Living and dying well for people with disability:

palliative and end of life care knowledge framework

phn
BRISBANE NORTH
An Australian Government Initiative

Acknowledgements

The Working Group developed this framework from May 2023 to February 2024.

Working group members:

- Andrea Coe, Blue Care
- Caroline Irle, Brisbane North PHN
- Caroline Kerr, Karuna Hospice
- Danielle Mason, Community Resource Unit (CRU)
- Elham Day, Hummingbird House
- Jason McKay, National Disability Services (NDS)
- Dr John Rosenberg, University of the Sunshine Coast
- Karen Atkinson, CPL- Choice, Passion, Life
- Kathy Carmichael, McArthur Community Care
- Margaret Rodgers, Community Resource Unit (CRU)
- Tracey Shaw, National Disability Services (NDS)
- Yody Espitia, Palliative Care Queensland

We thank Dr Andrea Grindrod, Director of La Trobe University's Public Health Palliative Care Program, for her generous time and for permission to use the *Disability and Palliative Care Intersectoral Partnership Framework* [1].

We also thank everyone who gave feedback and helped us to develop and improve this framework.

We thank Zoe du Cann at *Easy To Read* for translating the framework into plain language including user testing, and for providing advice.

This activity was supported by funding from the Department of Health and Aged Care under the Greater Choice for At Home Palliative Care measure.

Terms Used

Disability

Disability is when a person's condition leads to

- impairment
- activity limitation or
- restrictions in participation[2].

Impairment means loss or differences in the functions of the body. Activity means being able to do tasks and actions. Participation means taking part in everyday life. Limitations and restrictions may be because of environmental factors. These factors include the physical environment, social situations, and cultural factors.

Palliative care supports quality of life for people who have a life limiting condition. Palliative care helps the person to live well for as long as possible. This care involves meeting all the person's needs: physical, psychological, social, and spiritual. People with disability might get this care for many years before death. All health and disability workers provide palliative care; this is called generalist palliative care. Specialists provide specialised palliative care to people with complex needs.

End-of-life care is a part of palliative care. It is the care a person gets in the last twelve months of their life. This includes active dying, as well as death and grief. Active dying is the last days or week of life. During this time there are end-of-life symptoms such as periods of unconsciousness, or changes in breathing or skin colour.

Carer means a family member or another person who cares for a person with disability. A carer may support a person with disability over many years. Some carers are unpaid. Other carers may be paid (for example, a carer payment through Centrelink).

Care providers are people who are employed to support the person with disability, their carers, and significant others. This includes support workers, personal care workers, nurses, allied health professionals and doctors.

Compassionate communities are communities where people support each other during dying, death, and grief. Each community member plays an active role. They communicate well and support each other in practical ways[3].

Grief is a natural feeling in response to loss. A loss can be a death, or it can be other life changes like getting a diagnosis or not being able to do things for yourself.

Bereavement is grief from losing someone important, like a family member or friend.

Curative treatment is medical treatment to cure a disorder or illness.

Contents

Why was this framework created?

In 2022, health and disability workers told us they did not know enough about palliative and end-of-life care for people with disability. Roles and responsibilities were not clear, and there was no guide to education and training opportunities. Without this knowledge, people with disability who need palliative care may not get the right care, at the right time, in the right place.

How was this framework made?

We made the first version using information from research. We improved it through four rounds of feedback (see Figure 1). We will keep improving it based on feedback from people using it in real life.

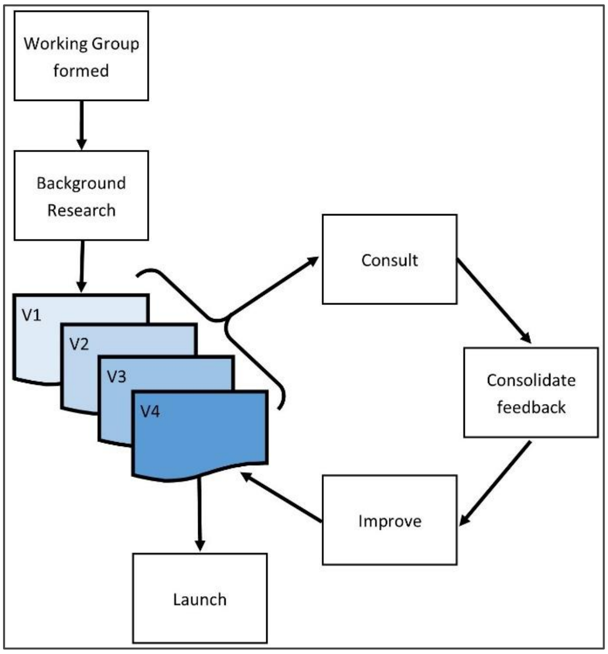


Figure 1: Framework development.

