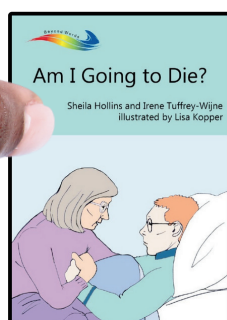
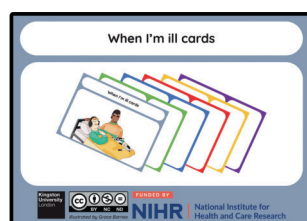



End of life care planning with people with a learning disability



GUIDE 3

A TOOLKIT OF RESOURCES FOR
SUPPORTING PEOPLE WITH A LEARNING DISABILITY

CONTENTS PAGE



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

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Hello...This toolkit is for you!

p5

Before you start

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What you want to happen before you die **p18**

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Funeral planning (Talking Mats)

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And finally...

p40

You've got this!

p41

Thank you :)

p43

These resources will ensure that individuals
continue to have a voice
(even when their voice may be gone).

I wouldn't want the final decisions around my life
to happen without my input so why is it okay for
others to not have that choice?



Ryan Mitchell

Support Worker and
VHS (old video format) collector



Please see licensing details on the last page.

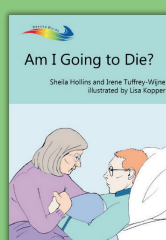
INTRODUCTION

HELLO...

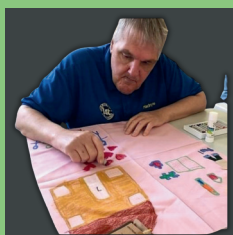
This toolkit is for **you**.

Here's what's inside:

WHAT YOU WANT TO HAPPEN **BEFORE** YOU DIE



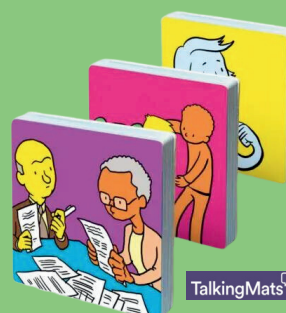
Am I Going To Die?
Books Beyond Words
book



No Barriers Here
The Mary Stevens
Hospice arts kit



When I'm ill
cards (**FREE**)



Thinking Ahead
Talking Mats cards

WHAT YOU WANT TO HAPPEN **AFTER** YOU DIE



Let's talk about funerals
pictures (**FREE**)



My funeral
cards (**FREE**)



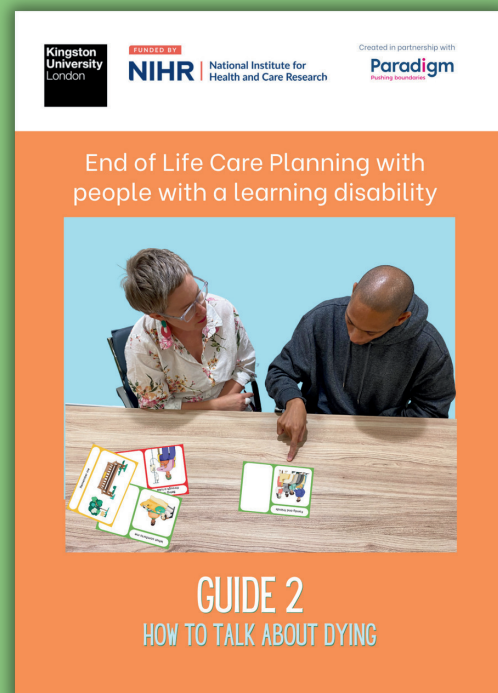
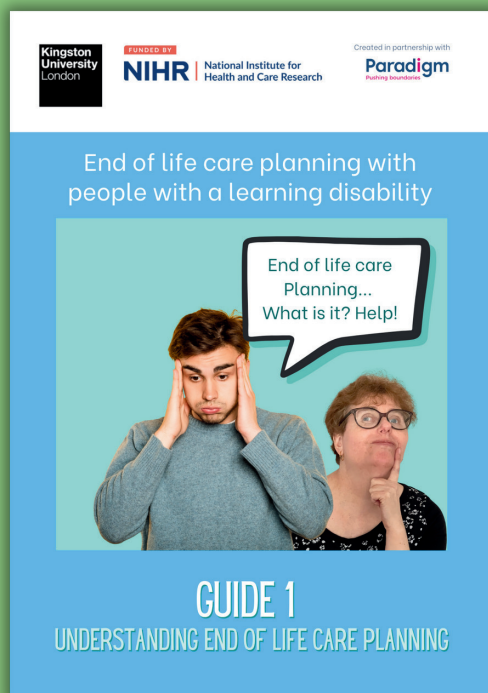
Funeral Planning
Talking Mats: pictures

Some of the resources on p5 are free to download, and we will give you guidance on how to use them. The other resources have been developed by No Barriers Here, Beyond Words and Talking Mats. They are not free but you may find them helpful, so we give you the links and some information about them.

