Improving palliative care for people with intellectual disability

Toolkit for people with intellectual disability and supporters
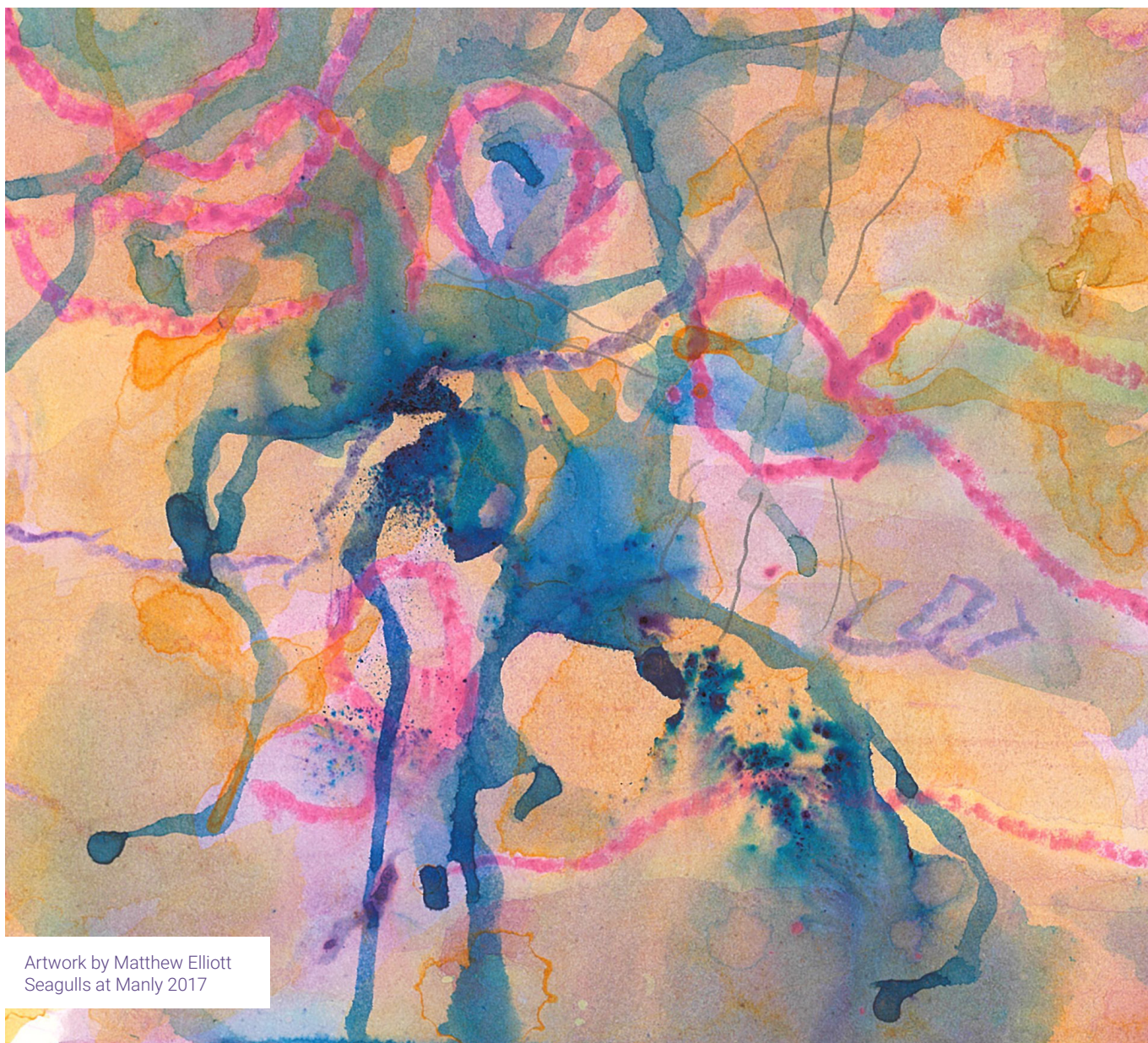
UNSW
SYDNEY

3DN
UNSW
Department of
Developmental
Disability
Neuropsychiatry

The information in the Toolkit offers general guidance for people with intellectual disability and their supporters.

By sharing information sheets in this Toolkit, the people that made this Toolkit do not guarantee the content is accurate.

