



Improving palliative care for people
with intellectual disability



National Toolkit for health professionals

June 2024

Artwork by Cara McLean
Hazy Daisy 2023



UNSW
SYDNEY



UNSW
Department of
Developmental
Disability
Neuropsychiatry

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What do you think helps people with intellectual disability to have a good end of life?

***“Ah, to be happy.
And be – and be -
- comfortable.”***

Person with intellectual disability¹

1 All quotes used throughout the Toolkit are anonymised responses from health professionals, people with intellectual disability and their supporters that consented to participate in project stakeholder consultations as part of 3DN's project on improving palliative care for people with intellectual disability..

Key information about the Toolkit

Users of the Toolkit

The Toolkit provides guidance on improving palliative care for people with intellectual disability. The Toolkit is primarily designed for health professionals and service managers within generalist and specialist health services providing palliative care.

Why the Toolkit was made

People with intellectual disability encounter significant barriers in accessing palliative care that meets their needs ^[1]. The Toolkit was developed to support implementation of a tailored model of palliative care for people with intellectual disability in Australia. There is also a [Toolkit for people with intellectual disability and their supporters](#) (e.g., family, friends and paid/unpaid carers) and an [Easy Read Story](#).

Why use the Toolkit

By utilising the Toolkit in conjunction with the tailored model of care, health professionals have the opportunity to transform the quality of palliative care for people with intellectual disability. Enhancements to service delivery will drive health equity for this population in line with the United Nations Convention on the Rights of Persons with Disabilities ^[1] and the [National Roadmap for Improving the Health of People with Intellectual Disability](#) ^[2]. Utilisation of the Toolkit may also support professionals to meet the National Safety and Quality Health Service (NSQHS) Standards such as 'Partnering with Consumers' ^[3].

How the Toolkit was made

The Toolkit was developed as part of a research project led by UNSW Sydney on improving palliative care for people with intellectual disability. [Visit the project website](#) to find out more and read through the project's findings.

The model of care and supporting toolkits were developed based on collective findings from the project, building on existing international research and guidance.

All project outcomes have been through an extensive consultation process with the research team and a Project Advisory Group comprising of people with intellectual disability, supporters of people with intellectual disability, and representatives from health, disability and advocacy services. The Toolkit also underwent external expert review.

How to use the Toolkit

It is recommended to read the [Tailored model of care document](#) first for context before using the Toolkit.

The Toolkit contains three sections:

Section 1 The context

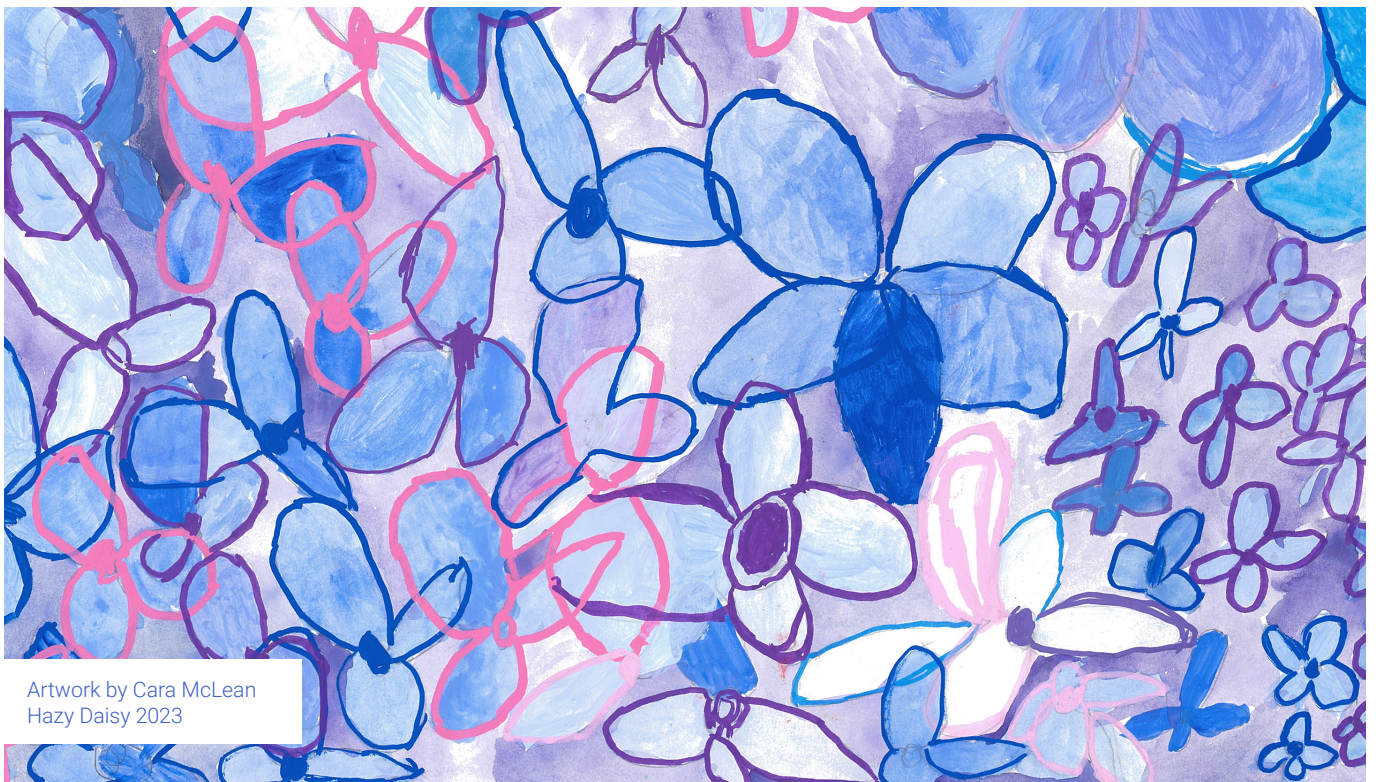
Context for improving palliative care for people with intellectual disability

Section 2 The role of health professionals in palliative care for people with intellectual disability

Information to support a health professional's role in delivering quality palliative care for people with intellectual disability including working with supporters and NDIS information

Section 3 Clinical and organisational strategies

Strategies and resources to support implementation of the model of care categorised into themes of action and coded by specialisation



Artwork by Cara McLean
Hazy Daisy 2023



Section 1

The context

This section includes the context for improving palliative care for people with intellectual disability

Section 1

The context

Background

- Intellectual disability is 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) ^[4].
- In Australia, about 1 percent of the population have a level of intellectual disability which requires the provision of specific supports ^[5].
- People with intellectual disability are more likely to die prematurely than people without intellectual disability ^[6].
- While the life expectancy of people with intellectual disability in Australia has improved over time ^[7], people with intellectual disability are more likely to experience life-limiting conditions as they age with leading underlying causes of death respiratory, circulatory, cancer and neurological conditions ^[6].

Barriers to quality palliative care for people with intellectual disability

- Palliative care is an approach that improves the quality of life of individuals and their supporters who are facing problems associated with a life-limiting condition^[8]. End-of-life care is part of palliative care, with a focus on care at the end of life ^[9].
- People with intellectual disability experience multiple barriers to accessing quality palliative care ^[10] including delayed access to palliative care services from late diagnosis of life limiting conditions ^[11, 12].
- People with intellectual disability living in supported accommodation experience inequity in access to community-based nursing and palliative care services and additional barriers to receiving care and dying within their own home².
- People with intellectual disability are recognised in the Australian National Palliative Care Standards ^[13] as a priority population group requiring improvements in care, yet there is currently a lack of guidance for health professionals on how to meet their needs.

2 Findings of stakeholder consultations conducted as part of 3DN's research project. Find out more about this study on the [project website](#).

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

The [Tailored model of palliative care for people with intellectual disability](#) outlines seven guiding principles that should underpin palliative care service delivery for people with intellectual disability:



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

Australia is a signatory to the [United Nation Convention on the Rights of Persons with Disabilities \(UNCRPD\)](#) ^[1] which sets out the fundamental human rights of people with disability.



