



## Part 2

# For supporters of people with intellectual disability

Artwork by Matthew Elliott  
Seagulls at Manly 2017

# 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 <sup>[2]</sup>.
- 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 <sup>[3]</sup>.
- 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](https://www.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](http://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 <sup>[4]</sup>.
- More people with intellectual disability are living into older age <sup>[5]</sup>; this means that people with intellectual disability are experiencing greater rates of life-limiting conditions such as cancer and other chronic health conditions <sup>[4]</sup>.
- 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 <sup>[6]</sup>.
- 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 <sup>[7]</sup>.

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](https://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



# 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 <sup>[8]</sup>:

- 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](https://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 <sup>(1)</sup>. 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 <sup>(13)</sup> 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](https://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<sup>1</sup>:



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](https://3dn.unsw.edu.au/toolkit-improving-palliative-care-health-professionals)

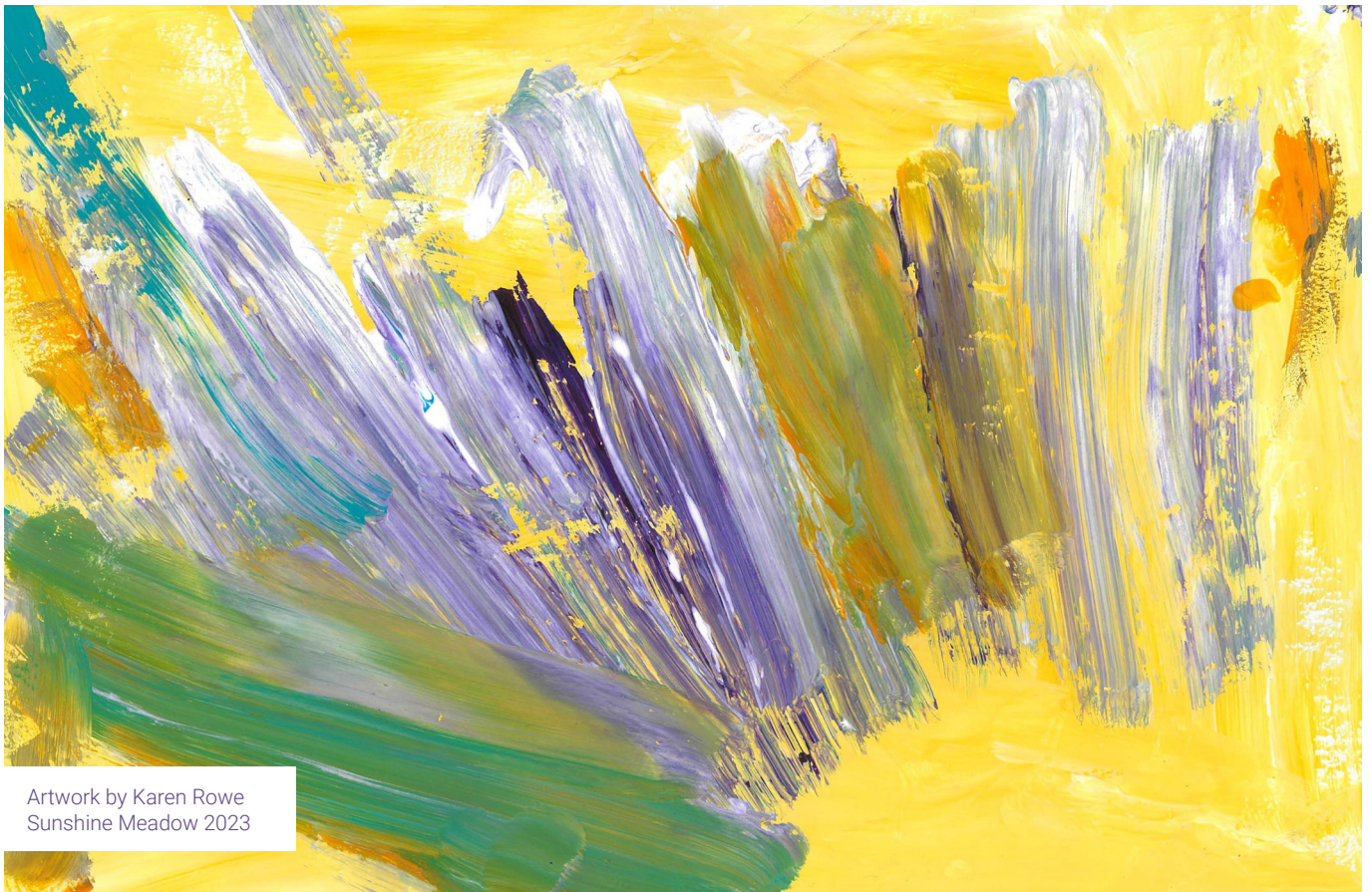
<sup>1</sup> The Guiding Principles were determined through an international Delphi study as part of 3DN's research project Improving palliative care services for people with intellectual disability. Find out more about this study on the [project website](#) here.