Speak to your family doctor or health worker for advice on **palliative care**.

Artwork by Matthew Elliott
Seagulls at Manly 2017

What is in the Toolkit

We have also made an Easy Read story – go to the Easy Read Story.

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

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

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 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

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].
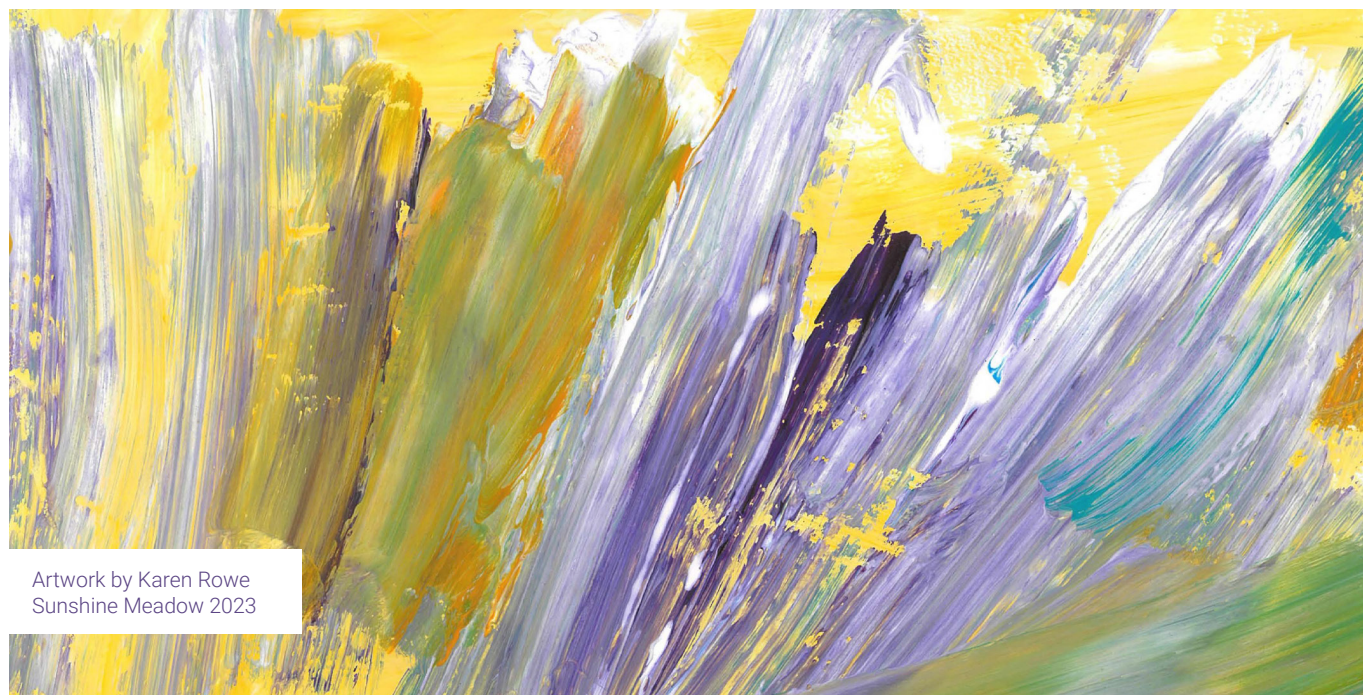
Artwork by Karen Rowe
Sunshine Meadow 2023

Part 2

For supporters of people with intellectual disability

About palliative care for people with intellectual disability

This section includes key information about palliative care for people with intellectual disability.

What is palliative care?

- Palliative care is support that improves the quality of life of a person and their supporters who are facing problems relating to a life-limiting condition [2].

- A life-limiting condition is a condition or illness that the person will die from.

- End-of-life care is part of palliative care, with a focus on care at the end of life [3].

- The main aim of palliative care is to help the person to live as well as possible, for as long as possible.

The resources on the following page have more information about palliative care.

About palliative care for people with intellectual disability

Resources

Resource - What is Palliative Care?

Go to

youtube.com/watch?v=qMbq0fP9kr4

Author

Australian Department of Health and Aged Care

Description

A short video that explains palliative care

Type

Video

Resource - Multilingual resources on palliative care

Go to

pallcarevic.asn.au/page/87/community-languages

Author

Palliative Care Victoria

Description

Simple fact sheets on how palliative care can help (information is available in over 20 language groups)

Type

Fact sheets (multilingual)

About palliative care for people with intellectual disability

Why do people with intellectual disability need tailored palliative care?