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 important partners in providing palliative care and may have varied support needs depending on the scope of their role.



Palliative care is person-centred and holistic

Care should be based on the person's needs, preferences and goals of care.



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.



Dying, death and grief are recognised as part of life

Conversations about dying, death and grief should align with the preferences and communication needs of people with intellectual disability and their supporters.



Care is well-coordinated and integrated

Well-coordinated and integrated care requires collaboration within and across both the health and disability sectors.



Care is high quality and evidence-based

Good quality palliative care for people with intellectual disability should be delivered by an equipped workforce and based on the latest evidence.



Section 2

The role of health professionals

This section provides information to support a health professional's role in delivering quality palliative care for people with intellectual disability

Section 2

The role of health professionals in palliative care for people with intellectual disability

Quality palliative care is not the sole domain of specialist services but a collective responsibility. From general practitioners to palliative care specialists, all health professionals have a role to play in enhancing palliative care for people with intellectual disability. The information below may support a health professional in enhancing several aspects of their role to deliver quality care for people with intellectual disability.

1. Identifying the need for palliative care

Delayed diagnosis of life limiting conditions among people with intellectual disability is a significant barrier to accessing palliative care. Timely and appropriate identification of the need for palliative care among people with intellectual disability could be enhanced through the use of the Comprehensive Health Assessment Program (CHAP) annual health assessment tool ^[14].

Resource

Comprehensive Health Assessment Program Tool (CHAP)

Click here

health.gov.au/resources/collections/comprehensive-health-assessment-program-chap-annual-health-assessment-for-people-with-intellectual-disability

Author

Australian Government Department of Health and Aged Care

Description

An evidence-based tool for conducting yearly health assessments for people with intellectual disability in Australia with two versions available for adults 18 years and over and young people aged 12 to 18 years old

Type

Tool

Section 2 - The role of health professionals

2. Multidisciplinary approach in palliative care delivery

People with intellectual disability accessing palliative care should have access to a skilled and knowledgeable multidisciplinary health team spanning different settings and services (including community services) that are equipped to meet their needs, including their physical, psychosocial and spiritual, information and communication needs ^[10].

The [Tailored model of care](#) document outlines the recommended personnel to be involved in delivering care, depending on the person's needs and preferences.

3. Collaborating effectively with supporters

Supporters have a significant role in providing support and care to people with intellectual disability with life-limiting condition/s. People with intellectual disability have varied support needs ⁽¹²⁾. Supporters of people with intellectual disability might include parents, siblings, friends and other unpaid carers, paid carers including disability support workers, supported accommodation providers, and the Public Guardian/Advocate if required.

Palliative care providers should, depending on the wishes and preferences of the person with intellectual disability, engage and recognise supporters of the person with intellectual disability as partners in providing palliative care (see Section 3 for more information).

Scope of a supporter's role

Health professionals should consider the scope of a supporter's role in providing care to a person with intellectual disability. 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:

- Participating in health consultations and supporting the person to follow through on any recommendations ^[4].
- Providing health professionals with background knowledge about the person's history, personality and functional abilities ^[4].
- Supporting the person to communicate with health professionals.
- Supporting the person to make decisions about their care.
- Making decisions about the person's care (if appointed as a decision-maker).
- 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 e.g. personal care, meal preparation, and transport.
- Supporting the person to celebrate their life and legacy.
- Requesting support for example respite care.

It is important to consider the factors that may limit the scope of a supporter's role during palliative care.

All supporters

- Supporters may have limited experience and knowledge of palliative and end-of-life care.
- Supporters may have their own age-related health and support needs, have a disability and/or live far away from the person they support.

Section 2 - The role of health professionals

Paid supporters

- Paid supporters (such as disability support workers) can have distinct professional and regulatory requirements that may limit what they can do in their role, including administration of certain medicines. Disability providers may have varying policies and procedures.
- Public officials appointed as decision makers (e.g., the Public Guardian or Public Advocate) may have limited experience supporting people with intellectual disability with life-limiting conditions.
- People living in supported accommodation will be supported by disability support workers. These supporters may not have health training and sometimes staff changes can occur which means the person attending an appointment may not always know the person well ^[4].

Information sharing

Care coordination requires effective information sharing, for example, between health and disability professionals. Sharing health information must be in line with confidentiality requirements. The following resource highlights information with examples of disclosing health information:

Further information

Guide to health privacy

Click here

[oaic.gov.au/privacy/privacy-guidance-for-organisations-and-government-agencies/health-service-providers/guide-to-health-privacy](https://www.oaic.gov.au/privacy/privacy-guidance-for-organisations-and-government-agencies/health-service-providers/guide-to-health-privacy)

Author

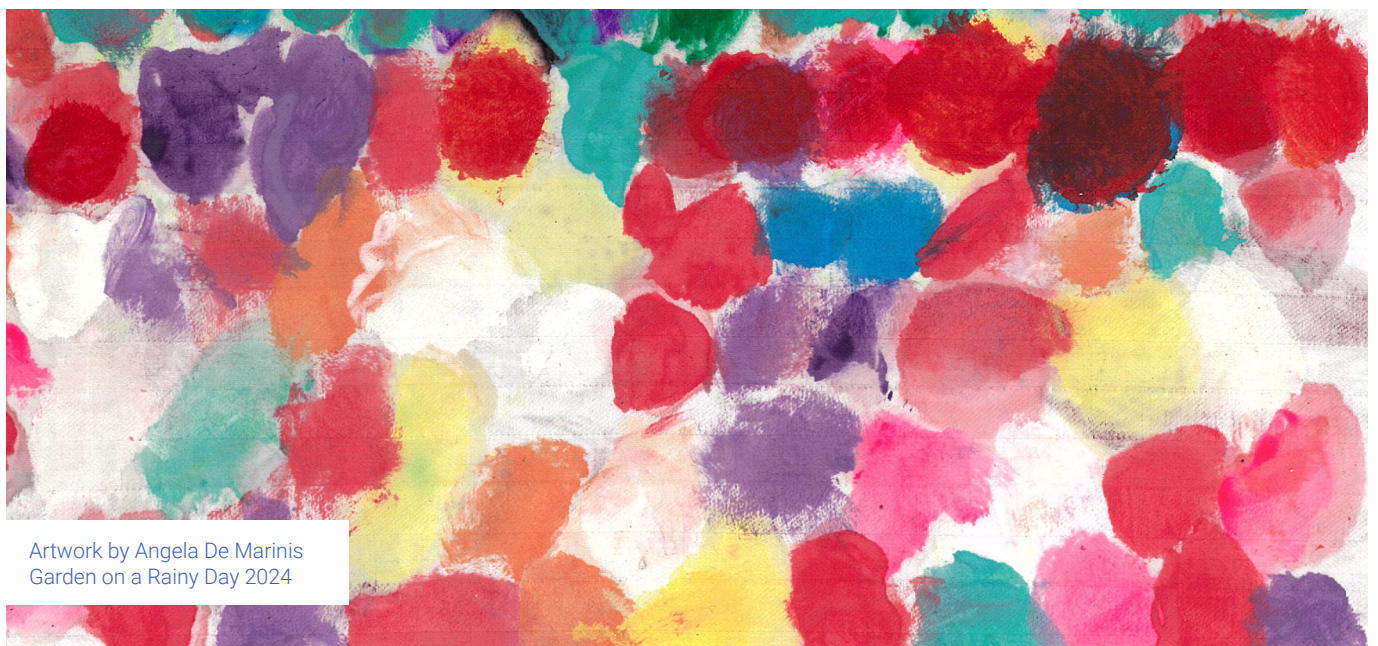
Australian Government Office of the Australian Information Commissioner

Description

Information for health service providers on health privacy in Australia with a Chapter (7) on patients with impaired capacity or an inability to communicate consent

Type

Website



Artwork by Angela De Marinis
Garden on a Rainy Day 2024

Section 2 - The role of health professionals

About the National Disability Insurance Scheme (NDIS) and palliative care

The NDIS provides funding to eligible people with disability to have access to services and support depending on individual needs ⁽¹¹⁾. 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

What is the health system responsible for?