This Guide 3 will help you support people with a learning disability to think and talk about what they want (and don't want!) at the end of their life. It will:

- **show you some great resources** that can help you open up conversations together.
- **give you guidance and tips** on how to use the resources.

End of life care is not an easy topic, so we have two other guides that can help you understand more about it and how to talk about it. You can find these [here](#).



The resources are in our toolkit to:

- **open up conversations** on illness, dying and end of life care planning.
- help people to **share their experiences**.
- create a way for people to **explore their options and share their preferences**.

**Preparation is
everything!**



INTRODUCTION

I need a support worker to help me because...

... decisions need to be made
but I'm in the shade.


So many options
for me to choose,
all it does is confuse.



Leon Jordan

Self-Advocate, Researcher
and always the Poet

LET'S GET GOING!



**THIS GUIDE WILL HELP YOU BUILD
ON THE SKILLS
YOU ALREADY HAVE, SO
TRUST IN WHAT YOU DO!**

If you would like to go back to the Contents page, click [here](#) .

BEFORE YOU START

About you

Whatever your role, please take a moment to think about who the supportive people are in your life that you could talk to. You might want to speak to them if you need help in reflecting on any difficult feelings that come up. **You are important.** So take care of yourself as well as the person you support.

PREPARE

Take time to look at and think about each resource and how/where you might use it with the person you support.

YOUR FEELINGS

Looking at the pictures may bring up memories or emotions for the person you support, but also for you. That is normal. It's important to acknowledge your own feelings.

HOW MUCH YOU SHARE

Of course the focus is on the person you support, but sometimes it helps to share our own feelings and experiences. It can show that we share a common humanity and that emotions are normal. But it needs to be right for you and appropriate for the person you support. Are there areas that are too difficult for you at this moment? This may be the case, for example, if someone close to you is terminally ill or has recently died.

SUPPORT FOR YOU

How can you take care of yourself? Who can you talk to? It could be anyone – perhaps your manager, colleague, friend or family member.

About the person you support

Think about the person you will use these resources with and consider the following ...

COMMUNICATION

How will they show you:

- what they are interested in,
- what they do (and DON'T) want to talk about right now
- what upsets them?

CHECK

Check what people understand about each topic.

RELATIONSHIPS

Some of the pictures show friends and family. Think about who the important people are for the person. What words do they use to talk about them? What if they don't have close relationships with family or friends?

EXPERIENCE OF DEATH AND LOSS

Most people will have experienced trauma, bereavement or other losses. It helps if you know this, but also be mindful that there may be things you don't know about when looking at the pictures. How will you respond?
Are you prepared?

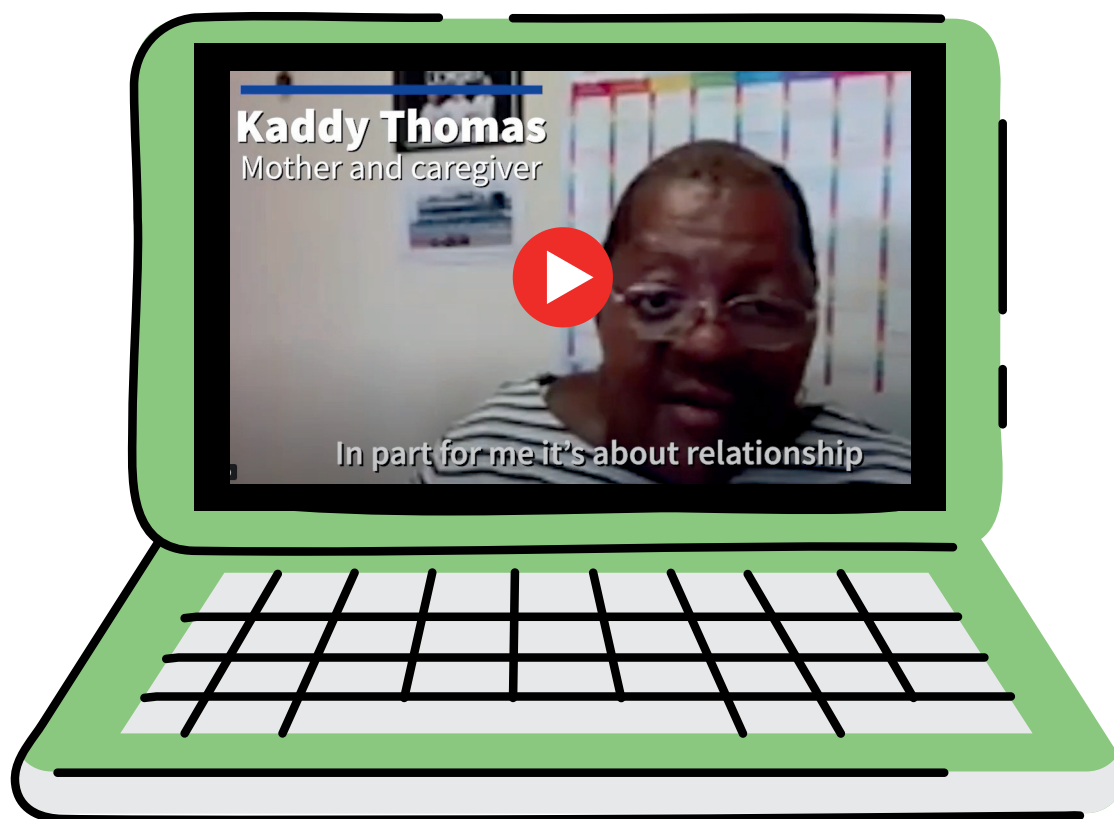
CULTURES AND VALUES

Think about their values, their personal traditions, their culture, religion, beliefs and the communities a person may be part of. Some of the pictures may help you learn about these together!

