you love to do, that you have not had to chance to do yet? It could be people who you would like to meet or see, a place in the country (or the world) that you have always wanted to visit, an event that you have always wanted to go to, but never managed to arrange. What would you do if you could?

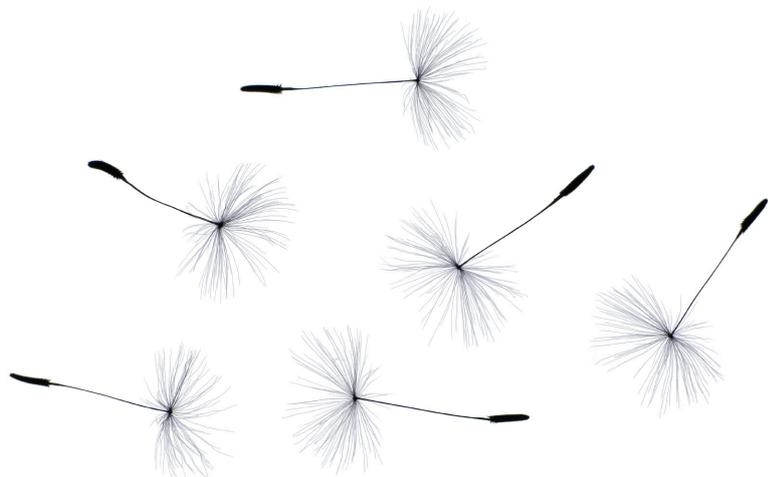
Now that you have filled this in, here are some questions:

If you have a long list, what would be the top three, the most important things that you want to do?

Start with one of the things on your list, what would it take for you to do this? What could you do? What would other people need to help with? Together can you make this happen, or as close to it as possible?

Please make some notes about what you want to do, or what others could help you with, for you to achieve at least one of the things that you want to do before you die.

Notes for actions



If I could, I would...

What I want and do not want in the future - hopes and fears

The previous pages were about aspirations; what you would love to do if you could. This section deals with the very practical things that you want or do not want to happen in the future. If you are unwell, this could be around treatments that you would be prepared to try, and ones that you do not want in the future.

It could be about where you live, who you live with, who might care for you. These can be hard questions to think about, but it is important to have these discussions so that people who love you know what your wishes are.

Here are some questions to get started. If you needed extra support, either as you get older, or if you became very unwell:

Would you want someone to come into your home to support you every day? What kind of person would you want to support you? What kind of person would not work for you at all?

Would you want someone to come and live in your home to support you if you needed a lot of support? Who would you consider - family, friend or only paid staff?

If you had to move out of your home to be supported, what would you want and not want to happen in relation to where you lived, for example, people who you would want to live close to, so they can visit? Would you consider living with your family, if that worked for them? Is there a particular place that you want to stay near to?

Now that you have filled this in, here are some questions:

Is there anything that you or others need to do to make it more likely that what you want to happen in the future can happen?

Is there anything that you or others can do to avoid what is on your list of what you don't want to happen?

Please make notes about what you want to do, or what others could help you with, that makes it more likely that you can have what you want in the future.

Notes for actions

Making changes to my life - my action plan

This is where you write what you want to do, or what others could help you with, that makes it more likely that you can have what you want in the future.

Please look back at the notes you have made on each left hand page. Think about what changes you would like to make, who could help you and when you would like to have done it.



Making changes to my life - my action plan

Who	What	By when

Thinking and planning for the end of your life



Looking back at my relationship circle, who would I like to do what towards the end of my life?

Your relationship circle records the people who are important to you. As you start to think about the end of your life, you might want to ask some of the important people in your life to play a part in your final arrangements. Just look at the list opposite, and for any that are relevant to you, look at your relationship circle and think about who you want to do ask.

Now that you have filled this in, here are some questions:

How are you going to ask the people you have mentioned? Is there anything or anyone who could help you do this?

Please go to the decisions and actions sheets on pages 29 and 30 and write what you want to do, or what others could help you with, to make sure that the people who matter to you are involved in your final wishes as much as you and they want to be. This could be part of your Living Will.

Notes for actions



Who would I like to do what towards the end of my life?

Who would you like to:

Say goodbye to towards the end of your life?

Be there in your last moments?

Organise your funeral?

Invite to your funeral?

Read at your funeral?

Organise a memorial or celebration of your life?

Write your obituary?

Other things I would like to ask people to do/help with:

Adding to ‘What I want and do not want in the future’, as I think about the end of my life

Look back at what you wrote on page 6 and think about the important people and what you might want them to help with. There are other decisions that you need to consider. Some of these decisions are usually made with family members, and it can be helpful to know what you want and don't want, and what that feels like from their perspective.

On the opposite page are some questions for you to say what you want, and don't want (and to hear the perspective of your family).

Now that you have filled this in, here are some questions:

Are there any differences between what you and your family want? How can you resolve these?

What needs to happen for what you want to take place? Who do you need to help you plan for them?

Please go to the decisions and actions sheets on pages 29 and 30 and write what you want to do, or what others could help you with, to make sure that what you want happens as much as possible.

Notes for actions



What do I want to add as I think about the end of my life?

What I want	What I don't want	My family's view
Where I want to die		
About my funeral (music, readings, flowers etc)		
About being buried or cremated (clothes, hair, makeup, jewellery)		
About the scattering of my ashes		
About what people do after my funeral (e.g. food, drink, a celebration, memorial)		
About a gravestone or marker for my ashes or burial place		
What else is important to me?		

How would I like to be remembered?

Look back at how you described your history and your memories on page 4. Are there particular ways that you would like who you are, and your life and contribution to be remembered?

The very first place that your life will be remembered will be at your funeral, if you choose to have one. Some people have asked that their one page profile (which you created on page 11) is given to the person conducting the funeral, so that they know what was important to you.

Here are other examples of how you could choose to be remembered:

A memorial plaque somewhere - for example on a bench in a favourite spot.

A tree, rose bush or similar, planted to remember you.

A trust or something similar set up in your name.

Something that you would like to have happen on your birthday each year, where people remember you.

Now that you have filled this in, here are some questions:

What do you or others need to do to ensure that you are remembered in the way that you choose?

Please go to the decisions and actions sheets on pages 29 and 30 and write what you want to do, or what others could help you with, so that you are remembered in the way you choose.

Notes for actions

How would I like to be remembered?

A large, hand-drawn speech bubble with a light blue background. The bubble has a thick black outline and a small tail pointing towards the bottom left. It is positioned centrally on the page, below the question. The background of the bubble is a solid light blue color.

What decisions need to be made and how I must be involved

Throughout this workbook, there are decisions and actions that you have made about what you want to happen towards the end of your life, for example about your funeral arrangements. On page 29 there is a sheet for you to write these on called 'My decisions and actions'.

There may be some decisions that other people need to be involved in, or even make on your behalf. The table on page 30 is a place to write how you must be involved in any decision made on your behalf, called 'My decision making agreements'.



My decisions and actions

What I want to happen towards the end of my life	Any actions needed for my decision to happen

My decision making agreement

Decision to be made	How I must be involved	How the decision is made and who makes the final decision