

Introduction

This Toolkit talks about difficult topics like death.

You can ask for help to read the Toolkit.

You could ask

- a family member
- a support person
- a friend.

You can talk to someone you trust about your feelings.

You do not need to read all the information at the same time.

The **Toolkit** is about **palliative care**.

A **Toolkit** is a document with information that helps people to do something.

Palliative care is help for people who have a serious health condition that they will die from.

This **Toolkit** was made to support people with intellectual disability to get good **palliative care**.

Making **palliative care** better is important because people with intellectual disability often find it hard to get good **palliative care**.

How to use the Toolkit

3DN wrote this information.

3DN is short for the Department of Developmental Disability Neuropsychiatry.

3DN is a **research group** at the University of New South Wales Sydney.

A **research group** is people working together to learn more about a topic.

When you see the word 'we' it means 3DN.

We made the **Toolkit** with

- People with intellectual disability
- **Supporters** of people with intellectual disability

Supporters are people that help with care or daily life.

This might be friends, family or paid and unpaid carers.

- Health and disability workers.

How to use the Toolkit

We have written some words in **bold**.

Bold means the letters are thicker and darker.

We explain what these words in **bold** mean.

We have shared different information in the **Toolkit**.

The information could be things like information sheets, **planning sheets** or videos.

Planning sheets are documents with empty boxes for a person to write or draw in to help them plan.

Some of these are in **Easy Read**.

Easy Read uses simple words with pictures.

When you click on the *website links* it go to to another place on the internet with the information sheets or videos.

We also made a **Toolkit** for **health workers**.

Health workers might include doctors and nurses.

The website link below can be given to **health workers** to find the **Toolkit**

www.3dn.unsw.edu.au/toolkit-improving-palliative-care-health-professionals.



Part 1

**This part is for people
with intellectual disability**

Artwork by Matthew Elliott
Seagulls at Manly 2017

This section is about palliative care

About palliative care

Palliative care is help for people who have a serious health condition that they will die from.

When a person dies it means that their body has stopped working and their life has ended.

Palliative care helps people manage their **symptoms** so they feel well until they die.

Symptoms are problems people might have with a health condition.

Symptoms might be things like having pain or feeling sick.

Palliative care will not make someone's life longer or shorter.

Palliative care is managed by **health workers**.

Other people can also assist with **palliative care**, like **supporters**.

A person might get **palliative care** at the same time as other **treatment** and care.

Treatments are things that can help a person feel better.

There is more information about **palliative care** in the information sheets shared on the next page.

This section is about palliative care

Information sheets about palliative care

Name – Preparing for palliative care

Go to

3dn.unsw.edu.au/resources/improving-palliative-care-resources#preparing

Who made it

3DN

What it is about

What **palliative care** can help with, where it might happen and who might be involved.

Preparing means to get ready for something.

Information type

Plain English and **Easy Read** information sheet

Name - Palliative care for you

Go to

health.nsw.gov.au/palliativecare/Documents/patient-information.pdf

Who made it

NSW Health

What it is about

Palliative care

Information type

Easy Read booklets

This section is about palliative care

Name - Let's talk about **palliative care**

Go to

pcvpallcarevic.blob.core.windows.net/assets/contentpage_htmlcontent/VALiD-A5-Booklet-Lets_Talk_PallCare-3-171120-wb.pdf

Who made it

Palliative Care Victoria

What it is about

What happens when someone is sick and needs **palliative care**

Information type

Easy Read booklets



Artwork by Ellie Rennie
Flowers in the Rain 2023

This section is about people that might help during palliative care

People that might help during palliative care

A **palliative care team** are **health workers**.

A **palliative care** team might include

- A family doctor
- **Specialist palliative care health workers**

Specialist palliative care health workers are people that know a lot about **palliative care**

- A physiotherapist
- A psychologist
- An occupational therapist
- A speech therapist
- Other **health workers**.

The information on the next page is about the different types of **health workers**.

This section is about people that might help during palliative care

Information sheet

Name - Adult health services

Go to

health.gov.au/resources/publications/adult-health-services-easy-read?language=en

Who made it

the Australian Government

What is it about

Information about the different types of health workers

Information type

Easy Read information sheet

A person might see different **health workers** for different needs.

A person's **supporters** might also be involved in **palliative care** if the person wants them to be.

This section is about people that might help during palliative care

How health workers might help

A family doctor and other **health workers** during **palliative care** might help a person with

- Pain
- Sickness
- Emotions such as sadness or worry
- Continuing their everyday activities
- Support with movement
- Support with religious or cultural beliefs
- Support for family and friends.