ASSUME NOTHING

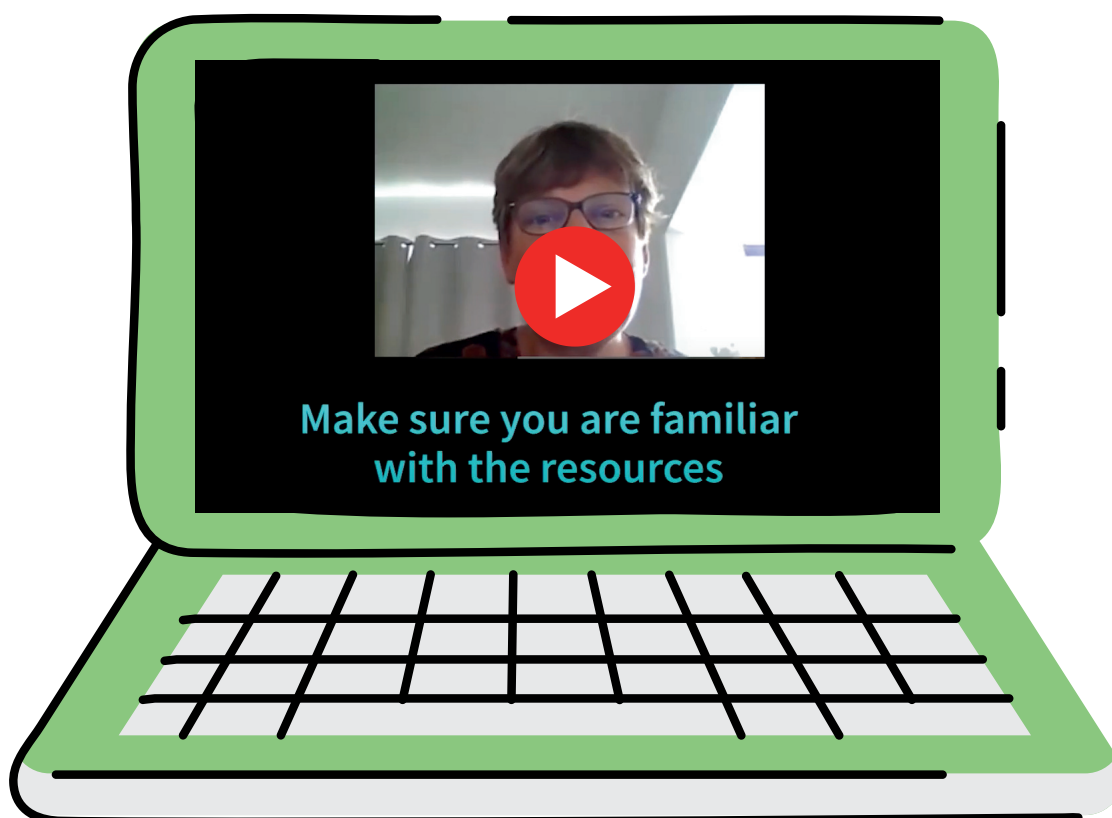
Don't assume people want things to be done in a certain way (e.g. because they follow a certain religion).
Expect the unexpected!

Top tips for using the toolkit:



Listen to some powerful top tips from a mother, a support worker, a manager, a nurse and a doctor in this 3 minute film.





Listen to this 1 minute video of Learning Disability Nurse Astrid's **Top Tips** about:



**Familiarising yourself
with the pictures.**

Choosing the right time and place.

Being led by the person.

Recapping and Recording.

Making a plan for 'what next'.

Debriefing.

I think I'd like people at my funeral to parade past my flat – for people to see that I lived independently.



Richard Keagan-Bull
Self-Advocate, Researcher
and Author

If you would like to go back to the Contents page, click [here](#)

A FEW PRACTICAL THINGS

Printing the pictures

You can **DOWNLOAD** the pictures in this toolkit, and either print them off or use them digitally (e.g. on a tablet or laptop).

The people with a learning disability who helped develop the pictures, wanted prints to be:

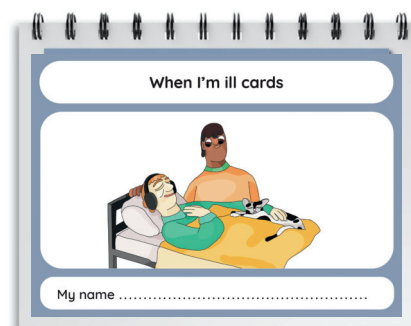
- **in colour**
- **single-sided**
- **A4**
- **perhaps even A3 size if you are using them in a group.**



Colour printing is more expensive, but it's worth it. **Having the pictures in colour really made people want to look at them** and helped them to engage with what can be a difficult topic.

