Kingston University London

FUNDED BY NIHR | National Institute for Health and Care Research

Created in partnership with Paradigm
Pushing boundaries

# End of life care planning with people with a learning disability

# GUIDE 1

## UNDERSTANDING END OF LIFE CARE PLANNING

**Of death,**
**we shouldn't be scared,**
**it's better to be**
**P.R.E.P.A.R.E.D !**

**Leon Jordan**
Self-Advocate,
Research Assistant, and always
the Poet

Please see licensing details on the last page.

# CONTENTS PAGE

Click on each title and you'll go straight to that page :)

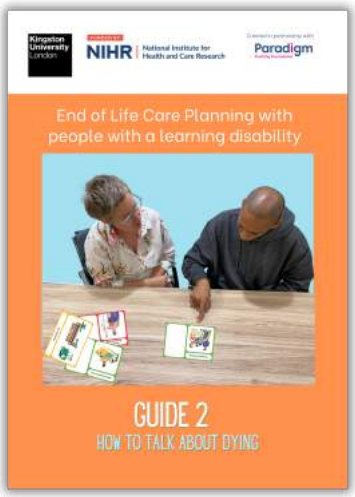

| | |
|---|---|
| Hello … this is for you! | 4 |
| A quick introduction | 5 |
| Talking about death in our society | 7 |
| Why should we talk about death? | 8 |
| 'Terry is going to die' party | 9 |
| Age UK's film 'Let's talk about death and dying' | 10 |
| Let's pause for a moment | 12 |
| What is end of life care planning? | 13 |
| How much can you plan in advance? | 15 |
| As a Support Worker, what can you do? | 16 |
| Capture what a good day looks like | 18 |
| What if someone has a profound learning disability? | 19 |
| The wishes of three people with a learning disability | 20 |
| Thought pieces | 21 |
| You got this! | 22 |
| Thank you | 23 |

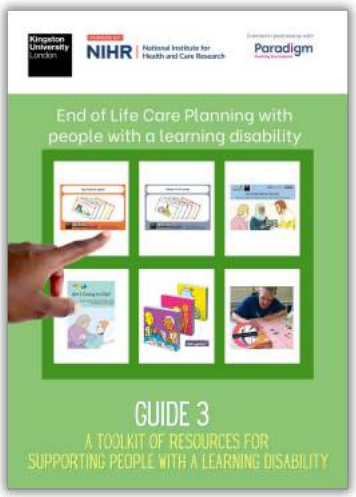
# HELLO ... THIS IS FOR YOU!

# A QUICK INTRODUCTION

This guide has been created to help you understand more about end of life care planning (with people with a learning disability).

This guide comes as part of a set of 3 guides on end of life care planning. You can find all three guides **here**.




You may wonder ... 'What is end of life care planning?' and 'How do I talk about end of life care planning with the people I support?' These are great questions and ones we are going to address through all the guides.

So, if you'd like to fast-track to what 'End of life care planning' is, click **here**.

Deciding on and sharing what we want at the end of life is a hugely empowering thing to do.

The process makes us reflect on what is (and isn't!) important to us.

This impacts not only what we want at the end of our life but how we live each day now... making the most of life while we have it!

End of life planning is important!

# Let's get started!

# TALKING ABOUT DEATH IN OUR SOCIETY

We can be 100% certain that death is going to happen to each one of us. If we want to support people with a learning disability to think about this, and to make plans, we **have** to talk about it.

But... in many cultures, societies and organisations, people don't talk about death and dying. There can be a taboo around it. How is it in your organisation, your culture? Do we need to change things and talk more about death and dying?

**Take a peek at this short film** 'Why don't people talk about dying' where Amanda, Richard and Irene talk about this:

# WHY SHOULD WE TALK ABOUT DEATH?

If we talk about death, and what we want towards the end of our lives, it helps us:

... gain more control and choice over how we live our life, our last days, how we die and how we'd like to be remembered.

... understand, address and share any worries, fears or wishes (with those who are important in our lives).

... have important conversations before it is too late!

... explore and communicate to others the support we'd like and need.

...minimise conflict and arguments between those around us because they have clarity about what we want.

... grow our confidence in asking questions and asserting ourselves.

# 'TERRY'S GOING TO DIE' PARTY

When we are in supporting roles, we can create the space for people to really explore and say what is right and important for them. It's a chance for **us** to uphold people's voices and choices. And what an honour to do that!