This section is about people that might help during palliative care

What supporters might assist with

A person's **supporters** can assist them to get good **palliative care**.

Supporters might help the person

- Feel more comfortable
- Make decisions about their care
- Talk to **health workers** about them and their needs
- Organise health appointments
- Go to health appointments
- Take medication
- Do daily tasks at home
- Tell people about the person's future wishes.

This section is about the NDIS

This information is for people who have a National Disability Insurance Scheme (NDIS) plan

About health services working with NDIS

The NDIS does not pay for **palliative care**.

The information below is about the NDIS and health services.

Name - Health services and the National Disability Insurance Scheme (NDIS)

Go to

dss.gov.au/sites/default/files/documents/07_2019/3249-dss-ndis-and-health-services-fact-sheet-er-fa-accessible-updated.pdf

Who wrote it

NDIS

What it is about

How health services and the NDIS should work together

Information type

Easy Read information sheet

This section is about what good palliative care should look like

What good palliative care should look like

Our **research group** has been working on ways to make sure people with intellectual disability get good **palliative care**.

We wrote information for **health workers** to help them understand how to give good **palliative care** to people with intellectual disability.

On the following pages we share what good **palliative care** should look like. We also share information sheets to help people with intellectual disability to get good **palliative care**.

This section is about what good palliative care should look like

Health workers giving **palliative care** should make sure that:

A person's rights are protected, respected and supported

Rights are rules about how everyone should be treated fairly.

A right is something everyone has.

Respect means that **health workers** listen to what someone wants and what is important to them.

The information sheets below are about health rights and **advocacy**.

Advocacy is people listening to the person so their rights and needs are met.

Name - Your right to good health care fact sheet

Go to

cid.org.au/resource/your-right-to-good-health-care-fact-sheet

Who wrote it

CID

What it is about

Rights to good health care and what good health care is

Information type

Easy Read information sheet

This section is about what good palliative care should look like

The website below has more information about **advocacy**.

Name - Individual **advocacy**

Go to

pwd.org.au/get-help/individual-advocacy

Who wrote it

People with Disability Australia

What it is about

Information and resources about a person's **rights**

Information type

Website

This section is about what good palliative care should look like

Health workers giving **palliative care** should make sure that:

Palliative care is person-centred and holistic

Person-centred care means the person is at the centre of decisions made about them.

Holistic care means all of a person's needs, including **physical, emotional, social** and **spiritual** needs, are looked after.

Physical needs are about how a person's body feels.

Emotional needs are about how a person feels, for example sad or worried.

Social needs are about connections with other people.

Spiritual needs are about what is important in a person's life.

The information sheet below can be used to write important things about someone's health to give to their **palliative care team**.

Name - Health Passport

Go to

hdc.org.nz/disability/my-health-passport/

Who wrote it

the New Zealand Government

What it is about

A health passport is a list of important information about someone and their health

Information type

Plain English and **Easy Read** booklet

This section is about what good palliative care should look like

The information sheet below explains what **palliative care** is.

Name – Preparing for **palliative care**

Go to

3dn.unsw.edu.au/resources/improving-palliative-care-resources#preparing

Who made it

3DN

What it is about

What **palliative care** can help with, where it might happen and who might be involved. It also includes a **planning sheet**.

Information type

Plain English and **Easy Read** information sheet

The video below is about making decisions.

Name - Making my own decisions

Go to

cid.org.au/resource/making-my-own-decisions

Who made it

Council for Intellectual Disability (CID)

What it is about

How to make decisions

Information type

Video

This section is about what good palliative care should look like

The **planning sheets** below help a person to think about the future and how they might want to celebrate their life.

Name - What If—Celebrating My Life

Go to

pcpld.org/wp-content/uploads/What-If-Celebrating-My-Life-Plan-EOL-2013.pdf

Who made it

the National Health Service (NHS) in the United Kingdom (UK) and St Andrews Hospice

What it is about

Questions about what the person would like their care to look like and how their life should be celebrated

Information type

Planning sheet

Name - My Future and End of Life Care Plan

Go to

stlukes-hospice.org.uk/wp-content/uploads/2021/10/Easy-Read-Future-Care-plan-Final-Feb-2016-.pdf

Who made it

Paula Hine and Jill Singh

What is it about

Things that are important to a person and how they would like to be cared for when they are sick

Information type

Easy Read planning sheet

This section is about what good palliative care should look like

Health workers giving **palliative care** should make sure that:

Dying, death and grief are part of life

Dying means that a person's life is ending.