- People with intellectual disability are more likely to experience health problems than people without intellectual disability [4].

- More people with intellectual disability are living into older age [5]; this means that people with intellectual disability are experiencing greater rates of life-limiting conditions such as cancer and other chronic health conditions [4].

- People with intellectual disability experience significant barriers to accessing palliative care that meets their needs, including:

  › Lack of education and training for health professionals about the palliative care needs of people with intellectual disability

  › Lack of experience and knowledge of palliative and end-of-life care among professionals within the disability sector

  › Communication difficulties between health professionals and people with intellectual disability

  › Lack of collaboration within and between health and disability sectors, including engagement and support for supporters of people with intellectual disability and limited sharing of information

  › Factors impacting service delivery such as staffing levels and funding of health and disability services [6].

- There is currently a lack of guidance for health professionals on how to meet the palliative care needs of people with intellectual disability.

Working with different health professionals and supporters in palliative care

This section provides information on the people involved in palliative care and guidance on how to work with health professionals.

Palliative care can involve multiple health professionals from different settings. Supporters may also be involved in palliative care, depending on the needs and preferences of the person with intellectual disability. Everyone involved, including supporters, bring unique expertise to meet the needs of the person receiving care.

People with intellectual disability might access palliative care in different settings, including hospitals, clinics, or at home.

Artwork by Angela De Marinis
Garden on a Rainy Day 2024

Working with different health professionals and supporters in palliative care

The role of health professionals

During palliative care, health professionals might support the person with intellectual disability with:

- Pain

- Sickness

- Emotions such as sadness or worry

- Continuing their everyday activities

- Support with movement.

- Support with religious or cultural beliefs.

Health professionals may also aid supporters of people with intellectual disability. Health professionals might offer supporters:

- Information about what to expect

- Help with how to manage symptoms

- Help on how to make the person feel more comfortable

- Assistance with finding equipment for the person with intellectual disability

- Counselling [7].

The resource on the following page has more information about how health professionals might help during palliative care.

Working with different health professionals and supporters in palliative care

Resource

Resource – Preparing for palliative care

Go to

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

Author

3DN

Description

A resource for a person with intellectual disability and their supporters with information about what palliative care is, who might be involved and what they might ask

Type

Plain English and Easy Read information sheet

Artwork by Bridget Kelly
Printing Shapes 2023

Working with different health professionals and supporters in palliative care

The role of a supporter and working with others

The scope of a supporter's role can vary depending on the nature of their role and the preferences of the person with intellectual disability. Some examples of activities supporters of a person with intellectual disability might be involved in are [8]:

- Participating in health consultations and supporting the person to follow through on the recommendations.

- Providing health professionals with background knowledge about the person's history, personality and functional abilities.

- Supporting the person to communicate with health professionals.

- Supporting the person to make decisions about their care.

- Making decisions about the person's care.

- Advocating for the person they support e.g. ensuring the person's needs are understood and respected.

- Providing emotional support and comfort for the person they support.

- Collaborating with health professionals to coordinate appointments, manage medications and identify concerns.

- Providing practical assistance such as personal care.

- Supporting the person to celebrate their life and legacy.

- Requesting support for example respite care.

Working with different health professionals and supporters in palliative care

Further information

Resource - Palliative care for carers

Go to

health.gov.au/topics/palliative-care/palliative-care-throughout-life/palliative-care-for-carers

Author

Department of Health and Aged Care

Description

Information and resources on palliative care for carers

Type

Website

Working with different health professionals and supporters in palliative care

About the NDIS and palliative care

This information is relevant for people that support someone with a National Disability Insurance Scheme (NDIS) plan.

The NDIS provides funding to eligible people with disability for disability services depending on individual needs [1]. The NDIS funds specific disability-related health supports where the supports are a regular part of the participant's daily life, and result from the participant's disability. The NDIS does not fund palliative care; the health system is responsible for treatment, diagnosis and care of health conditions including palliative care, and allied health and therapies [13] related to health conditions.