Here are some ideas about how to organise or keep the pictures – whatever works best for the person you support:

- Keep them loose.
- Put them in a folder, on a ring or in a c
- Pin them up on a wall, or peg them onto a 'washing line'.
- Laminate them (this might work particularly well for the Let's Talk About Funerals pictures)



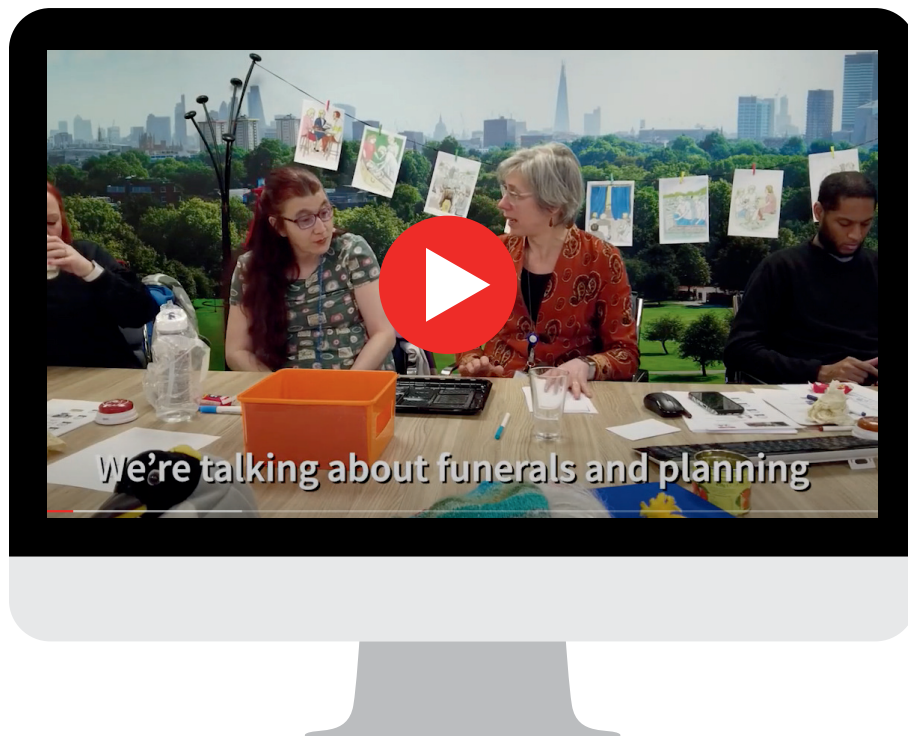
You may have more ideas!

Preparing the ‘No Thank You’ option

It is important that people have a clear way of showing us that they DON'T want to talk about a picture. They may not want to talk about ANY of the pictures. But how will you know?

We have found it very helpful to have a BIN alongside the pictures. This could be an actual bin, or simply a box on the table – somewhere people are actively encouraged to put any pictures they don't like to look at or talk about.

Watch this 3 minute video where having a bin helped Sui Ling to show that she didn't want to plan her funeral.



We strongly suggest having a ‘bin’. It’s empowering!

It’s not always easy for people to say ‘no’, so support their brave choice and applaud them for it... But do try and find out WHY they have put a picture in the bin, and address any worries the person has.

RECORDING AND SHARING INFORMATION

Simply having these conversations is not enough. You may have had some amazing conversations with someone about what they want at the end of their life. But if you don't write down what has been said, the person's choices and preferences will be lost!

With no record about what was said, this could cause all sorts of stress and arguments between people.

Don't let this happen!

It's really important to record everything, for example, by taking photos or writing it down. You can use the recording sheets we have created for the illness cards and funeral cards [here](#).



Name:	Who filled this in:	Date:
Good day 		
Bad day 		
Who helps me decide 		
Family and friends 		
What comforts me 		

Recording sheet for illness cards

Name:	Who filled this in:	Date:
Burial 		
Cremation 		
Coffin 		
Grave 		
Cemetery 		

Recording sheet for funeral cards

If you need to, meet again to carry on the conversationbecause, of course, we all grow/change our ideas over time.

Does the person have a copy? Do they have a hospital passport or an emergency health bag that this information should be added to? Are there people that the person wants to share the information with – a partner, friend, family member, other support workers or medical staff? The right people need to know and the person should lead on this if possible.