**Listen to support worker Louise and self-advocate Richard** talk about how they ended up going to 'Terry is going to die' party in this 6 minute film. It's rather wonderful!

If you would like to go back to the Contents page, click here .

# AGE UK'S FILM 'LET'S TALK ABOUT DEATH AND DYING'

Press the film play button below to watch a short (5 min) film from Age UK called 'Let's talk about Death and Dying'.

Then list below 3 things the film mentions about why talking about death and dying can be helpful.

1.

2.

3.

Maybe I could stay in my home?
I may need a carer to stay with me
24/7 ... cos that's something I would
like to do, rather than move out
of my home actually.

**Amanda Cresswell**
Self-Advocate,
Researcher and cat lover

# LET'S PAUSE FOR A MOMENT

How comfortable do you feel in talking about death and dying? Put an 'x' on the line.

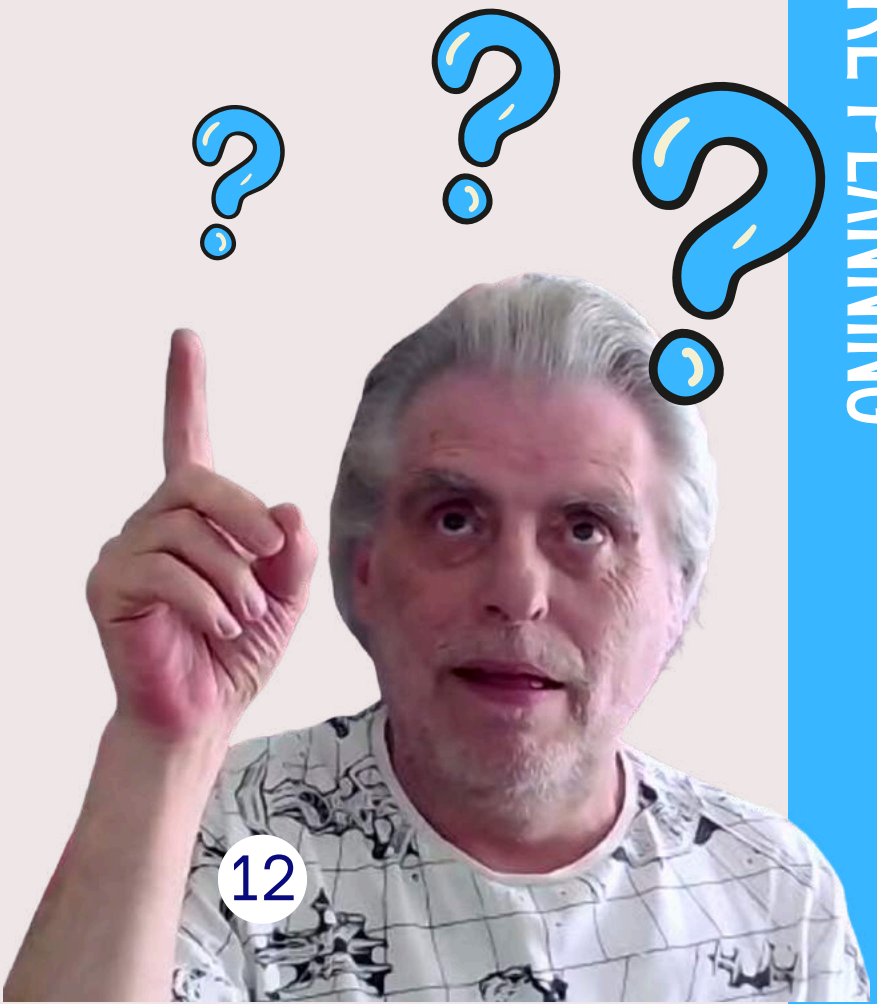
NOT AT ALL COMFORTABLE — QUITE COMFORTABLE — SUPER CCOMFORTABLE

How confident do you feel in talking with people about end of life care planning at the moment? Put an 'x' on the line.

NO CONFIDENCE — A LITTLE CONFIDENT — SUPER CONFIDENT

What are you worried about? Be honest?

What would help you feel more comfortable and confident?



# WHAT IS END OF LIFE CARE PLANNING?

You may have heard some of these terms. They have all been used to describe the process of 'planning for dying'. It can be confusing! Different people (and different organisations) use different words.

So, let's clarify what we mean in this guide. And if you decide to call it something different, that's fine...as long as the person you are talking with understands!

Learning disability services are very familiar with **Person Centred Planning (PCP)** - helping people to think about what is important to them and how they want to live (and be supported) throughout their lives. You're probably already doing this!