Further information

Resource - Who is responsible for the supports you need - Health

Go to

ourguidelines.ndis.gov.au/how-ndis-supports-work-menu/mainstream-and-community-supports/who-responsible-supports-you-need/health#healthsystem

Description

The NDIS website outlines who is responsible for different support needs between NDIS and health services

Type

Website

What should good palliative care look like for people with intellectual disability?

This section provides information and resources on what tailored palliative care should look like for people with intellectual disability and supporters.

We have made a document, Tailored model of palliative care for people with intellectual disability, for health professionals that outlines what tailored palliative care for people with intellectual disability should look like, including where it should be delivered, who should deliver it and how to measure it.

Artwork by Cara McLean
Hazy Daisy 2023

The model of care is based on seven guiding principles[1]:

Human rights are protected, respected and upheld as per the United Nations Convention on the Rights of Persons with Disabilities

Family, carers and supporters are recognised and valued as partners in providing palliative care, when desired by the person with intellectual disability, and are supported to enact their roles

Palliative care is person-centred and holistic

Access to quality care is equitable

Dying, death and grief are recognised as part of life

Care is well-coordinated and integrated

Care is high quality and evidence-based

The next section includes resources and further information that might help people support a person with intellectual disability to get good palliative care.

Information and resources to help health professionals achieve the Tailored model of care are provided in the National Toolkit for Health Professionals. Disability professionals may also find this information relevant.

Go to

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

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1   The Guiding Principles were determined through an international Delphi study as part of 3DN's research project Improving palliative care services for people with intellectual disability. Find out more about this study on the project website here.

Guiding principle 1

Human rights are protected, respected and upheld as per the United Nations Convention on the Rights of Persons with Disabilities

The United Nation Convention on the Rights of Persons with Disabilities (CRPD) sets out the fundamental human rights of people with disability.

The following resources have more information about health rights for the person and their supporters:
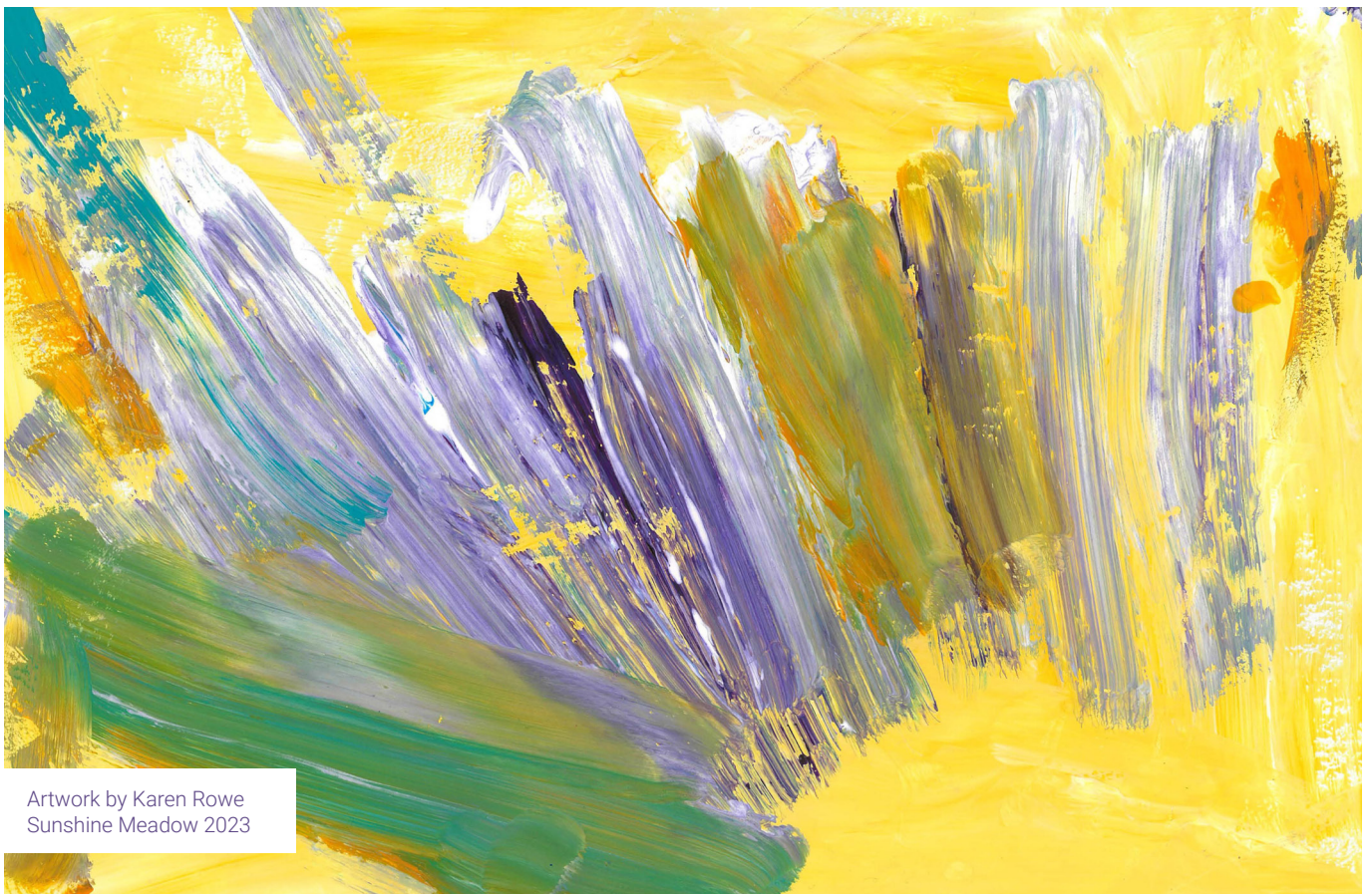
Artwork by Karen Rowe
Sunshine Meadow 2023

