



Northern Health
and Social Care Trust

WHEN SOMEONE DIES GUIDANCE DOCUMENT

How do I start
this
conversation?
HELP!



Created by NHSCT Learning Disability and Palliative Care Working Group and approved by the NHSCT
ALD Service User Forum. Review Date: March 2027

If you wish to reproduce this resource please contact Palliativecare.events@northerntrust.hscni.net

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Introduction

This guidance booklet has been created to help families, carers and health professionals support a person with a learning disability to understand more about what happens when someone they know dies. This could apply to a range of people e.g. family member, friend, colleague or famous person.

This guidance booklet contains useful advice on how to use the 'NHSCT, When Someone Dies - A booklet to help support you when someone you know dies' resource. Both booklets should be used alongside each other.



Please spend time reading this guidance booklet before you begin discussions with the person you are supporting - there is some information you will need to gather prior to exploring the 'When Someone Dies' resource.

Things that are important to remember

People with learning disabilities experience grief like anyone else. Each person with a learning disability will grieve in their own way.

Some people may feel that withholding information about death from a person with a learning disability can minimise anxiety, however, generally, this is not helpful.

Having a learning disability does not mean that a person cannot be affected by, understand or deal with a bereavement.

Most people with a learning disability will progress naturally through the grieving process.

Delayed reactions to grief are common within the learning disabled population.

Whilst some people may appear to cope well at the time of the loss, they may experience difficulties in the weeks, months or even years after the death.

The person's communication skills will have a significant impact on their ability to understand what has happened and on their ability to express their thoughts, feelings and opinions.



The relationship between communication skills and bereavement

Most people with a learning disability will have some form of communication difficulty.

Some people with a learning disability have difficulty understanding spoken language. Many will have difficulty understanding large pieces of information, unfamiliar words and concepts.

Some people with a learning disability may be able to express their emotions using speech, signs or symbols.

People with limited expressive communication skills may rely on non-spoken means of communication including a change in their behaviour to express how they are feeling.

It is important to understand the communication needs and skills of the person you are supporting in order to support them more effectively.

What information do I need to gather?

You will need to gather the information and items below before you read the 'When Someone Dies' booklet with the person you are supporting. This is not an exhaustive list - feel free to add anything you feel may be helpful to the person you are supporting

Information/Item required	Tick or provide information
• Pen/Pencil/Colouring Pencils	
• Tissues/comforting belonging	
• The name of the person who has died	
• What is the relationship between the person you are supporting and the person who has died?	
• A photo of the person who has died	
• Will there be a wake and if so, where?	
• Will the wake be private or open to public?	
• Will the person be in a coffin, open or closed?	
• Will there be a funeral service?	
• What is the date and time of the funeral?	
• Is there an option to watch the funeral via live stream?	
• Will the person who has died be buried or cremated?	
• Will the person you are supporting be attending the funeral, not attending or watching via live stream?	



Beginning the conversation

This section of the guidance booklet provides some advice on how to approach each page of the booklet. We hope it will help you feel more confident to talk openly about the person who has died with the person you are supporting.

Where possible, this should be completed by someone who knows the person with the learning disability well.

Grab your 'When Someone Dies' booklet!



PLEASE NOTE:

If you have concerns at any stage about the service user's mental health, please bring them to the attention of their next of kin or named worker.

It may also be helpful to revisit some pages with the person you are supporting at different points of the grieving process.



Let's get started

Page 1 - Title Page – When someone dies

Read the title of this document to the person you are supporting. Give them time to process the words you have said and symbols on the page. Remember not everyone can read, you may have to support with this.

Page 2 - Contents Page

This booklet does not need to be completed in one sitting. Use your judgement as to whether this would be or would not be appropriate for the person you are supporting.

You can tick each section as you complete it and add notes if appropriate

Page	Page Title
8.	Title page- When someone dies
9.	Contents page
10.	Using this resource
11.	The person who has died
12.	Let's talk about what dying means
13.	What does dying mean?
14.	Why do people die?
8.	What happens when someone dies?
9-10.	How might I feel when someone dies?
11-14.	What happens after someone dies?
15-19.	What is a funeral?
20.	The person's funeral
21-22.	After the funeral
23-24.	What is grief?
25-26.	Things that might help you feel better
27.	Rest in Peace

Page 3 - The Person Who Has Died

On this page you introduce the person who has died. This may help the person you are supporting to understand that this booklet is about this special person.

Here the person you are supporting can add a photograph of the person who has died; only if they want to.

Encourage the person you are supporting to write the name of the person who has died. They may need help with spelling the person's name or might need to copy the name or you may need to write the name for them.

This may be a nice opportunity to start to talk about the person who has died and how they know them.

Page 4 - Let's talk about what dying means

This page gently introduces the topic of what dying means. Please read the title of the page to the person you are supporting.



Page 5 - What Does Dying Mean?

The visuals on this page are used to help describe the cycle of life, explaining that people and animals are first born, they then grow and at the end of their life they die.

An example of how you may discuss this page is below:

- “When a dog is born, it is a small puppy”
 - “The puppy will grow bigger to an adult dog”
 - “When a dog gets to the end of their life they die, this happens to all dogs at some time in their life’.
-
- “When a person is born, it is a small baby”
 - “Over time the baby will grow bigger into a child, then an adult”
 - “When a person gets to the end of their life they die, this happens to all people at some time in their life”.



Page 6 - Why Do People Die?