WHAT YOU WANT TO HAPPEN
BEFORE YOU DIE

WHEN I'M ILL CARDS

WHAT YOU WANT TO HAPPEN BEFORE YOU DIE



These cards are most useful for:

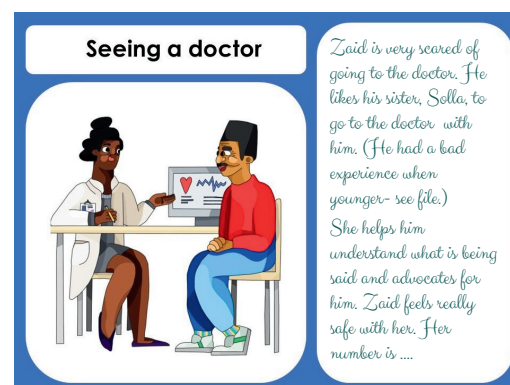
- **Planning ahead** for what might happens when someone's health is getting worse, they are getting more ill or frail, and they may come to the end of their lives.
- **Thinking and talking** about different aspects of illness, treatment, and dying.
- **Helping people think and talk about how they (would) feel** about different these aspects, **what their preferences are**, and **what would help them cope** if their preference is not an option.
- **Recording** people's ideas, experiences, preferences & support needs.
- The cards were designed to support end of life care planning, but might also be useful at other times in someone's life – especially if their health and support needs change.

IMPORTANT:

These cards are NOT designed to discuss and record yes/no options:

Many end of life choices (e.g. 'Home, hospice or hospital?') are not black-and-white. They may depend on many things that are difficult to know in advance (such as the person's condition, prospects, treatment options and prognosis; availability of care options; and their social circumstances).

- The cards are designed to help everyone know how the person feels about (in this example) going to the doctor. What makes it hard? What makes it possible? What would make them feel safe? What are their 'red lines'?



- This will help to make sure that **decisions (when they need to be made) can be firmly based on the person's wishes.**
- The person will need YOU to help with this – someone who knows them well!

The cards can be used:






- directly **with the person themselves.**
- **with family/friends/supporters** who know the person well (if the person prefers not to think or talk about choices themselves, or if they lack capacity).

Each card has a single image, with a simple heading and space to write what you have discussed. Each card introduces a specific aspect of illness and end of life care planning. There are 5 sections:

1. **About me**
2. **Where**
3. **Treatment**
4. **Needing help**
5. **Before I die**

Each section also includes an empty card, for you to add different aspects. You can print/add as many of these as you like.

You can record people's thoughts and wishes on the individual cards and then on the recording sheet (right) that you can download [here](#). Read more about recording and sharing the information [here](#).

Name:	Who filled this in:	Date:
Good day 		
Bad day 		
Who helps me decide 		
Family and friends 		
What comforts me 		

The records should be reviewed regularly. People will change, and as their health deteriorates, their priorities and preferences will change. The closer to dying, the more regularly things may change. You may also find that someone who was able to tell you their thoughts in the past, becomes too unwell to do this – so you now need to talk with family/friends/supporters as well.

BEFORE YOU START:

Read the TOP TIPS on the next page.

Remember to have a **NO THANK YOU** option.

Our Top Tips:



Getting ready

- **Print the pictures out in colour and in A4 size.**
- **How to show them:** Keep them loose, in a folder, on a ring, in a book, or on a device.
- **Make sure the space feels comfortable** for everyone.
- **Make sure you have enough time.**
- **Have a NO THANK YOU option** ready (a box or bin works well). If the person uses this, try to understand why – they may not understand the card, or they find it too upsetting/too early/not necessary to decide, or they may not know what to say or choose.

Choosing cards: different options

- **It is unlikely that you need to go through all the cards.** You can remove the ones that are not relevant (for example, certain treatment options). However, do keep in mind that things may change – it may be useful to have thought ahead about something that is not relevant now.
- **Let the person pick the card(s)** they want to talk about, or you choose and show specific card(s) you think they might like to talk about.
- **Look at the cards one at a time.**

Talking about the cards

You might ask:

- **What would it be like for you to... ? or**
- **What do you think about...** e.g. being in hospital/having a nurse in your house/being helped in the shower.
- **What is good about... ?**
- **What is difficult about... ?**
- **What would make ... easier?**



- **Why would people...** need an operation/help with eating/go to a nursing home... etc? This might help you find out why someone might say YES or NO to something. E.g. do they think that going to hospital will make them better?
- **What do we think the person would say, if they could tell us? What are their 'red lines'?** ... These are questions you could consider with the person's family/friends/caregivers, if a person has more profound disabilities.

Writing on the cards

- **Each card has space to write or draw.** Use it in whatever way the person wants.
- **They might want to write/draw themselves, or you might write for them.**
- If you do this with the person's family/friends/caregivers: **Record what was discussed; whose views are represented; and whether there were differences of opinion.**
- **Remember to add the date.**

Remember...

- **If the person gets upset, that's okay.** Expect it. Just stay alongside them. Give them space for their feelings and talk about it.
- **End the session on a positive note.** Have a chat about how it was. Be proud together that you have talked about this!

Afterwards

- **Let the person keep their cards,** if they want to, in a way/place they choose.
- **It will be important for some others (like healthcare professionals) to know what you've talked about,** and what is on the cards. Talk and agree about with who, and how, you will share this.
- **Make a plan for recording** (see here) and **reviewing REGULARLY.**



If you would like to go back to the Contents page, click [here](#).