**End of life care planning** is really just extending this way of exploring and thinking into the very end of someone's life. You may want to start thinking about this because someone has a life-limiting condition, or because someone is getting old or frail, or because someone wants to be well prepared.

This guide is about planning for the care and support of people in their last months, weeks and days of life, death and just after death.

So, **End of life planning** covers:

1. Thinking about what you want to happen (and don't want to happen) in the days, weeks and months BEFORE you die. We call this '**When I'm ill planning**'.

2. Thinking about what you want to happen AFTER you die. We call this '**Funeral planning**'.

If you would like to go back to the Contents page, click here .

# HOW MUCH CAN YOU PLAN IN ADVANCE?

Funeral plans can be made in advance – even years in advance! You may change your mind, of course, and you can always change your plan. But it's possible to think and talk together and make specific 'After I die' choices. There are resources in our toolkit to help with this.

Making specific choices for the final months of your life is much more difficult.

It is not always possible to make these choices in advance, because they are context-specific. You don't know when or how it's going to happen! Things change - your circumstances, your physical condition, your feelings and wishes.

# AS A SUPPORT WORKER, WHAT CAN YOU DO?

The person you support will need YOUR help to make sure they and their wants/needs are “known”.

Some people (for example, those with more severe or profound learning disabilities) struggle to express their wishes in a way that others easily understand. Understanding them, and helping them communicate what matters to them, is an important job for their supporters, alongside their family and friends. But even those who can speak for themselves may not be well enough to express their wishes, when things change and specific (sometimes unexpected) choices need to be made.

You need to stand in the person’s shoes and speak with/for them (if they can’t). You need to:

- Find out what matters most to the person. What makes a good day for them? What makes a bad day? (This may be different from what you value!)
- Think about what you can do to make as many ‘good days’ as possible.

When you know the person's values, you can think together about whether the benefits of certain choices (e.g. aimed at prolonging life, or maintaining hard-won independence) still outweigh the disadvantages.

When would the person you support feel that the loss of quality of life becomes too big a price to pay?

# CAPTURE WHAT A GOOD DAY LOOKS LIKE

Watch Irene Tuffrey-Wijne and Jean Willson talk about the importance of capturing what a good day is like for people with profound disabilities like Jean's daughter Victoria. The film is 5 minutes long.

Talk to the person you support about what a good day looks like for them – what makes their heart sing? It can include big things or little things, like starting the day with a coffee in a certain cup or putting on their favourite football team scarf! What the person says may be very different to what you value in life. They may not know (to begin with) what a good day is like for them because they may have never been given the space to think like this before. Keep exploring!

When people are ill, and especially if they are getting closer to the end of life, what makes a good day may change. For example, they may no longer have the energy to do things they really enjoyed, and now prefer to rest rather than do those things. It may become more important to be comfortable and free of pain. They may want to access more box sets of series they love!

If they used to love walking by the sea, could you bring the sound of the sea to them or look at photos/videos if they can no longer walk by the sea? What can you do to ease the way?

# WHAT IF SOMEONE HAS A PROFOUND LEARNING DISABILITY?

Too often people with profound learning disabilities are not included in conversations around end of life care. People should be assumed to have capacity unless proven otherwise as detailed here **Practical Guide to Supported Decision-Making**.

You can use the knowledge you have about a person, their life and what they like and don't like in life, and 'translate' that into what they might want when they are close to dying. Jo Watson (and colleagues), a researcher in Australia, explains how in **this webinar** (her 12-minute talk starts at 10:22).

Jean Willson, mother of Victoria describes below in this 30 minute film, how she and Victoria's support workers, helped Victoria die in the way she would have wanted. Their story is a wonderful example of how these end of life conversations are so important.

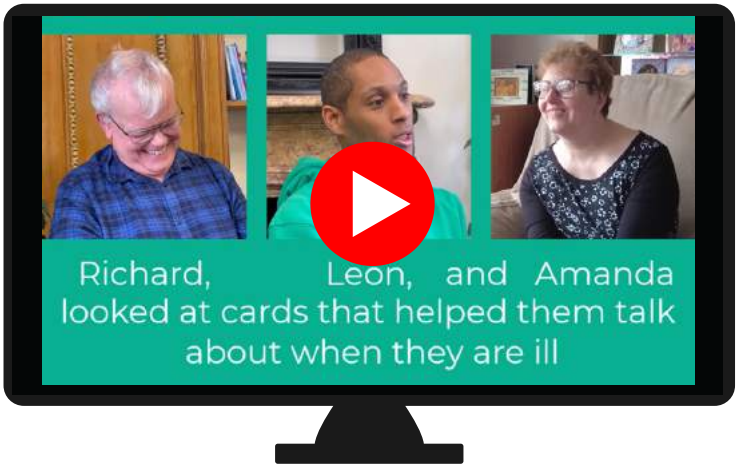
Click here to go back to the content page.