This page explains how people can die at different ages in their life and for different reasons. Take time to look at each picture and read the corresponding words out aloud to the person you are supporting.

Keep the discussion as simple and to the point as possible - help the person you are supporting by answering any questions they have as simply as you can.

Page 7 & 8 - What Happens When Someone Dies?

These pages explain what happens a person's body when they die. This includes the lack of ability to breathe, talk and move anymore.

Read through each section and look at the symbols together slowly to allow the person you are supporting to process the information they are hearing and seeing.

Page 9 & 10 - How The Person You Are Supporting Might Feel When Someone Dies

These pages explore the different feelings a person may experience when someone they know dies. Our aim is to normalise all feelings or lack of feeling.

Read through each feeling and take time to explore how the person you are supporting feels. Use the question mark box at the end to discuss other feelings a person may have. Reassure them that all or no feelings are okay.

Give the person you are supporting time to express themselves.

Page 11 - 14 - What Happens After Someone Dies?

Information you will need to consider:

- Is the person having a wake, where is this, is it private or public and will the coffin be open or closed?

These pages explore the things you cannot do with a person once they have died, what can happen in the days after a person has died and preparations for a funeral service.

Read through the contents of these pages and be open to further discussion if you think this is helpful to the person you are supporting. For example you might want to:

- When explaining what a coffin is, you may ask the person you are supporting whether they have seen a coffin before.
- Explain where the person who has died will have their coffin- for example at home or in a funeral home.
- Explain whether their coffin will be opened or closed.
- If appropriate, ask the person you are supporting whether they would want to see the person who has died in the coffin or not. You may want to explain here how a person may look different e.g. pale, eyes closed etc.
- Discuss whether the person you are supporting wants to attend the wake of the person who has died.



Page 15-19 - What is a Funeral?

These pages explain what a funeral is. Be prepared to answer any questions the person you are supporting may have about a funeral.

On page 18, the topic of a cremation is introduced. It may be appropriate to explain how a person's ashes in an urn can be placed somewhere special; this could be in your home or somewhere else. Discuss this as appropriate to the arrangements for the person who has died.

Page 20 – The person's funeral

Information you will need to consider:

- Time and date of the funeral
- The location of the funeral
- Whether there will be a burial or cremation service
- Is there an option to watch the funeral via live stream?
- Will the person you are supporting be attending or watching on live stream?

This page is all about the funeral of the person who has died. This may be difficult for the person you are supporting to discuss. At the end of this page, you can discuss whether the person you are supporting will be attending the funeral, not attending or watching via live stream.

It is important to remind them that their choice is okay, and that they can change their mind if they want.

Page 21 & 22 – After the Funeral

These pages explore how a person may feel after a funeral of someone they have known.

Read through the contents allowing time for the person you are supporting to process what you are saying and look at the symbols to support their understanding.

Page 23 & 24 - What is Grief?

This page helps explain what the word grief means in simple language.

Page 25 & 26 - Things That Might Help You Feel Better

These pages aim to validate the person you are supporting's feelings while providing advice on how they can try help make themselves feel better.

Read through these pages and be open to further discussion if appropriate.



Page 27 - Rest in Peace (Optional Exercise)



This page can be used to help the person you are supporting express themselves further.

They may want to add a photo of the person who has died, draw a picture or add stickers etc.



This page can be removed and put into a frame for the person you are supporting to keep somewhere special and safe.

It is important to give the person you are supporting choice over whether they want to personalise this page, keep it in the booklet or remove it. They should also be given choice as to where they put this special page e.g., in a photo frame and where.



Final comments

It is important to inform all members of the person with a learning disabilities support team that this booklet is being utilised. This includes; family, carers, supported living staff, day services and all other relevant health and social care professionals.

Further information

More information and resources can be found here:

- **‘When Someone Dies’ Easy Read & Guidance Document (March 2025)**
- Bereaved NI - <https://bereaved.hscni.net>
- Victoria and Stuart Project – End of Life Planning with People with Learning Disabilities - <https://www.victoriaandstuart.com/end-of-life-care-planning-toolkit>
- PCPLD Network – Palliative Care for People with Learning Disabilities - <https://pcpld.com>
- Mencap - Your guide to Communicating with people with a learning disability https://www.mencap.org.uk/sites/default/files/2016-12/Communicating%20with%20people_updated%20%281%29.pdf
- Liaise with your local ALD Speech and Language Therapist for further communication support if required.
- Books Beyond Words Series – ‘When Somebody Dies’, ‘When Mum Died’ and ‘When Dad Died’, all by Sheila Holling and Irene Tuffrey-Wijne. All available for loan from your local library – if unavailable at your local library, ask them to request them from any of NI Death Positive Libraries.

THANK YOU!



Acknowledgments

Thank you to those who helped co-produce these resources.

- NHSCT Adult Learning Disability Team: ALD Speech and Language Therapy, Practice Educators/Acute Liaison Nursing Team, Health Facilitation Nurse & Nurse Consultant.
- Trust Bereavement Coordinator: Nursing Safety, Quality & User Experience.
- Palliative Care Colleagues & all members of the NHSCT Learning Disability and Palliative Care Working Group.
- NHSCT ALD Service User forum

Photos, symbols and visuals used include;

- Tobii Dynavox Picture Communication Symbols® (PCS)
<https://uk.tobiidynavox.com/products/picture-communication-symbols-pcs>
- Photo Symbols UK <https://www.photosymbols.com/>

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