Death means that a person's body stops working and their life has ended.

Death is part of life and happens to everyone at some point.

Grief is feelings a person might have when someone they know dies.

Grief is different for everybody, but might include feelings like sadness, anger or worry.

The information below and on the next two pages are about **death** and **dying**.

Name - Talking about **death** and **dying**

Go to

health.nsw.gov.au/palliativecare/Documents/talking-about-death.PDF

Who made it

New South Wales (NSW) Health

What it is about

Information with pictures about **death** and **dying**

Information type

Easy Read information sheet

This section is about what good palliative care should look like

Name - We are living well but dying matters

Go to

youtube.com/watch?v=gJCzKLEx6Mw

Who made it

CHANGE (UK)

What it is about

People with intellectual disability talking about their future wishes and talking about **dying**, **death** and **grief**

Information type

Video

Name - Books Beyond Words

Go to

booksbeyondwords.co.uk

Who made it

Books Beyond Words (UK)

What it is about

Word-free picture books to understand **death** and **dying**

Information type

Books. These books cost money to order.

This section is about what good palliative care should look like

Name - Your feelings

Go to

mariecurie.org.uk/help/support/publications/all/easyread-feelings

Who made it

Marie Curie (UK)

What it is about

For someone living with an illness they will die from, how they might feel and what might help

Information type

Easy Read booklet

The following information explains end of life and **grief**.

Name - End of life and **grief**

Go to

be.macmillan.org.uk/be/s-853-end-of-life-and-bereavement.aspx

Who made it

Macmillan Cancer Support (UK)

What it is about

Feelings when **dying** and changes that can happen at the end of life

Information type

Easy Read booklets

This section is about what good palliative care should look like

Health workers giving **palliative care** should make sure that:

Supporters are involved in palliative care if the person they support wants them to be.

Supporters get help if they need it.

It is important to share information with **health workers** about who should be involved in **palliative care**.

The **planning sheet** below can help a person to decide who they would like to be involved in their care.

Name - Working together with my team

Go to

3dn.unsw.edu.au/improving-palliative-care-resources#myteam

Who made it

3DN

What it is about

A **planning sheet** to complete with **supporters** to find out who should be involved in **palliative care** and how they can work together

Information type

Plain English and **Easy Read planning sheet**

Information for supporters can be found in Part 2 of the **Toolkit**.

This section is about what good palliative care should look like

Health workers giving **palliative care** should make sure that:

Access to good quality palliative care is fair

A person with intellectual disability has the right to get the same health care as other people.

Fair means getting treated the same as other people.

Getting fair access means that **health workers** may make **reasonable adjustments** to care.

Reasonable adjustments mean changing the way things are done to make it fair. Examples of **reasonable adjustments** that **health workers** might make are:

- Using **Easy Read** information or pictures
- Using a communication device
- Giving a quieter space for meetings
- Giving a longer appointment time.

This section is about what good palliative care should look like

The information sheet below is about **reasonable adjustments**.

Name - Questions to ask about **Reasonable Adjustments**

Go to

safetyandquality.gov.au/publications-and-resources/resource-library/about-me-questions-ask-about-reasonable-adjustments-fact-sheet

Who made it

Australian Commission on Safety and Quality in Health Care

What it is about

Information on **reasonable adjustments** including questions to ask **health workers**

Information type

Easy Read information sheet

The template below can be given to the **palliative health team** to write information about **palliative care** services.

Name - **Palliative care** services

Go to

3dn.unsw.edu.au/improving-palliative-care-resources#services

Who made it

3DN

What it is about

Health workers can write about the **palliative care** services and support available

Information type

Plain English and **Easy Read** template

This section is about what good palliative care should look like

Health workers giving **palliative care** should make sure that:

Supporters and health workers work well together to assist someone in palliative care

The **planning sheet** below can be used to help **health workers** and **supporters** work together.

Name - Working together with my team

Go to

3dn.unsw.edu.au/improving-palliative-care-resources#myteam

Who made it

3DN

What it is about

A **planning sheet** to complete with **supporters** to help the different people that assist a person in **palliative care** work together

Information type

Plain English and **Easy Read planning sheet**

This section is about what good palliative care should look like

Health workers giving **palliative care** should make sure that:

Palliative care is good quality and based on the most up to date knowledge

We have made a Toolkit for health workers on how to make **palliative care** better for people with intellectual disability.

The **Toolkit** below can be shared with **health workers**.