Click here

dss.gov.au/sites/default/files/documents/06_2019/attachment-drc-communique-fact-sheet-health-related-supports.pdf

Author

The National Disability Insurance Agency

Description

Information on the responsibility for support between the NDIS and health services with examples

Type

Fact sheet



Section 3

Clinical and organisational strategies

This section presents strategies and resources to support implementation of the model of care

Section 3

Clinical and organisational strategies

This section presents various strategies and links to resources³ to aid implementation of the [Tailored model of palliative care for people with intellectual disability](#)⁴. The included strategies were developed to support achievement of the guiding principles, which are highlighted in each section.

Strategies have been structured by the level of their intended application (i.e., clinical or operational) and recommended actions. Some strategies are for immediate use in clinical practice or at specific points in a patient's palliative care pathway, while others aim to contribute to long-term system-level improvements.

To facilitate health professionals in understanding what strategies might be most relevant to them, strategies have been coded into one of three levels based on complexity and specialisation:

1	Foundational i.e. all health professionals
2	Specialist palliative care
3	Highly specialised palliative care for people with intellectual disability

The eight themes of action are:

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6.	Service design	38
7.	Service planning, quality and improvement activities	40
8.	Advocacy	46

3 The resources included are based on current recommendations from the research team, advisory group and external experts. By sharing these resources, the authors do not endorse or guarantee their content. Professionals are recommended to check the relevancy of the content to their own settings and context.

4 The strategies to achieve the guiding principles of the model of care were determined through an international Delphi study conducted as part of 3DN's research project. Find out more about this study on the [project website](#).

Section 3

Part A: Clinical strategies

1. Getting to know the person and supported decision making

It is important to get to know the person to understand them. Consider asking about how they communicate, what they like, what they want out of palliative care and who they might like to support them ^[10, 16].

When communicating with a person with intellectual disability, adapt communication to the person's preferences and needs. This might include non-verbal methods such as facial expressions, gestures, pictures, electronic devices, and signs ^[17]. Providing information in an accessible format will help the person and their supporters make decisions about their care.

"I like to make my own decisions."

Person with intellectual disability

"A lot of work had gone into communication with the person and then they were able to tell us where they wanted to be and what they wanted to do and who they wanted to be with them when they were dying."

Health professional



Star means the resource is highly recommended by 3DN

Strategy	Level of specialisation
Recognise the person with intellectual disability as a valued member of the community with a human right to be supported to receive care and die in locations of their choice; respect wishes of the person palliating and fulfil them where possible.	1
Recognise individuals as being capable of expressing preferences and directing care; support people with intellectual disability to be included and involved in making decisions about their care (as appropriate for cognitive and communication skills, and to the extent of their preferences).	1
Proactively work with the person with intellectual disability and their supporters, from the initial point of contact, to develop a clear understanding of a person's communication preferences and needs.	1
Ensure that communication needs of the person are met (e.g., through the use of alternative communication methods) and recognised as likely to change over time.	1
Provide the person with intellectual disability and their supporters with accessible information about the available choices and options for palliative care and end of life care services.	1
Work with the person with intellectual disability, family, carers, and supporters to develop a clear understanding of the person's end of life preferences, values and wishes, including physical, psychological, social, cultural, and spiritual needs; with consent from the person with intellectual disability (or as otherwise required by law), share this information with others who provide care.	1
Recognise the expertise of family, carers and supporters who know the person well (both unpaid and paid); work collaboratively with supporters of people with intellectual disability when developing care plans to meet the person's goals, needs and wishes for end of life care.	1
Work collaboratively to coordinate timely involvement of the Public Guardian (if appointed) in palliative care planning, including communication between the Public Guardian, the person with intellectual disability, family, carers, and supporters; when needed, educate the Public Guardian about the needs of people with intellectual disability who have life-limiting conditions.	1
Identify potential for conflict between preferences of the person with intellectual disability, family, carers, supporters, and health professionals, and act to ensure the preferences of the person with intellectual disability are central to the decision-making process.	1
Recognise that values, preferences and wishes may change over time; support an ongoing and open dialogue between the person with intellectual disability, family, carers, supporters and health professionals that aligns with the person's preferences and communication needs.	1
Provide evidence-based information about diagnosis, prognosis and management to the person with intellectual disability and their supporters in a format that can be understood by them and meets their preferences and needs.	1

Clinical strategies

Resources on communication

Intellectual Disability Health Education



Click here

idhealtheducation.edu.au/health-professionals/

Author

3DN and Council for Intellectual Disability (CID)

Description

An e-learning resource for health professionals on intellectual disability health

Type

Online learning

Just Include Me



Click here

cid.org.au/resource/just-include-me-health-elearning/

Author

CID

Description

Training for health professionals including Just Include Me, Communication Essentials, Behaviour as Communication, Reasonable Adjustments, Consent and Decision Making

Type

Online learning

Working with people with intellectual disabilities in healthcare

Click here

cddh.monashhealth.org/wp-content/uploads/2021/01/2017-working-with-people-with-intellectual-disabilities.pdf

Author

Monash Health

Description

Information for health professionals about working with people with intellectual disability including communication tips

Type

Factsheet

Clinical strategies

Communication and People with Intellectual Disabilities

Click here

hospitalinclusion.au/downloads

Author

La Trobe University

Description

Guidance on communication and people with intellectual disability

Type

Fact sheet

Communicating with people with learning disabilities

Click here

youtube.com/watch?v=TPDxa7NzLCY

Author

Surrey and Borders Partnership NHS Trust (United Kingdom - UK)

Description

A Speech and Language Therapist explains how to communicate with people with intellectual disability

Type

Video



Artwork by Ellie Rennie
Flowers in the Rain 2023

Clinical strategies

Resources on supported decision making

End of Life Law for Clinicians

Click here

palliativecareeducation.com.au/course/index.php?categoryid=5

Author

Queensland University of Technology

Description

Training program for all health professionals focusing on the law relating to end-of-life decision-making with a module on inclusive and end-of-life decision-making for diverse populations

Type

Online learning

Involving people with intellectual disabilities in end of life decisions

Click here

youtube.com/watch?v=zNPI_dXgbKA&t=244s

Author

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

Description

A webinar on facilitating supported end of life decision making for people with intellectual disability

Type

Video

The La Trobe Support for Decision Making Practice Framework Learning Resource

Click here

supportforddecisionmakingresource.com.au

Author

La Trobe University

Description

An evidence-based framework and training to guide professionals through the process of supporting people with cognitive disabilities to make decisions

Type

Online learning

Clinical strategies

Supported Decision Making Framework



Click here

cid.org.au/resource/sdm-framework/

Author

CID

Description

Guidance on facilitating supported decision making for people with intellectual disability

Type

Framework and resources

Resources to share accessible information

Palliative care services



Click here

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

Author

3DN

Description

A template to be completed by health professionals with information about local palliative care services to share with service users

Type

Plain English and Easy Read template

Palliative care resources



Click here

health.nsw.gov.au/palliativecare/Pages/easy-read-resources.aspx

Author

NSW Health

Description

Resources about palliative care to share with service users and a guide on how to use the resources for health professionals

Type

Easy Read resource and guide

Clinical strategies

Let's talk about death (VALiD)

Click here

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

Author

Palliative Care Victoria

Description

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

Type

Easy read booklets

Tailorable Easy Read health letters

Click here

cid.org.au/resource/easy-read-health-letters/

Author

CID

Description

Customisable templates for health professionals to provide accessible health information to service users for referrals, appointments, directions to clinics and medicine instructions

Type

Easy Read templates

Say less show more

Click here

aci.health.nsw.gov.au/networks/intellectual-disability/resources/say-less-show-more

Author

Agency for Clinical Innovation (ACI)

Description

A selection of simple photo stories and support materials for health professionals to use with a person with intellectual disability to explain the steps involved in common medical procedures such as a blood test

Type

Online photo stories and online learning

Clinical strategies

2. Delivery of care

Reasonable adjustments, proactive approaches to symptom management and holistic assessments should be applied and tailored to the person’s preferences.