## 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/RightsAndResponsibilities-PatientsCarersAndFamilies.pdf](https://cclhd.health.nsw.gov.au/wp-content/uploads/RightsAndResponsibilities-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](https://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](http://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](http://cid.org.au)

**Description**

A disability rights organisation led by people with intellectual disability

**Type**

Website

## Guiding principle 2

### 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 <sup>[6]</sup>.

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](https://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](https://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](https://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**

[ids.org.au/site18/wp-content/uploads/2018/08/Wills-18072018.pdf](https://ids.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](https://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](http://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](http://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](https://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](https://idhealtheducation.edu.au/disability-professionals)

**Authors**

3DN

**Description**

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

**Type**

Online learning

## Guiding principle 3

### Death, dying and grief are recognised as part of life

Talking about dying is important for everyone <sup>[10]</sup>. 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 <sup>[11]</sup>.

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](http://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](http://caresearch.com.au/tel/Modules)

**Author**

Talking End of Life <sup>[11]</sup>

**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](http://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](http://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](http://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](http://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](https://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](https://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=1Z4luRcbJJE](https://youtube.com/watch?v=1Z4luRcbJJE)

**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](https://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](http://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](http://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](http://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](https://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](https://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



## 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](https://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

## Guiding principle 7

### 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](https://3dn.unsw.edu.au/toolkit-improving-palliative-care-health-professionals)





# Definitions

<i>Term</i>	<i>Definition</i>
<b>End-of life care</b>	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 <sup>[3]</sup> .
<b>Holistic care</b>	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 <sup>[12]</sup>
<b>Intellectual disability (may also be referred to as learning disability)</b>	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).
<b>Life-limiting condition</b>	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 <sup>[3]</sup> .
<b>Palliative care</b>	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 <sup>[2]</sup> .
<b>Person-centred care</b>	Care that respects and responds to the needs, values and preferences of a patient <sup>[13]</sup> .
<b>Supporter (may also be referred to as carer, support network, support person)</b>	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.

# References

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13. Australian Commission on Safety and Quality in Health Care (2023) *Person-centred care*, accessed 30th May 2024.



Artwork by Matthew Elliott  
Seagulls at Manly 2017

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The project builds on the substantial work carried out on palliative care and intellectual disability in Australia and internationally. The project has benefitted from the expert advice and guidance of a Project Advisory Group and expert reviewers.

## Research Team

Julian Trollor<sup>1</sup>, Rachael Cvejic<sup>1</sup>, Olivia Burton<sup>1</sup>, Janelle Weise<sup>1</sup>, Preeyaporn Srasuebkul<sup>1</sup>, Amanuel Hagos<sup>1</sup>, Peiwen Liao<sup>1</sup>, Simone Reppermund<sup>2</sup>, Claire Vajdic<sup>3</sup>, Meera Agar<sup>4</sup>, Janeane Harlum<sup>5</sup>, Rebecca Strutt<sup>6</sup>, Maria Heaton<sup>6</sup>, Tracey Szanto<sup>7</sup>, Vanessa Evans<sup>7</sup>, David Currow<sup>8</sup>, Richard Chye<sup>9</sup>.

<sup>1</sup> National Centre of Excellence in Intellectual Disability Health, Faculty of Medicine and Health, UNSW Sydney

<sup>2</sup> Centre for Healthy Brain Ageing, Discipline of Psychiatry and Mental Health, School of Clinical Medicine, Faculty of Medicine & Health, UNSW Sydney

<sup>3</sup> The Kirby Institute, UNSW Sydney

<sup>4</sup> Improving Palliative, Aged and Chronic Care through Clinical Research and Translation, University of Technology Sydney

<sup>5</sup> South Western Sydney Local Health District

<sup>6</sup> South Eastern Sydney Local Health District

<sup>7</sup> Agency for Clinical Innovation, New South Wales Government

<sup>8</sup> Research and Sustainable Futures, University of Wollongong

<sup>9</sup> Palliative Medicine, St Vincent's Hospital Sydney

## Project Advisory Group and external reviewers

The Project Advisory Group, expert reviewers and wider team that supported on the project include Paige Black, Shu Hua Chan, Josephine Clayton, Helen Eggleton, Heike Fleischmann, Tahli Hind, Pia Karjalainen, Margaret Kyrkou, Debra Letica, Nicole Marchisone, Amanda McRae, Laura Nichols, Annabel Norrie, Sarah Spiller and Chris Madden.

## Artwork



The artwork used in this document and all project outputs has been created by people living with disability. Artwork has been provided by Studio ARTES, an independent, not for profit organisation that provides creative programs to adults with disability. All artwork has been individually credited. For more information visit [www.studioartes.org.au](http://www.studioartes.org.au).

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