Guiding principle 1

Resources about healthcare rights

Resource - Your Healthcare Rights and Responsibilities: A guide for patients, carers and families

Go to

cclhd.health.nsw.gov.au/wp-content/uploads/RightsAndResponsbilities-PatientsCarersAndFamilies.pdf

Author

NSW Health

Description

A document providing information about rights and responsibilities for seeking and receiving healthcare in New South Wales (NSW)

Type

Guide

Resource - Your healthcare rights

Go to

healthdirect.gov.au/your-healthcare-rights

Author

Healthdirect Australia

Description

Free advice about healthcare rights and national contacts to make a healthcare complaint

Type

Website

Guiding principle 1

Further information

Organisation - Inclusion Australia

Go to

inclusionaustralia.org.au

Description

The national voice for people with intellectual disability and their families

Type

Website

Organisation - Council for Intellectual Disability (CID)

Go to

cid.org.au

Description

A disability rights organisation led by people with intellectual disability

Type

Website

Palliative care is person-centred and holistic

It is important that people with intellectual disability are provided holistic care that is based on the person's needs, preferences and goals of care [6].

The following resources have further information about preparing for palliative care, tools to plan ahead and resources for supported decision making.

Resource on preparing for palliative care

Resource – Preparing for palliative care

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

Author
3DN

Description
A resource for a person with intellectual disability and their supporters with information about what palliative care is, who might be involved and what they might ask - it also includes a planning sheet to use and can be shared with health professionals

Type
Plain English and Easy Read information sheet

Guiding principle 2

Resources about advance care planning

Resource – Guidebook for Supporters

Go to
understandable.org.nz/advance-care-planning

Author
Understandable (New Zealand)

Description
A guidebook to explain how to support someone with intellectual disability to make a care plan (linked to My plan for a good life, right to the end)

Type
Guidebook

Resource – Growing Older, Planning Ahead Cards

Go to
tuffrey-wijne.com/?page_id=860

Author
Irene Tuffrey-Wijne

Description
Conversations cards for families living with older people with intellectual disability that may want to think about their future, parental death and transitions of care

Type
Conversation cards (online and print versions available)

Guiding principle 2

Resource – Wills for people with intellectual disability

Go to

idrs.org.au/site18/wp-content/uploads/2018/08/Wills-18072018.pdf

Author

Intellectual Disability Rights Service

Description

A Fact sheet with general information to support a person with intellectual disability choosing to complete a will

Type

Fact sheet

Resource – Prof Irene Tuffrey-Wijne 'Planning ahead for the end of life with people with learning disabilities'

Go to

youtube.com/watch?v=2Ge2_Jbvm48

Author

Palliative Care for People with Learning Disabilities (PCPLD) Network United Kingdom (UK)

Description

A webinar on planning ahead for the end of life with people with intellectual disability