“Don’t just assume that somebody has understood...just check in with them and make sure that there’s understanding.”

Supporter of a person with intellectual disability

“[It] was such a help having a big team involved because people get carried along on that wave...”

Health professional

“Everything was communicated back to the [person’s family member], either in writing or over the phone. The support workers were kept informed at regular meetings.”

Supporter of a person with intellectual disability

Strategy	Level of specialisation
Allocate longer appointment times for a person with intellectual disability, if needed.	1
Identify opportunities for reasonable adjustment of spaces where people receive palliative care to meet the needs of the person with intellectual disability, e.g., allocation of quiet areas for people with sensory requirements.	1
Proactively support people with intellectual disability who may be experiencing cumulative disadvantage/inequity in access to services, e.g., people from culturally and linguistically diverse backgrounds.	1
Provide continuity with individual palliative care providers, teams, and/or services so that the person with intellectual disability becomes familiar with teams and care settings.	1
Identify actual and potential barriers to end of life and palliative care services (e.g., location, disability, language/communication, socioeconomic status and culture); proactively address barriers where possible to facilitate timely access to care.	1
Establish collaborative relationships between palliative care providers, the person with intellectual disability, family, carers and supporters as early as is needed to ensure optimal care.	1

Clinical strategies

Strategy	Level of specialisation
Work collaboratively with the person with intellectual disability, family members, disability workers, and other health professionals to identify and address palliative care needs, e.g., through flexible case management.	1
Clearly communicate with family, carers and supporters to support development of realistic expectations about the person's condition and its management.	1
Ensure clear communication and documentation of end of life care plans with those providing care and support, including how plans are to be implemented.	1
Clarify roles and responsibilities of family, carers and supporters of the person with intellectual disability when determining goals of palliative care and actively support them to fulfil their roles.	1
Make reasonable adjustments in delivering end of life care to meet the needs of the person with intellectual disability, e.g., use of assisted technologies where appropriate.	1
Ensure completion of optimal assessment and pharmacological management plan; review medication (including pain management) regularly.	1
Consider the potential value of complementary therapies and support research to further develop an evidence-base.	1
Support the person with intellectual disability to participate in their chosen activities, social roles and relationships as actively as possible for as long as possible.	1
Ensure that comfort and wellbeing of the person with intellectual disability is maximised with adequate pain and symptom control.	1
Work collaboratively with the person with intellectual disability, family, carers, supporters and health professionals to determine need for carer respite services.	1
Work proactively and collaboratively with the person with intellectual disability, their supporters, and disability service providers to identify and assess potential changes in a person's support needs that may arise from a life-limiting condition.	1
Proactively identify and address potential barriers to suitability of a preferred location to receive care and/or place of death (e.g., resources required, equipped personnel available, policies and procedures at preferred locations).	1
Where a preferred setting to receive palliative care is not suitable, work collaboratively with the person with intellectual disability, family, carers and supporters to identify alternative options, with consideration of the person's physical, psychological, social, cultural, and spiritual needs.	1

Clinical strategies

Resources on working with the person and their team

Working with the person and their team



Click here

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

Author

3DN

Description

Short guidance document to support health professionals to work collaboratively with a service user with intellectual disability, their supporters and other health professionals

Type

Fact sheet

Resources on reasonable adjustments

Reasonable Adjustments

Click here

safetyandquality.gov.au/our-work/intellectual-disability-and-inclusive-health-care/reasonable-adjustments

Author

ASQHC

Description

Information on reasonable adjustments in health care with examples and further resources

Type

Website

End of Life Care Guideline Reasonable Adjustments

Click here

bild.org.uk/wp-content/uploads/2020/01/Improving-End-of-Life-Care-for-LD-Jan-2019-FINAL-1.pdf (page 6)

Author

Nottinghamshire Healthcare NHS Foundation Trust and Sherwood Forest Hospitals NHS Foundation Trust (UK)

Description

Practical guidance on reasonable adjustments to consider at palliative and end of life stages as part of a wider toolkit to ensure quality and equitable care for people with intellectual and developmental disabilities

Type

Resource pack

Clinical strategies

Further information on assistive technology

What do we mean by assistive technology?

Click here

ourguidelines.ndis.gov.au/supports-you-can-access-menu/equipment-and-technology/assistive-technology/what-do-we-mean-assistive-technology

Author

NDIS

Description

Information on assisted technology

Type

Website

Resource on improving hospital experiences for people with intellectual disability

Admission2Discharge (A2D) Together

Click here

a2d.healthcare/for-health-professionals/

Author

South Eastern Sydney Local Health District, NSW Health

Description

Information and resources for health professionals working in hospitals to improve experiences for people with a cognitive disability and their supporters including a template for palliative care

Type

Website and resources

Resource on clinical skills in end of life care

Clinical skills in end-of-life care: End-of-life Essentials

Click here

endoflifeessentials.com.au/Education-Modules/Clinical-skills-in-end-of-life-care#teams

Author

Flinders University, ASQHC

Description

Education modules for health professionals in clinical skills for end of life care

Type

Online learning

Clinical strategies

Toolkit to share with a person with intellectual disability and their supporters

Improving palliative care for people with intellectual disability - Toolkit for people with intellectual disability and their supporters



Click here

3dn.unsw.edu.au/toolkit-improving-palliative-care-people-with-intellectual-disability-supporters

Author

3DN

Description

A toolkit for people with intellectual disability and supporters with recommended resources for service users to improve palliative care

Type

Toolkit and resources

Clinical strategies

3. Preparing for death and bereavement

People with intellectual disability may have varied understanding of death and dying. Communication around the topic should be tailored based on the preferences, culture and needs of the person. This might include the use of accessible resources, such as story books, to support discussion.

All supporters, including family, unpaid and paid carers, friends and co-residents of supported accommodation should be supported during bereavement.

"Prepare [them] for what's going to happen...make sure they know all about what's going to happen in the end."

Person with intellectual disability

"...the issue around coroner's cases is often a barrier, I think staff in group homes are often scared...if the person dies in the group home...it becomes a coroner case and I think there is a stress and anxiety around that."

Health professional

Clinical strategies

Strategy	Level of specialisation
Offer accessible information and resources to support the person with intellectual disability to develop an awareness of dying, death and grief, provided this aligns with the preferences and needs of the person.	1
Proactively engage the person with intellectual disability, family, carers and supporters in conversations about dying, death and grief that are appropriately staged and paced according to illness trajectory.	1
Ensure conversations about dying, death and grief align with a person's values, cultural/religious beliefs and individual preferences, including time, location, and frequency of conversations.	1
If aligned with communication needs and preferences, use accurate language and concrete examples when talking about death; avoid euphemisms when communicating with people with intellectual disability.	1
Facilitate and support opportunities for people with intellectual disability to participate in culturally appropriate end of life activities or rituals, if desired.	1
Within scope of practice, assist the person with intellectual disability with preparing end of life legal documents (e.g., a Will), if requested; identify and engage substitute decision-makers as required.	1
Support family, carers, supporters and health professionals with education and training on talking about dying, death and grief with people with intellectual disability to ensure they are prepared to have conversations with individuals, and are equipped to identify opportunistic times for conversations.	1
Provide education and support for family, carers, and supporters (including disability support workers and supported accommodation staff) for planning for and handling of the death process that might occur at home, including strategies for comfort care, after death care, and after death processes.	1
Identify specific bereavement and support needs for family, carers, and supporters of people with intellectual disability; facilitate access to tailored grief and bereavement information and services before and/or after death of the person, including referral for ongoing support if needed.	1
Acknowledge bereavement among co-residents in supported accommodation; work with disability support workers and supported accommodation services to ensure access to appropriate and accessible bereavement support for co-residents who wish to engage with such support.	1
Work collaboratively with family, carers and supporters to support them in their involvement in coronial reviews, where required.	1
Contribute to broader efforts promoting the development of clear pathways and strategies that would support sensitive management of coronial review processes for expected deaths of people with intellectual disability.	1

Clinical strategies

Resources on communicating about death and dying

Talking End of Life...with people with intellectual disability (TEL)



Click here

caresearch.com.au/TEL/

Author

The University of Sydney, Keele University (UK) and Unisson Disability

Description

Details on how to teach people with intellectual disability about the end-of-life, designed for disability support workers but also helpful for health professionals and educators

Type

Online toolkit

How to Break Bad News to People with Intellectual Disabilities

Click here

tuffrey-wijne.com/?page_id=90

Author

Irene Tuffrey-Wijne, Professor of Intellectual Disability and Palliative Care

Description

Guidelines on breaking bad news to someone with intellectual disability

Type

Book

Resource to share with supporters

The Dying Process

Click here

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

Author

Palliative Care Australia

Description

Information to share with supporters of someone dying to help them understand, anticipate and respond to the last few weeks and days of life

Type

Online brochure

Clinical strategies

For more resources on death, dying and grief to share with the person with intellectual disability and their supporters, see the [Toolkit for people with intellectual disability and supporters](#).