# THE WISHES OF THREE PEOPLE WITH A LEARNING DISABILITY

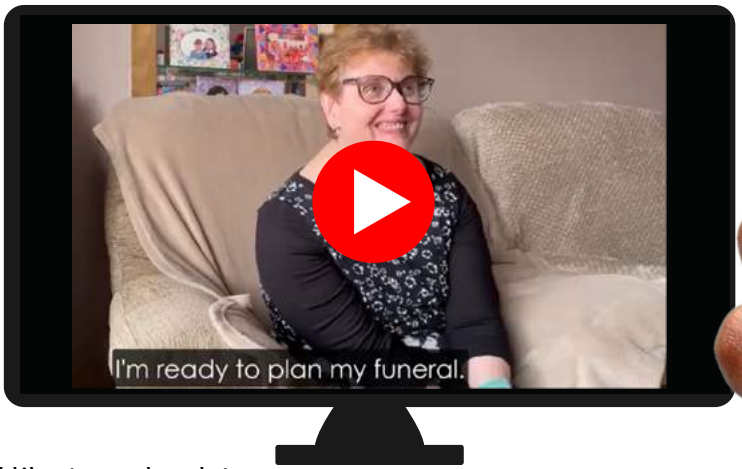
End of life planning covers lots of different things.

Press the play buttons below to find out what people with learning disabilities (who were involved in producing this toolkit) have to say about THEIR wishes.

Here is a 15 minute film of Richard, Leon and Amanda talking about planning for when they are ill and dying:




Here is a 16 minute film of Richard, Leon and Amanda talking about funeral planning:




If you would like to go back to the Contents page, click here .

# THOUGHT PIECES

Use these 'Thought pieces' to help you reflect on what you would do. You can do this on your own or in a team

## Thought piece 1:

Imad, who has severe disabilities, has been a smoker all his life. He is now terminally ill with lung cancer. His doctors has told the team that he only has a few months left to live.

Some staff members think that Imad should not smoke anymore, and try to stop him from doing it. But Imad REALLY likes smoking. His 'Circle of support' agree that it is unlikely that stopping smoking now will help him to live any longer, and that he shouldn't be made to stop smoking if he doesn't want to.

When Imad becomes too weak to do his own roll-ups, and too weak to smoke them, staff roll them for him, because he finds it comforting to simply hold the cigarette. All staff (especially new staff and agency staff) have to be reminded of Imad's wish, so they can support it.

How do you feel about Imad's wish to smoke, and about the decision to support it? How can you make sure that all staff support Imad's choice, even if they don't agree with it?