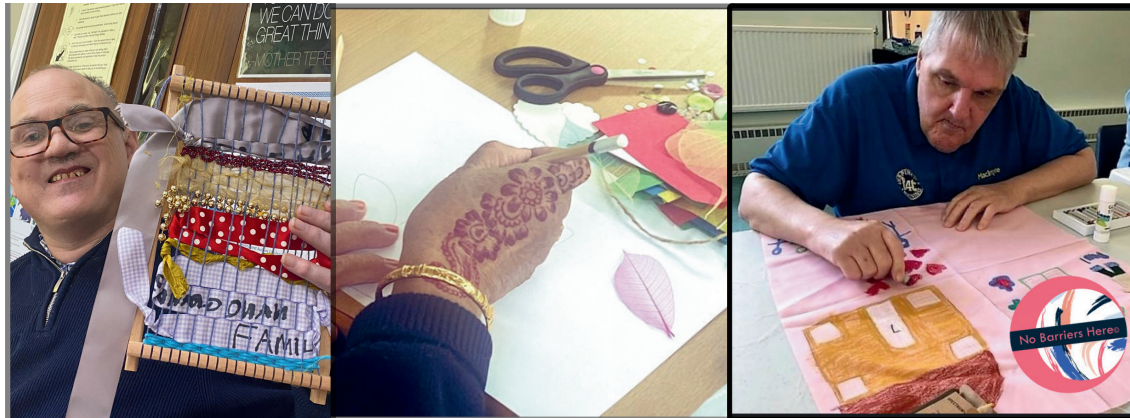




WATCH THIS

7 minute film showing how to use the **When I'm ill** cards.

NO BARRIERS HERE (THE MARY STEVENS HOSPICE)



No Barriers Here is a series of arts workshops that help people think about their choices and wishes for future care. It offers a less verbal approach and moves away from traditional written advance care planning forms.

No Barriers Here was co-produced by people with learning disabilities, Dudley Voices for Choice (an advocacy organisation), The Mary Stevens Hospice and an art psychotherapist.

It was developed in 2019 and co-delivered during the Covid-19 pandemic to support people with learning disabilities to participate in meaningful advance care planning using arts-based methods.

No Barriers Here has since been used with other people who are underserved in palliative and end of life care. Healthcare workers need to be trained to use No Barriers Here.

[This link](#) will take you to the No Barriers Here website where you can find out more information.

Watch this 7 minute film to find out more:



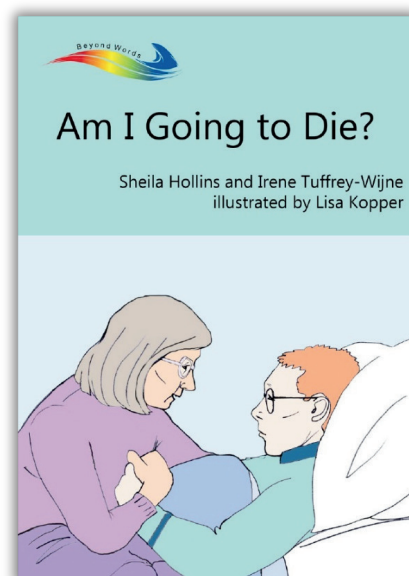
WHAT YOU WANT TO HAPPEN **BEFORE** YOU DIE

AM I GOING TO DIE? (BEYOND WORDS)

You can use the word-free picture book ***Am I Going to Die?*** to help people to talk about their thoughts, feelings and experiences by describing what is going on in the pictures.

The Books Beyond Words series is made up of picture stories with no words. They include a guide to reading them, as well as a link to other resources, tips and questions that can help with having conversations.

Click [here](#) to visit the Beyond Words Bookshop, where you can buy the book.



If you know someone with a learning disability who is very ill, you can use the pictures in this book and the sample storyline to help them understand more about their illness and dying.

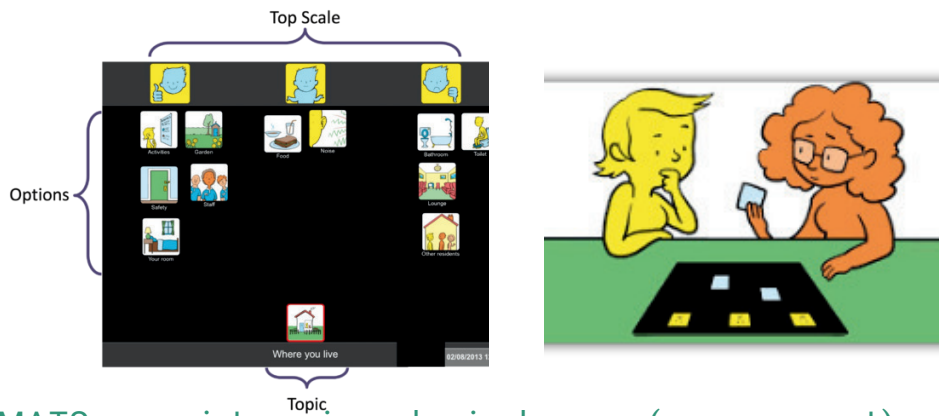
**Down's Syndrome Association
Journal, 2009**

Although the story in *Am I Going to Die?* is fictional, it is based on the real life experiences of ten people with learning disabilities. The book draws on what was important for the participants when they were ill and dying and demonstrates best practice as identified by them.