Further information

Use of Euphemisms to Avoid Saying Death and Dying in Critical Care Conversations—A Thorn by Any Other Name

Click here

jamanetwork.com/journals/jamanetworkopen/fullarticle/2797041

Authors

Michael Pitt, Marissa Hendrickson and Jordan Marmet (JAMA Pediatrics, 2023)

Type

Journal article

Section 3

Part B: Organisational strategies

4. Workforce equipping and continuing professional development

Limited education and training opportunities for health and disability professionals is a barrier to provision of high quality palliative care for people with intellectual disability ^[10]. Many health professionals report not feeling confident in meeting the needs of people with intellectual disability ^[18] with minimal content in medical and nursing curriculums ^[19, 20]. Health and disability workforces should be supported to develop and apply the required knowledge and skills to support people with intellectual disability with life-limiting conditions ^(1, 18). This is important for both generalist and specialist health professionals.

"I think what would be useful for the palliative service is having access to education about how best to communicate with people [with] intellectual disability..."

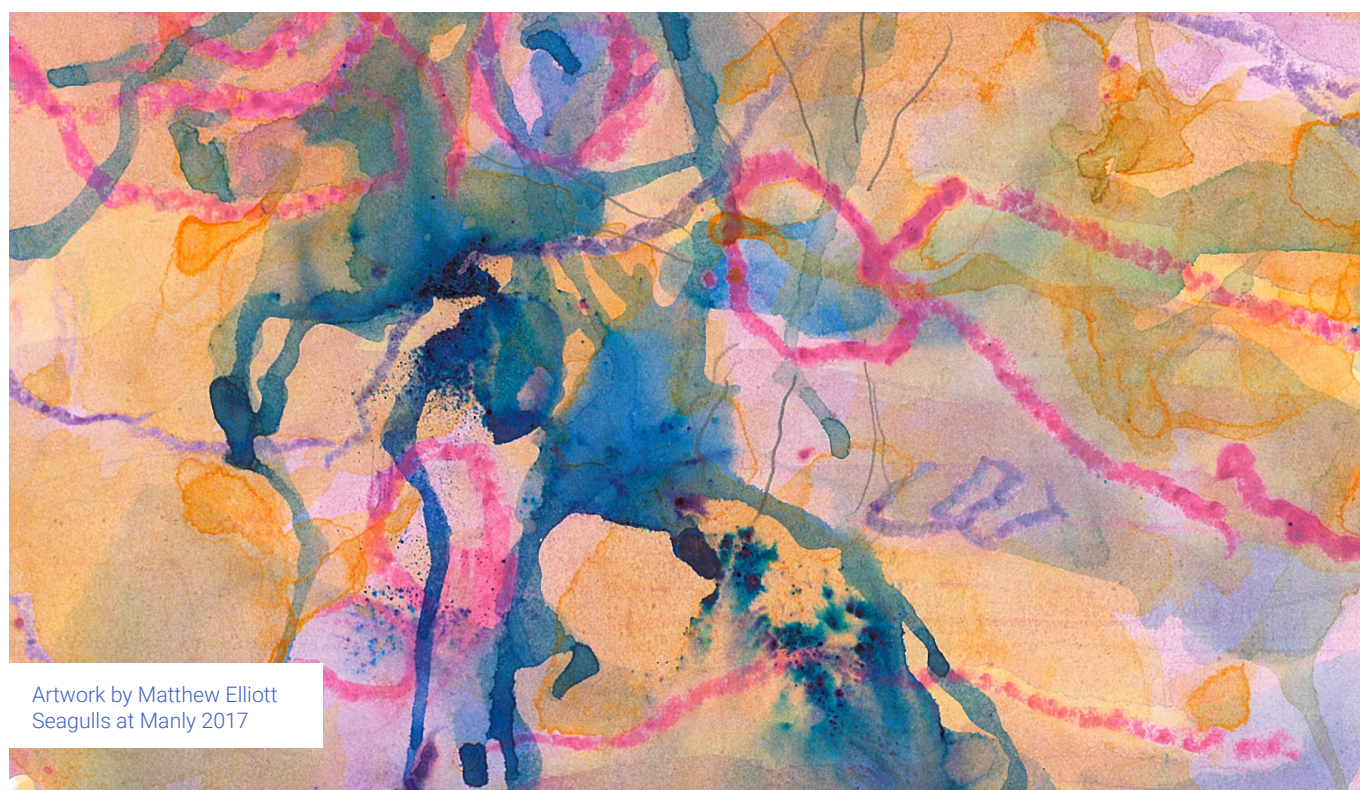
Health professional



Artwork by Cara McLean
Hazy Daisy 2023

Organisational strategies

Strategy	Level of specialisation
Ensure individuals requiring palliative care have access to a skilled and knowledgeable workforce that is aware of the palliative approach to care and has the capacity to provide such care.	1
Develop sustainable cross-training for health and disability professionals on recognising and meeting the health and support needs of people with intellectual disability who have life limiting conditions.	3
Equip health and disability professionals with resources on available referral services for people with intellectual disability and life-limiting conditions when needed, including specialist intellectual disability health and specialist palliative care services.	1
Encourage discussions about dying, death and grief among health and disability professionals as required to meet the care needs of the person with intellectual disability; recognise that staff may have different cultural and religious beliefs about these practices	1
Within scope of role, contribute to curriculum reviews of relevant vocational and university programs to promote enhanced inclusion of intellectual disability palliative care content.	3
Engage in cross-sector (e.g., health, disability, aged care) education and training to promote early recognition of and response to life-limiting conditions among people with intellectual disability.	1



Artwork by Matthew Elliott
Seagulls at Manly 2017

Organisational strategies

Training on intellectual disability

Intellectual Disability Health Education



Click here

idhealtheducation.edu.au/health-professionals/

Authors

3DN and CID

Description

Modules for health and mental health professionals on intellectual disability health including Introduction to Intellectual Disability, Improving Communication, Consent, Decision-Making and Privacy

Type

Online learning

Building capacity in NSW health services for people with intellectual disability: the Essentials



Click here

aci.health.nsw.gov.au/projects/intellectual-disability-essentials

Author

ACI

Description

A self-assessment tool to determine areas for change and resources to improve health services for people with intellectual disability

Type

Website

Healthy Dying for People with Intellectual Disability (HD4PWD)

Click here

pallcaretas.org.au/hd4pwd

Author

Palliative Care Tasmania (PCT)

Description

Practical resources to build disability and health service provider's capacity and capability

Type

Toolkit

Organisational strategies

Resources on palliative care and end-of-life

End-of-Life Essentials

Click here

endoflifeessentials.com.au/

Authors

Flinders University and ACSQHC

Description

Education modules designed to assist doctors, nurses and allied health professionals in delivering end-of-life care

Type

Online learning

End of Life Law Toolkit

Click here

eldac.com.au/Toolkits/End-of-Life-Law

Author

Flinders University

Description

Practical information about law at end-of-life such as Voluntary Assisted Dying, Capacity and Consent to Medical Treatment and Advance Care Directives

Type

Toolkit

Further information

Delivering high quality end of life care for people who have a learning disability

Click here

england.nhs.uk/publication/delivering-high-quality-end-of-life-care-for-people-who-have-a-learning-disability/

Author

NHS England (UK)

Description

Guidance for service providers and health and social care staff providing or delivering care to people with intellectual disability at the end of their lives

Type

Toolkit

Organisational strategies

5. Collaboration within and across sectors

Collaboration with health and disability professionals is essential for quality palliative care for people with intellectual disability, including clear communication and documentation of palliative care plans and working together to comprehensively address health and support needs. Collaboration helps to bridge gaps in knowledge, skills and efforts across disciplines and sectors. Benefits of collaboration include improved capacity to adapt communication, tailor care plans, provide holistic care, and provide better continuity of care.