Type

Video

Guiding principle 2

Resources on supported decision making

Resource - Supported decision making resources

Go to

waindividualisedservices.org.au/supported-decision-making-resources

Author

Western Australia's Individualised Services (WA)

Description

Information, videos and resources (also in Easy Read for supporters) for guidance on supported decision making

Type

Website

Resource - Supported decision making

Go to

providers.dffh.vic.gov.au/sites/default/files/2017-07/Supporting-decision-making-quick-reference-guide.pdf

Author

State Government Victoria (VIC)

Description

A quick reference guide for people who work with people with a disability who are making decisions

Type

Guide

Guiding principle 2

For disability service providers

Resource - Advance Care Planning Policy Development – Guidance for Disability Service Providers

Go to

understandable.org.nz/advance-care-planning

Author

Understandable (New Zealand)

Description

Guidance for disability service providers to develop their own policies on advance care planning

Type

Policy guide

Resource - Intellectual Disability Health Education - A Person-Centred Approach

Go to

idhealtheducation.edu.au/disability-professionals

Authors

3DN

Description

An online learning module by for disability professionals about a person-centred approach

Type

Online learning

Death, dying and grief are recognised as part of life

Talking about dying is important for everyone [10]. People with intellectual disability might have varied understandings of death and dying. Health professionals and supporters might also find it hard to talk about death and dying with people with intellectual disability [11].

Conversations about death, dying and grief should be tailored to the person's communication needs and preferences. This might include the use of accessible resources, such as story books, to support discussion.

The following resources include accessible information that supporters can use with people with intellectual disability to help them to understand the concept of death, dying and grief. Other resources are for supporters to understand the dying process, and training and guidance on how to have important conversations on death and dying.

Artwork by Ellie Rennie
Flowers in the Rain 2023

Guiding principle 3

Resources on talking about death and dying

Resource - How to break bad news to people with intellectual disabilities

Go to

tuffrey-wijne.com/?page_id=90

Author

Professor Irene Tuffrey-Wijne

Description

Guidelines for supporters on breaking bad news to someone with intellectual disability

Type

Book

Resource - Talking End of Life...with people with intellectual disability

Go to

caresearch.com.au/tel/Modules

Author

Talking End of Life [11]

Description

Resources to show disability support professionals and other supporters how to teach people with intellectual disability about end of life

Type

Online learning

Guiding principle 3

Resources on death and dying for supporters

Resource - Intellectual Disability Health Education – Multiple modules

Go to

idhealtheducation.edu.au/disability-professionals

Author

3DN

Description

Modules for disability professionals on death, dying and end-of-life

Type

Online learning

Resource – Death and dying: what to expect

Go to

hospiceuk.org/information-and-support/death-and-dying-what-expect

Author

Hospice UK

Description

Practical information for supporters about the dying process including what dying looks like in the last few weeks and moments

Type

Website

Guiding principle 3

Resource – The Dying Process

Go to

palliativecare.org.au/wp-content/uploads/2015/05/PCA002_The-Dying-Process_FA.pdf

Author

Palliative Care Australia

Description

A resource for supporters that outlines what happens during dying and death for example, changes you may notice and what you can do to help

Type

Guide

Resource to use with a person with intellectual disability

Resource - Books Beyond Words

Go to

booksbeyondwords.co.uk

Author

Books Beyond Words (UK)

Description

Word-free picture books to use with people with intellectual disability to support their understanding about death and dying

Type

Books (cost to order)

Guiding principle 3

Resource – Life, death and loss cards

Go to

paradigm-uk.org/wp-content/uploads/2023/06/Life-death-and-loss-cards-Final-limited-page-numbers-2.pdf

Authors

Jo Giles and Claire Lam (UK)

Description

Discussion starter cards to use with people with intellectual disability to facilitate conversations about life, death and loss

Type

Conversation cards to print

Resource – Let's talk about death

Go to

pallcarevic.asn.au/page/86/easy-english-resources

Author

Palliative Care Victoria (VIC)

Description

A series of booklets and posters with pictures to use with people with intellectual disability to talk about death

Type

Easy Read booklets

Guiding principle 3

Resources to support people with intellectual disability with bereavement

Such as friends, co-residents and family of the person with intellectual disability who has a life limiting condition.