Inside Palliative Care. Volume 8, June 2009

THINKING AHEAD (TALKING MATS)

Some people find **TALKING MATS** a helpful way to think about, and communicate, their feelings or views on a difficult topic.



TALKING MATS uses pictures in a physical space (e.g. on a mat), or digitally. You can find out more about TALKING MATS [here](#).



TalkingMats

The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.

The THINKING AHEAD pictures are used to support and encourage conversations about end of life care. There are pictures on 3 topics:

1. Care and treatment wishes
2. Affairs
3. Personal values

You can click [here](#) to find out more and buy this set of pictures.

TALKING MATS recommend that all their purchasers complete their training before using their products.

If you would like to go back to the Contents page, click [here](#).

WHAT YOU WANT TO HAPPEN AFTER YOU DIE

LET'S TALK ABOUT FUNERALS PICTURES

WHAT YOU WANT TO HAPPEN AFTER YOU DIE



These pictures are most useful for:

- **Starting conversations** about funerals and remembering people.
- **Introducing concepts and ideas** about different aspects of funerals and memorials.
- Helping people **think and talk about their own experiences** of funerals.
- **Talking about feelings** about funerals.
- Exploring **what kind of funeral or memorials** they would like for those they love, and for themselves.

It is possible that people talk about specific funeral choices or decisions, but that is not the main purpose of these pictures. There should be no pressure to answer any specific questions!

BEFORE YOU START:

Read the TOP TIPS on the next page.

Remember to have a **NO THANK YOU** option!

Our Top Tips:



Getting ready

- **Print the pictures out in colour and in A4 size.**
- **How to show them:** Keep them loose, in a folder, on a ring, in a book, or on a device.
- **Make sure the space feels comfortable** for everyone.
- **Make sure you have enough time.**
- **Have a NO THANK YOU option ready** (a box or bin works well).

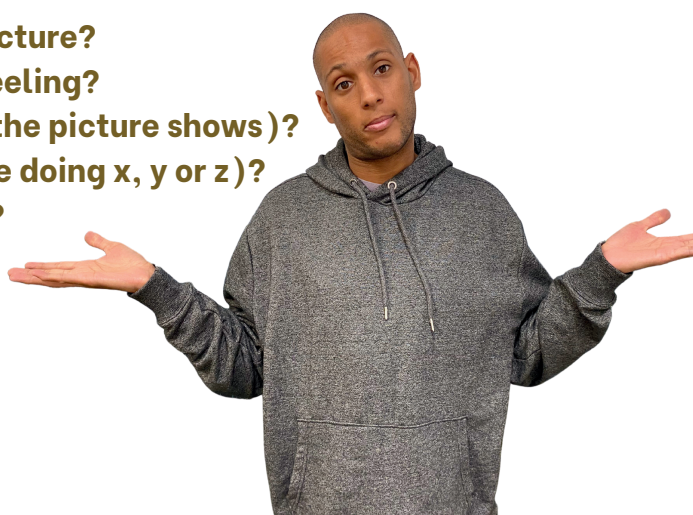
Choosing cards: different options

- **You can let the person choose the picture(s)** they want to talk about, or you can present them with specific picture(s) you think they might like to talk about.
- **You can look at one or more pictures in a group**, and talk about it together. Print them large or project them onto a screen.
- **You don't have to go through all the pictures.** You can spend a whole session talking about just one picture – you never know where the conversation might go!
- **Be led by the person.** You may not need to say or ask anything at all – it doesn't matter what YOU think you should talk about. Just listen!

Talking about the cards

You might ask:

- **What is happening in this picture?**
- **How do you think they are feeling?**
- **Have you ever... (whatever the picture shows)?**
- **Why do you think... (they are doing x, y or z)?**
- **What do YOU think about...?**
- **Have you thought about what YOU might want...?**



- **If the person gets upset, that's okay** (and normal!). Expect it. Just stay alongside them. Give them space to feel sad, cry, and talk about it.
- **If you get upset or are touched by something, that's okay too** (and normal!). It can be helpful for people to see they are not alone in feeling like this. Just make sure it's in balance and you are there, first and foremost, for the person.
- **End the session on a positive note.** Have a chat about how it was. Be proud together that you have talked about this!
- **If the person expressed specific opinions or choices, consider using [My Funeral Cards](#)** to further conversation and record choices.



If you would like to go back to the Contents page, click [here](#).



WATCH THIS

4 minute film showing how you can use
the **Let's talk about funerals** pictures.

Go back to the [Contents Page](#)

MY FUNERAL CARDS

WHAT YOU WANT TO HAPPEN AFTER YOU DIE



These cards are most useful for:

- **Planning ahead** for what happens AFTER you die (your funeral and how you want to be remembered).
- **Introducing concepts** about different aspects of funerals and memorials.
- **Helping people think and talk about their ideas**, choices and preferences.
- **Recording people's ideas**, choices and preferences.