“Where it’s worked well, it’s been a conversation between a range of people, rather than just one person making the call, making the decision”

Supporter of a person with intellectual disability

Strategy	Level of specialisation
Encourage and foster collaboration between palliative care, general health services, and specialist intellectual disability health services.	1
Establish links between health, disability and aged care services through the development of local provider networks.	3
Develop a cross-sector community of practice for professionals working with people with intellectual disability who have life-limiting conditions; include frontline and managerial staff to promote development of actions and responses to issues raised.	3
Create a mutually agreeable mechanism for shared understanding of palliative care plans of a person with intellectual disability (including resuscitation plans) among family/guardians, supported accommodation staff, health services and emergency responders, e.g., through easily transferrable electronic medical records.	1
Develop flexible care pathways to support transitions between care settings (including home); engage with relevant existing transition care services to support this process.	1

Organisational strategies

Resources

Working with people with intellectual disability and their team



Click here

idmhconnect.health/i-am-professional/working-people-intellectual-disability-and-their-team

Authors

3DN and CID

Description

Information about working collaboratively with other services and agencies including considerations for working with specific services and tools to assist collaboration. This resource has been developed specifically for mental health however information may be helpful for palliative care.

Type

Website with resources

HELP

Click here

healthyendoflifeprogram.org

Author

Healthy End of Life Program (HELP)

Description

HELP aims to build the capacity of sectors, organisations, and communities to deliver a public health approach to end-of-life care

Type

Program and App

Further information

Palliative Care for People with Learning Disabilities (PCPLD) Network

Click here

pcpld.org/events-and-conferences

Description

Events, conferences, webinars and podcasts set up to bring together service providers, people with intellectual disability and supporters to support coordinated care

Type

Website

See information about the ACI: [Intellectual Disability Network](#) in the next section.

Organisational strategies

6. Service design

Innovation in service delivery can address the barriers for people with intellectual disability to access quality palliative care. Important themes to consider in service design for implementation include training for professionals, dissemination activities and collaboration with other organisations ^[21].

“Ideally it’s allowing people to be in their own communities, their own homes, as much as possible”
 Health professional

Strategy	Level of specialisation
Develop the role of a specialist palliative and end of life care service for people with intellectual disability.	3
Establish and adequately fund palliative care service navigators or care coordinators to facilitate access to palliative care for people with intellectual disability living in metropolitan, rural and remote areas.	3
Develop clear pathways for supported decision making that include people who do not have an identifiable supporter who can contribute to medical decision making.	1
Build capacity for flexible care delivery (e.g., home visits/in-reach, use of technology and virtual care where appropriate) tailored to the needs that are to be met.	1
For people living in supported accommodation, establish flexible access to appropriate prescribers to ensure timely provision and administration of required medications in partnership with primary and community health care providers.	1
Determine feasibility of establishing a network of trained peer supports (paid and unpaid) to work with family, carers and supporters of a person with intellectual disability at end of life; if feasible, offer to connect peer supports with family, carers and supporters who feel they may benefit from this type of service (before and/or after death of the person they are supporting).	3

Organisational strategies

Training

Just Include Me – Virtual Care

Click here

cid.org.au/resource/just-include-me-health-elearning

Author

CID

Description

Online self-paced training for health professionals with a module on virtual care

Type

Online learning

Further information

Agency for Clinical Innovation (NSW)

Click here

aci.health.nsw.gov.au

Author

ACI

Description

Information about the lead agency for innovation in clinical care in NSW. Clinical Networks include: [Intellectual Disability Network](#) and End of Life and [Palliative Care Network](#).

Type

Website



Artwork by Cara McLean
Hazy Daisy 2023

Organisational strategies

7. Service planning, quality and improvement activities

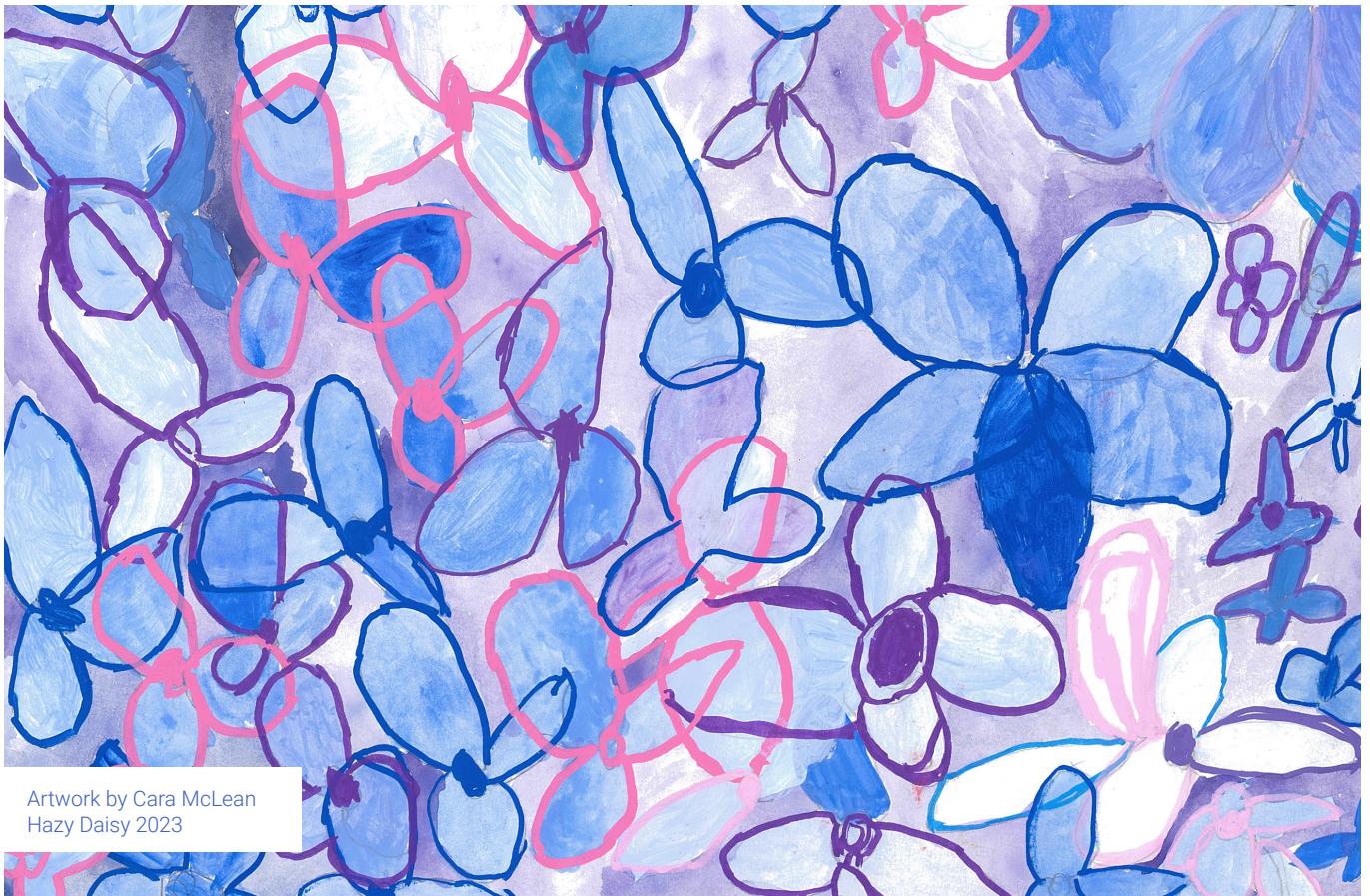
When service planning, quality and improvement activities include consultation with key stakeholders, care can be better tailored to the needs of the people it involves.