Resource – Supporting people with learning disabilities in bereavement webinar

Go to

youtube.com/watch?v=1Z4IuRcbJJE

Author

PCPLD Network (UK)

Description

Discussion on research, practice and experience in supporting people with intellectual disability with bereavement

Type

Video

Resource – Let's talk about death

Go to

dsscotland.org.uk/wp-content/uploads/2019/05/DSS_LETS-TALK-ABOUT-DEATH_WEB.pdf

Author

Down's Syndrome Scotland (UK)

Description

A document for people with intellectual disability to complete when someone they know has died

Type

Booklet

See Part 1 of the Toolkit for a full list of Easy Read resources about dying and grief to support a person with intellectual disability.

Guiding principle 4

Family, carers and supporters are recognised and valued as partners in providing palliative care, when desired by the person with intellectual disability, and are supported to enact their roles

Family, carers and supporters are essential to providing palliative care and should be recognised and supported to enact their roles. The resources below provide further information and online learning.

Resource - Carer Gateway

Go to
carergateway.gov.au

Author
Australian Government

Description
Information, online courses, peer support groups, counselling and much more for carers

Type
Website with resources

Guiding principle 4

Further information and training for supporters

Resource - I am a Carer

Go to

palliativecare.org.au/im-a-carer

Author

Palliative Care Australia

Description

Information for carers including a directory of services in locations around Australia for palliative care

Type

Website

Resource - Intellectual Disability Health Education – Multiple modules

Go to

idhealtheducation.edu.au/disability-professionals

Author

3DN

Description

Modules on Death, Dying and End-of-Life, Supporting Carers, Colleagues and Self-Care for disability professionals

Type

Online learning (cost)

Guiding principle 5

Access to quality care is equitable

People with intellectual disability should be able to access palliative care services as would any other member of the community. The following resources include a template to share with health workers to collect contact information about local services available and a resource to use with the person you support about reasonable adjustments:

Template to be given to palliative care team to complete

Resource - Palliative care services

Go to

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

Author

3DN

Description

A template to be completed by the person's palliative care team with information about the local services and supports to help both the person and supporters during palliative care.

For example, out of hours contact details.

Type

Template

Guiding principle 5

Resource on reasonable adjustments

Resource - About Me – 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

Author

Australian Commission on Safety and Quality in Health Care

Description

Information on health care and reasonable adjustments including questions to ask to make a person's health care accessible

Type

Easy Read fact sheet

Artwork by Matthew Elliott
Seagulls at Manly 2017

Guiding principle 6

Care is well-coordinated and integrated

To ensure that people with intellectual disability receive high quality care, everyone involved in care delivery should work collaboratively across both the health and disability sectors.

The following resource is a planning sheet to complete with the person you are supporting about how the different people involved in care could work together.

Resource - Working together with my team

Go to

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

Author

3DN

Description

A planning sheet for the person with intellectual disability to complete with supporters (if preferred) to help identify who should be involved in palliative care and how they should work together

Type

Planning sheet

Care high quality and evidence-based

Palliative care for people with intellectual disability should be high quality and based on the latest evidence.

We have made a Toolkit for health professionals on how to give good palliative care to people with intellectual disability.

You may wish to share the link with health professionals providing care to people with intellectual disability.

Go to

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

Artwork by Angela De Marinis
Garden on Rainy Day 2024

Definitions

Term	Definition
End-of life care	The care and services given to people and their families as they are reaching the end of their life. End-of-life care is an important part of palliative care [3].
Holistic care	Complete or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the person, their response to illness and the effect of the illness on their ability to meet self-care needs [12]
Intellectual disability (may also be referred to as learning disability)	A developmental condition affecting a person's cognitive skills (e.g., learning, memory and problem solving) and adaptive behaviour skills (e.g., communication and social skills).
Life-limiting condition	An illness that cannot be cured that the person will likely die from. Life-limiting illnesses can include cancer, motor neuron disease, end-stage kidney disease and dementia [3].
Palliative care	An approach that improves the quality of life of individuals and their families who are facing problems associated with a life-limiting condition. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual [2].
Person-centred care	Care that respects and responds to the needs, values and preferences of a patient [13].
Supporter (may also be referred to as carer, support network, support person)	Any key person providing support to the person with intellectual disability. This may include existing supports and newly engaged supports, including paid and unpaid disability support, guardians, friends, family, independent advocates and professional mediators.

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Artwork by Matthew Elliott
Seagulls at Manly 2017

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