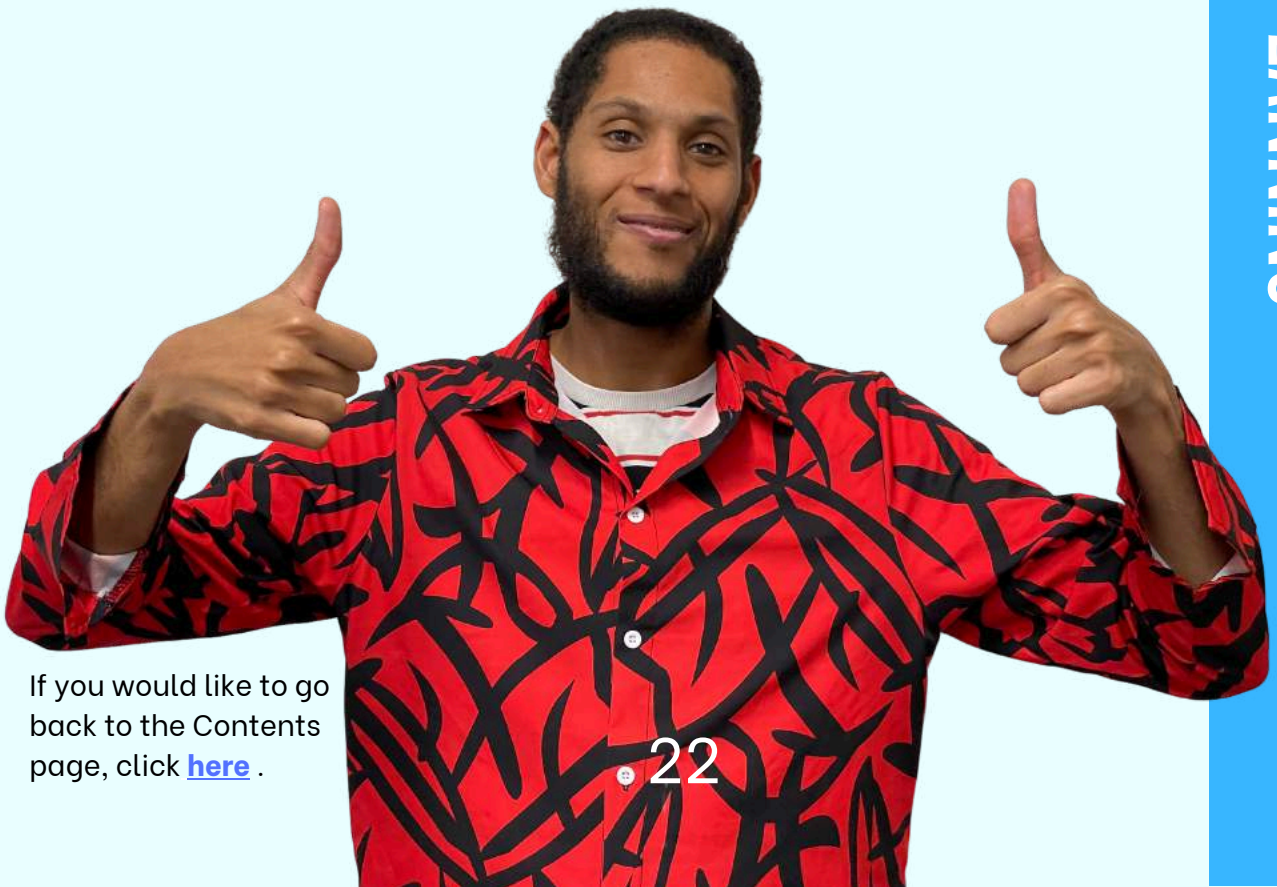
## Thought piece 2:

Sylvia, who struggles to get out bed and has one-to-one support, loves songs from 'The Sound of Music'. Clare, her support worker, is fed up with listening to the same songs all day and wants to put something else on – but her manager explains that the choice of music in Sylvia's bedroom should always be Sylvia's, not Clare's.

This music is part of what makes a good day for Sylvia.
Can you think of ways to support this if Sylvia is in bed all day?
E.g. friends coming for karaoke if Sylvia is well enough or Sylvia watching the film in bed?.

# YOU GOT THIS!

BELIEVE IN YOURSELF!



If you would like to go back to the Contents page, click here .

## Thank you to those of you who helped co-produce this resource. You were AMAZING!

David Hoskins, David Whilton, Jordan Smith, Pat Charlesworth, David Whilton, Jordan Smith, Pat Charlesworth, Sui-Ling, Mika Pickles, Jan Blair, Martin Boniface, Jo Allmond, Ryan Mitchell, Mia Green, Kaddy Thomas, Parmi Dheensa, Jan Kendall, David, Phoebe Mooney, Astrid Ubas, Jo Elverson, Tina Murray, Brenda Pothecary, Chris O'Donnell, Sarah Pope, Meg Wilding, Sarah Swindells and Nicola Payne.

## Thank you to those in the Research Team (also known as 'The A Team'!)

David Jeffrey, Leon Jordan, Richard Keagan-Bull, Amanda Cresswell, Jo Giles, Sarah Gibson, Andrea Bruun, Becky Anderson-Kittow and Irene Tuffrey-Wijne.

## Thank you to www.paradigm-uk.org for creating this resource with us.

## Thank you to our funder:

NIHR | National Institute for Health and Care Research

Copyright: Kingston University. Contact: I.Tuffrey-Wijne@kingston.ac.uk

This work is licensed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License. No content within the toolkit is to be extracted without permission of the copyright holder. To view a copy of this license, visit http://creativecommons.org/licenses/by-nc-nd/4.0/ or send a letter to Creative Commons, PO Box 1866, Mountain View, CA 94042, USA.

If you would like to go back to the Contents page, click here .