Go to

3dn.unsw.edu.au/toolkit-improving-palliative-care-health-professionals



Artwork by Angela De Marinis
Garden on a Rainy Day 2024

This section is a story about Joe getting good palliative care

A story about Joe getting good palliative care

We made the story below to assist you to understand good **palliative care**.

The story below is made up and not about a real person.

It might not happen to you.

For the **Easy Read** Story go to - 3dn.unsw.edu.au/improving-palliative-care-easy-read-story.

About Joe

Joe lives in an apartment by himself.

Joe likes to walk his dog and spend time in the community garden.

Joe gets support from his sister and his disability support worker.

Joe likes to communicate by

- talking with simple words
- using **Easy Read**
- using pictures.

This section is a story about Joe getting good palliative care

Joe goes to his family doctor for help

Joe has a serious health condition that he will die from.

Joe has been feeling sick and having more pain.

Joe made a time to see his family doctor.

Joe and his disability support worker met with his family doctor to get help

Joe and his doctor talked about getting help from a **palliative care team**.

A **palliative care team** are **health workers**

The **palliative care team** will help Joe feel well and have less pain.

The family doctor tells the **palliative care team** about Joe.



Artwork by Cara McLean
Hazy Daisy 2023

This section is a story about Joe getting good palliative care

Information about palliative care

Joe's family doctor gives him an **Easy Read** information sheet about **preparing** for **palliative care**.

Preparing means to get ready for something.

To find the information sheet about **preparing** for **palliative care** go to - 3dn.unsw.edu.au/improving-palliative-care-resources#preparing.

It has information about

- What **palliative care** is
- Who might be involved
- Questions that **health workers** might ask.

The information sheet also has parts to fill out.

Joe looks at the information sheets with his **supporters**.

The information helps Joe to understand what **palliative care** is.

The information helps Joe to think about questions he might like to ask the **health workers**.

Joe feels less worried about visiting the **palliative care team** after reading the information.

The information sheet helps Joe think about who he wants to be involved in his care.

Joe decides that he wants his sister and disability support worker to be involved in his care.

This section is a story about Joe getting good palliative care

Getting ready for Joe's first palliative care appointment

The **palliative care team** reads important information about Joe from his family doctor.

The **palliative care team** call Joe before the appointment to ask if he needs any **reasonable adjustments**.

Reasonable adjustments means changing the way things are done to make it fair.

Joe tells the **palliative care team** how he likes to communicate.

Joe said he wants to bring his sister and disability support worker to the appointment.

This section is a story about Joe getting good palliative care

During the appointment

The **palliative care team** use simple words and **Easy Read** to communicate with Joe.

The **palliative care team** ask Joe

- What do you like?
- What don't you like?
- What is important to you?

Joe said that he wants the **palliative care team** to visit him at home.

The **palliative care team** include Joe in decisions about his care.

The **palliative care team** give information to

- Joe's sister
- Joe's disability support worker.

Everyone talks about how they could work together to take care of Joe.

This section is a story about Joe getting good palliative care

Information sheet for everyone to work together

Joe uses an information sheet to help everyone work together.

To find the information sheet about working together go to - 3dn.unsw.edu.au/improving-palliative-care-resources#myteam.

The sheet asks lots of questions like

- Who should be involved in **palliative care**?
- How should **supporters** be told important information?

Making a care plan

The **palliative care team** talk to Joe and his **supporters** to write a **care plan**.

A **care plan** says what needs to be done for a health condition.

The **palliative care team** make sure everybody understands and are happy with the plan.

This section is a story about Joe getting good palliative care

Resources about palliative care support

The **palliative care team** give Joe **Easy Read** information about **palliative care** services.

The sheet has information about **palliative care** services in Joe's local area.

To find the **Palliative care** services sheet go to -

3dn.unsw.edu.au/improving-palliative-care-resources#services.

The sheet must be given to a **palliative care team** to fill out.

Having information about support for the future makes Joe feel less worried.

Everyone knows who to call if they need more help.

This section is a story about Joe getting good palliative care

After Joe's palliative care appointment

Everyone follows the plan to support Joe.

Joe is given **medicine** to help with his pain and sickness.

Medicine is sometimes called medication or drugs.

The **palliative care team** visit Joe in his house every week.

Each time Joe sees the **palliative care team** everyone talks about

- What Joe likes about his care
- If his needs have changed.

Working together helps the **palliative care team** to understand Joe's wishes and needs.

Joe's sister and disability support worker know how to support Joe.

Joe is happy that everyone is working together in a way he wants them to.

This is the end of the story.

Word list

This is a list of some important words used in this **Toolkit**. It tells you what the words mean.

Access means a person has the right to get the same health care as other people.