"You need extensive collaboration with key stakeholders to nut it out and have it work effectively."

Health professional

"There needs to be evidence that things are working"

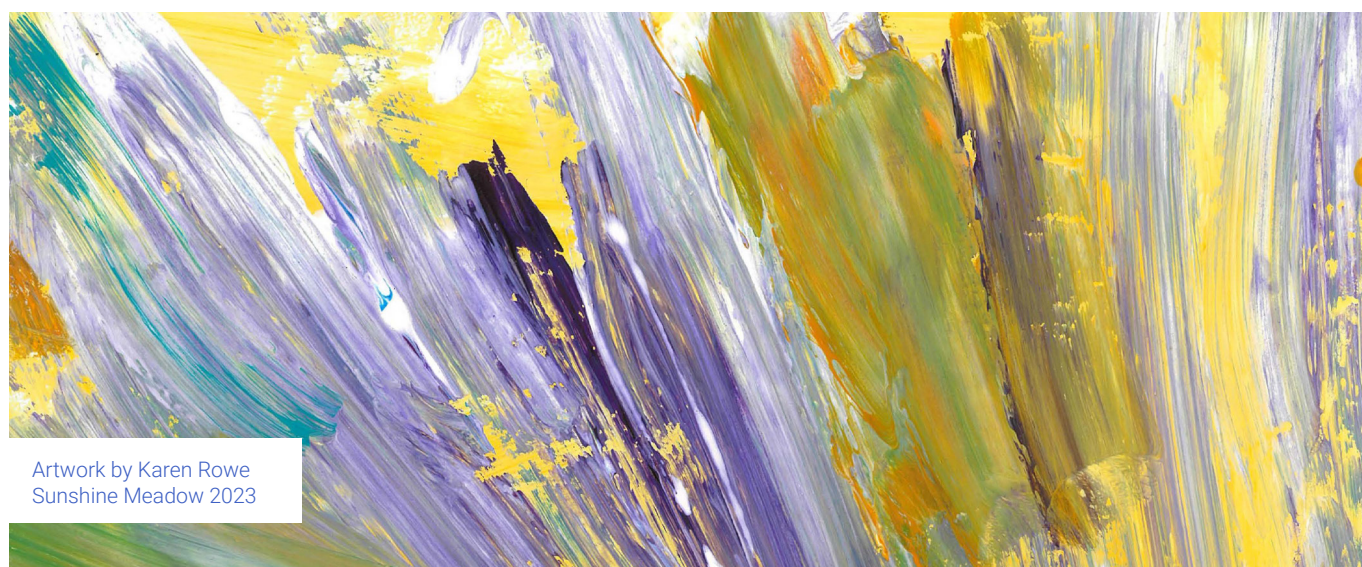
Health professional



Artwork by Cara McLean
Hazy Daisy 2023

Organisational strategies

Strategy	Level of specialisation
Actively engage people with intellectual disability, their family, carers and supporters in co-design of palliative care quality improvement activities.	2
Ensure palliative care service development initiatives include strategies to address the needs of First Nations peoples.	2
Ensure palliative care service development initiatives proactively consider access for people living in rural, regional and remote areas, and in all residential settings (e.g., family home, supported accommodation, residential aged care, and prisons).	2
Ensure that people with intellectual disability are not discriminated against and are able to access suitable support, as any other member of the community would be, when approaching end of life.	1
Establish a mechanism to identify people with intellectual disability within existing clinical data collections (e.g., the Palliative Care Outcomes Collaboration) that would enable benchmarking of palliative care service provision and outcomes for people with intellectual disability.	2
Establish and build on an evidence-base, drawn from both health and disability sectors, to determine best practice approaches to care (including from the perspectives of people with lived experience); ensure appropriate synthesis, interpretation and dissemination of information.	3



Artwork by Karen Rowe
Sunshine Meadow 2023

Organisational strategies

Resources on consultation and engaging stakeholders

Engagement and consultation with people with intellectual disability

Click here

inclusionaustralia.org.au/resource/engagement-and-consultation-with-people-with-an-intellectual-disability

Author

Inclusion Australia

Description

Guidance on engaging with people with intellectual disability in an accessible way for researchers and consultants developing projects

Type

Guide

Engaging stakeholders

Click here

nhmrc.gov.au/guidelinesforguidelines/plan/engaging-stakeholders

Author

National Health and Medical Research Council (NHMRC)

Description

Guidance on engaging stakeholders including useful resources

Type

Website

Resource on service planning

Palliative Care Service Development Guidelines

Click here

palliativecare.org.au/publication/quality/

Author

Palliative Care Australia

Description

Guidance on expectations for palliative care services in Australia including workforce and system capabilities

Type

Guidelines

Organisational strategies

Resources on service evaluation

Tailored model of palliative care for people with intellectual disability



Click here

3dn.unsw.edu.au/tailored-model-palliative-care

Author

3DN

Description

Included in this document are proposed outcome measures for the model covering measures of service response to needs, clinical patient measures, patient (or proxy) reported measures, supporter reported measures and clinician reported measured

Type

Model of care

Tailorable Easy Read health letters

Click here

cid.org.au/resource/easy-read-health-letters

Author

CID

Description

Customisable templates for health professionals to provide accessible information to collect service feedback

Type

Easy Read templates



Artwork by Angela De Marinis
Garden on a Rainy Day 2024

Organisational strategies

The following Tools may be useful to measure outcomes recommended by the [Tailored model of care](#)⁵:

Disability Distress Assessment Tool (DisDAT)

Click here

stoswaldsuk.org/how-we-help/we-educate/education/resources/distress-and-discomfort-assessment-tool-disdat

Description

Information and DisDAT tool ^[22] to identify and understand distress and its causes for people who communicate in ways other than speech

Type

Assessment Tool

My Pain Profile

Click here

nottinghamshire.eolcare.uk/content/my-pain-profile

Author

Nottinghamshire NHS (UK)

Description

A tool based on the Abbey pain scale ^[15] to use with the person with intellectual disability to assess pain and techniques for pain management

Type

Assessment Tool

Pain Assessment in Advanced Dementia Scale (PAINAID)

Click here

aci.health.nsw.gov.au/_data/assets/pdf_file/0017/212921/Pain-assessment-advanced-dementia-scale.pdf

Description

A tool to measure pain by scoring behaviour by observation ^[23]

Type

Assessment Tool

⁵ These tools are not all tailored for use with people with intellectual disability.