The cards can be used:

- Directly **with the person** themselves
- **With family/friends/supporters** who know the person well (if the person prefers not to think or talk about choices themselves, or if they lack capacity)

Each card has a single image, with a simple heading. Each card introduces a specific aspect of funerals and memorials.



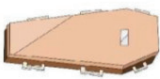

There are 4 sections:

1. **What happens with my body**
2. **The day of my funeral**
3. **Remember me**
4. **Planning my funeral**

WHAT YOU WANT TO HAPPEN AFTER YOU DIE

Each section also includes an empty card, for you to add different aspects. You can print/add as many of these as you like.

You can record people's thoughts and wishes on the individual cards and then on the recording sheet (below) that you can download [here](#). Read more about recording and sharing the information [here](#).

Name:	Who filled this in:	Date:
Burial 		
Cremation 		
Coffin 		
Grave 		

If you would like to think or talk more widely about funerals, explore feelings, or explain some of the concepts, consider using [Let's Talk About Funerals](#) pictures first on p29 first.

BEFORE YOU START:

Read the TOP TIPS on the next page.

Remember to have a **NO THANK YOU** option!

Our Top Tips:



Getting ready

- **Print the pictures out in colour and in A4 size.**
- **How to show them:** Keep them loose, in a folder, on a ring, in a book, or on a device.
- **Make sure the space feels comfortable for everyone.**
- **Make sure you have enough time.**
- **Have a NO THANK YOU option ready** (a box or bin works well). If the person uses this, try to understand why – it might be because they don't understand the card, or they find it too upsetting/too early/not necessary to decide, or they don't know what to say or choose.

Choosing cards: different options

- **Let the person pick the card(s)** they want to talk about
- **You choose and show specific card(s)** you think they might like to talk about.
- **Look at the cards one at a time.**
- **Go through all the cards, OR just pick the ones that are relevant.**
- **Look at one or more cards in a group** (print them large enough, or project them onto a screen). You can talk about it together, OR people might want to watch one group member going through the cards (they may inspire each other, or give each other ideas).

Talking about the cards

With each picture, you might ask:

- **How about?**
- **What do you think about?...** (being buried/being cremated/having flowers at your funeral...)
- **Would you like to have?...**
- **Do you want?...** This works well for some people, but remember that such



‘closed questions’ (YES/NO questions) might leave less room for discussion, uncertainty, or alternative choices.

- **What do we think the person would choose, if they could tell us?**
This is a question you could consider with the person’s family/friends/caregivers, if a person has more profound disabilities.

Writing on the cards

- **Each card has space to write or draw.** Use it in whatever way the person wants.
- **The person might want to write/ draw themselves,** or you might write for them.
- **If you do this with the person’s family/friends/caregivers,** record what was discussed; whose views are represented; and whether there were differences of opinion.
- **Remember to add the date.**



Remember...

- **If the person gets upset, that’s okay (and normal!).** Expect it. Just stay alongside them. Give them space to feel sad, cry, and talk about it.
- **If you get upset or are touched by something, that’s okay too (and normal!).** It can be helpful for people to see they are not alone in feeling like this. Just make sure it’s in balance and you are there, first and foremost, for the person.
- **End the session on a positive note.** Have a chat about how it was. Be proud together that you have talked about this!

Afterwards

- **Let the person keep their cards,** if they want to, in a way/place they choose.
- **Should anyone else know about what you’ve talked about?** Ask the person! For example, family or caregivers may get worried if the person tells them about having made a funeral plan.
- **Make a plan for recording and reviewing.**
- **Make sure you share the recorded information with right people.**



WATCH THIS

5 minute film showing how to use the **My funeral** cards.

Click [here](#) to go back to the Contents page.

The cards are really good and the pictures because if people can't communicate with language, then they can point to the pictures and say 'This is how I feel inside' ... 'This is how I want my funeral to be'.

And that's why it's so important
- why we've done them for
ANYONE to use

Amanda Cresswell

Self-Advocate, Researcher
and cat lover



FUNERAL PLANNING CARDS (TALKING MATS)

Some people find **TALKING MATS** a helpful way to think about, and communicate, their feelings or views on a difficult topic.

TALKING MATS uses pictures in a physical space (e.g. on a mat), or digitally. You can find out more about TALKING MATS [here](#).



TalkingMats

The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission.

The TALKING MATS Funeral Planning pictures can be used to support and encourage conversations and choices about funerals. There are pictures on these 3 topics:

1. Funeral planning
2. Service planning
3. Eulogy

Talking Mats training is required before using the Thinking Ahead and Funeral Planning resources.

You can find out more about these TALKING MATS pictures [here](#).

If you would like to go back to the Contents page, click [here](#).

AND FINALLY ...

you got this!

AND FINALLY ...

We are cheering you on!
(Literally! Press play!)



AND FINALLY ...

We hope this resource is helpful
and that it gives you confidence
to do a good job!

Don't let things worry you.
Have confidence in yourself!

You can do it!

David Jeffrey

Self-Advocate, Researcher
and Elvis memorabilia
collector



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 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 Potheary, 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



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