Advocacy is people listening to someone so their rights and needs are met.

Advance care planning means making decisions about the health care a person wants in the future.

Assistive technology is physical support or equipment to support a person to do something more easily.

A **care plan** says what needs to be done for a health condition.

To **communicate** is how a person understands and share their feelings or information.

Family doctor is sometimes called a GP. A GP is the doctor that a person sees when they are sick or need a health check.

Grief is feelings a person might have when someone they know dies.

A **guardian** is a person who helps a person make decisions about parts of their life when they cannot make decisions by themselves.

Medicine is sometimes called medication or drugs.

Medicine can be in

- A tablet
- A pill
- A drink
- An injection.

NDIS is short for National Disability Insurance Scheme.

NDIS participants are people with disability who have a NDIS plan.

Word list

Palliative care is help for people with a serious health condition that they will die from.

Reasonable adjustments means changing the way things are done to make it fair.

Respect means that health workers must listen to what a person wants and what's important to them.

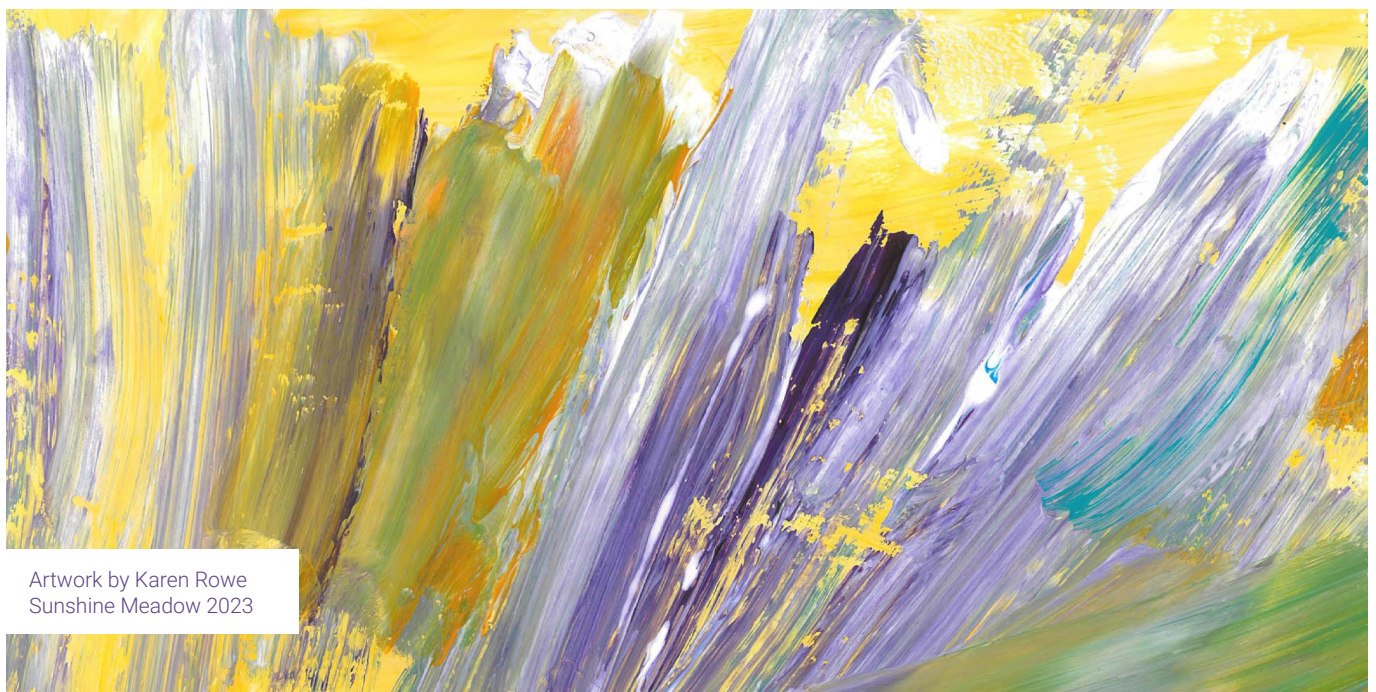
Rights are rules about how everybody should be treated fairly. A right is something everyone has.

Specialists are people who know a lot about **palliative care**.

Supporters are people who help with care or daily life such as friends, family, guardians or paid and unpaid carers, and disability support providers.

A **Toolkit** is a document with information that helps people to do something.

Some words on this list are from the *Intellectual disability Mental Health Connect website* ^[1].



Artwork by Karen Rowe
Sunshine Meadow 2023