Organisational strategies

Further information

First Peoples Disability Network (FPDN)

Click here

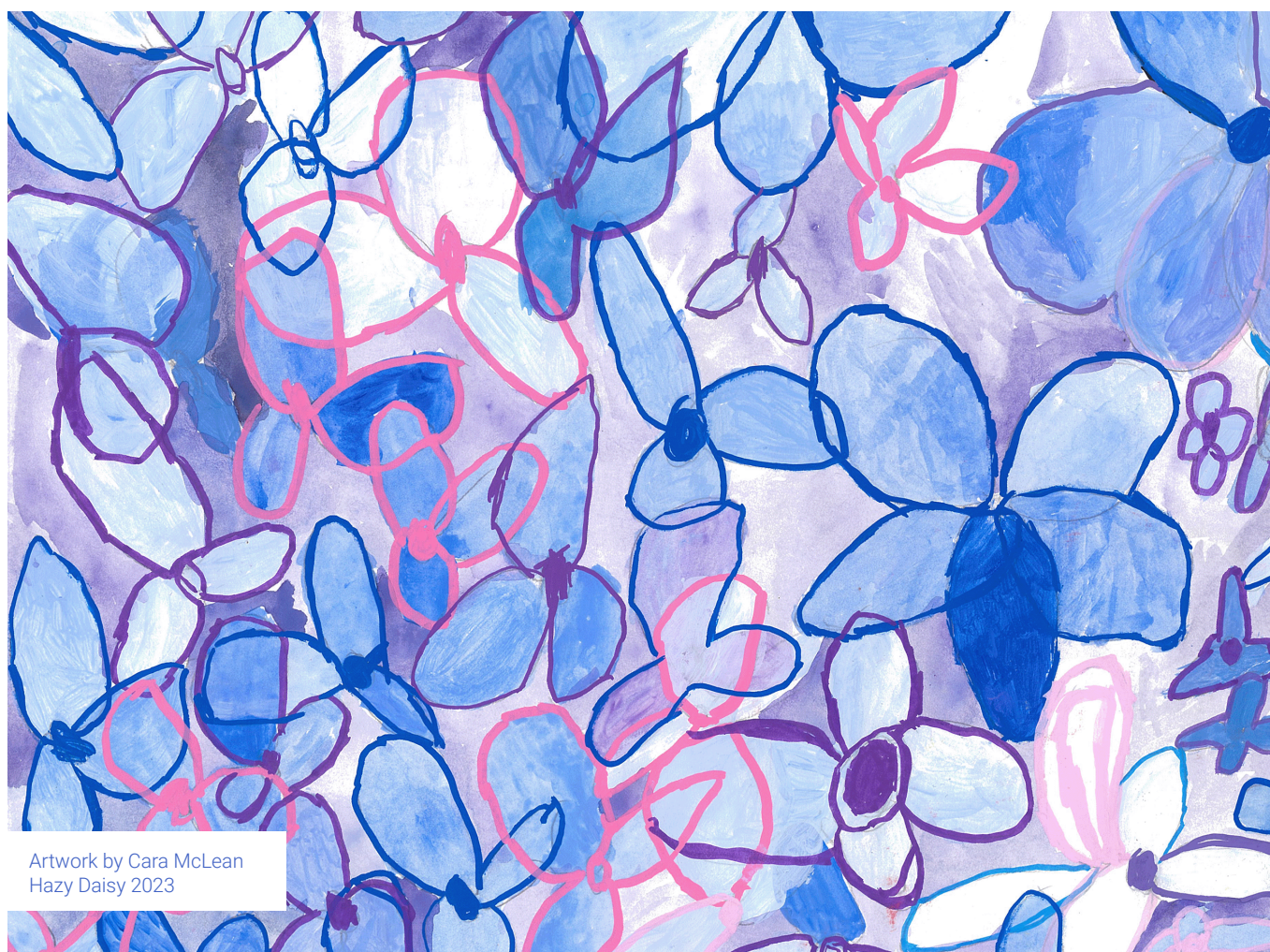
fpdn.org.au

Description

Information about a national organisation of and for Australia's First Peoples with disability, their families and communities

Type

Website



Artwork by Cara McLean
Hazy Daisy 2023

Organisational strategies

8. Advocacy

Contribution to advocacy efforts and national guidelines are crucial to support system-level change for improving palliative care for people with intellectual disability.

Strategy	Level of specialisation
Contribute to advocacy efforts for more inclusive social policies to ensure individuals with intellectual disability have access to appropriate palliative care and supports at end of life.	3
Contribute to advancement of a nationally consistent implementation of supported decision making.	3
Contribute to advocacy efforts promoting partnership between health and disability sectors, including appropriate funding and development of governance structures required to support a transdisciplinary approach to palliative care for people with intellectual disability.	3
Contribute to advocacy efforts promoting recognition of high intensity support needs of people with intellectual disability and life-limiting conditions and highlight the need for timely, flexible, and appropriate funding to respond to increasing support needs.	3



Artwork by Matthew Elliott
Seagulls at Manly 2017

Organisational strategies

Further information

Palliative Care Australia – Members

Click here

[Palliativecare.org.au/members](https://palliativecare.org.au/members)

Description

Membership information for involvement in national and state policy and advocacy for the national peak body for palliative care

Type

Website

Inclusion Australia

Click here

inclusionaustralia.org.au

Description

The national voice for people with intellectual disability and their families

Type

Website

Council for Intellectual Disability

Click here

cid.org.au

Description

A disability rights organisation led by people with intellectual disability

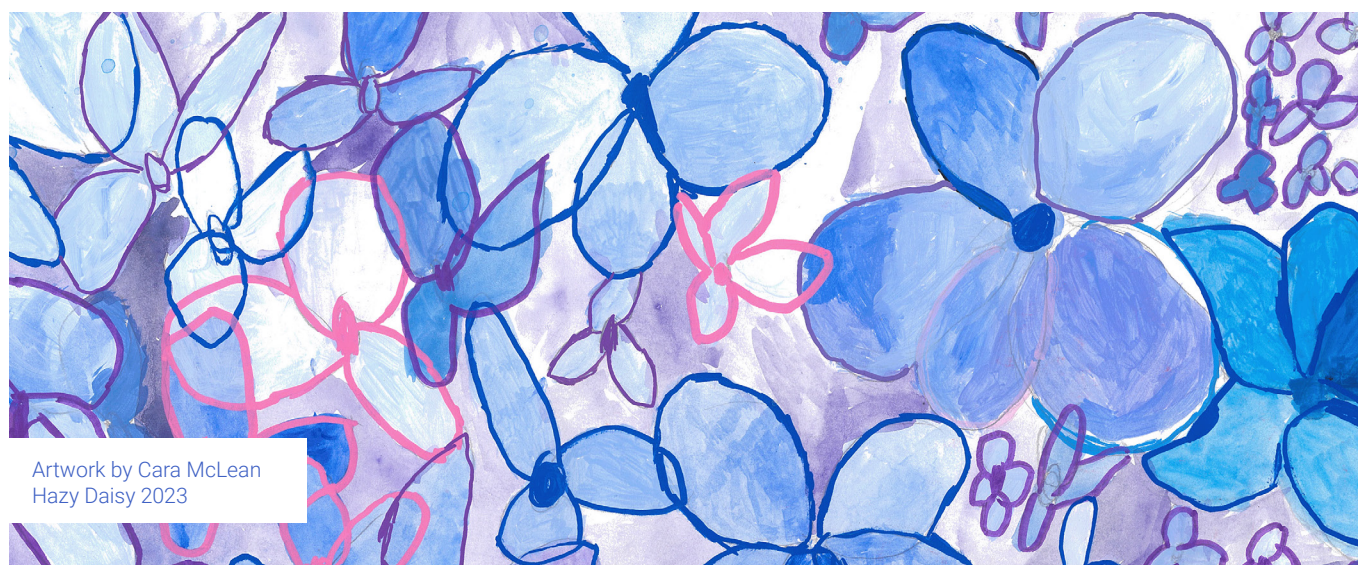
Type

Website

Definitions of key terms

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 ^[9] .
Generalist palliative care	A type of care for people living with a life-limiting illness provided by health professionals with general knowledge and minimum core competencies in palliative care ^[24] .
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 ^[25]
Integrated care	The provision of seamless, effective, and efficient care that reflects the whole of a person's health needs from prevention through to end of life, across both physical, psychosocial, and mental health and in partnership with the individual, carers, and family members ^[26] .
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 neurone disease, end-stage kidney disease and dementia ^[9] .
Multidisciplinary team	A team made up of at least one patient and multiple health professionals from different disciplines working together to address multiple aspects of a patient's care ^[27] .

Term	Definition
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 ^[8] .
Peer support	Emotional, social, and practical assistance provided by non-professionals to encourage behaviours such as healthy diets or medication adherence ^[28] .
Person-centred care	Care that respects and responds to the needs, values and preferences of a patient ^[32] .
Specialist palliative care	A type of care for people living with a life-limiting illness provided by health professionals with specialised skills and training in palliative care. The person living with a life limiting illness may have more complex needs that may not be met by generalist palliative care ^[24] .
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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Project Advisory Group and external reviewers

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Artwork



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