Who helped us make this framework?

Over five months, we asked 218 people for their thoughts about this framework. Seventy-seven people gave feedback through writing, interviews, and group discussions. These 77 people included:

- People with disabilities and their carers
- Disability and palliative care organisations
- Disability service providers
- Disability accommodation providers
- Specialist palliative care services
- Community palliative care services
- Services that support people with disabilities in hospitals and health
- Aboriginal and Torres Strait Islander services
- General practitioners
- Government departments
- Academics and researchers.

Purpose

The purpose of this knowledge framework is to:

- Describe the knowledge that care providers need when they support people with disability though their palliative and end-of-life journey.
- Share education and training resources for people working in disability and health.

Scope: Who is this for and what does it cover?

This framework is for care providers who support people of any age with any disability and life-limiting conditions.

It covers the time from diagnosis to bereavement (see figure 2).

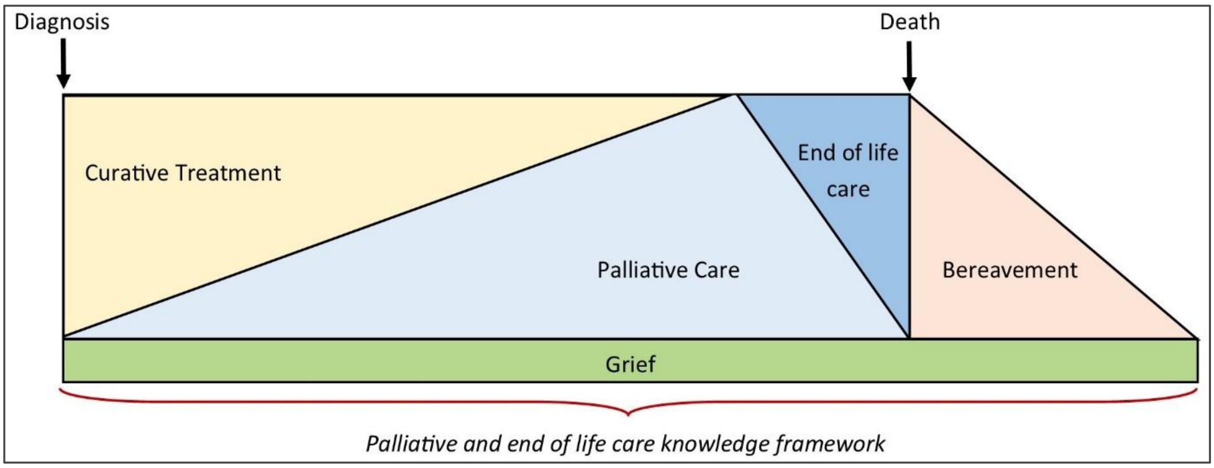


Figure 2: Life period covered by the framework.

This framework provides base level knowledge and is not specialised.

Palliative and end of life care are not simple topics. Individuals should be supported by their organisations to use the framework as an educational tool build their knowledge.

Scope of practice

- Health professionals offer support within their scope of practice. This is determined by the Australian Health Practitioner Regulation Agency (AHPRA) or their professional peak body for non-AHPRA registered professionals.
- The scope of disability workers is defined by the National Disability Insurance Scheme (NDIS) and by their employer’s guidelines.
- The influence of care settings on the scope of practice is not considered.

This framework does not include Voluntary Assisted Dying (VAD). You can find more information about VAD in the Useful Links section.

Underpinning Principles

1. Dying, death, grief, and bereavement are part of life.

2. People with disability have a right to life, to have the value of their life recognised, and to make choices about their lives and deaths.

3. Individuals are respected and supported in making decisions about their lives.

4. The person, their carers, family, friends, and all care providers have a role to play in palliative care. Each contribution is important and respected.

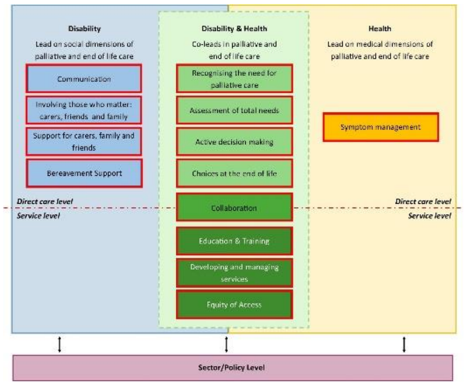
5. Quality care is accessible, acceptable, fair, based on evidence, and supported by a skilled team of different professionals.

6. Care is holistic and integrated to provide continuous support for people with disability, their carers, family, and friends.

7. Palliative care is everybody’s responsibility in a compassionate community. Each person has a role in supporting people with caregiving, dying, death, loss, and bereavement.

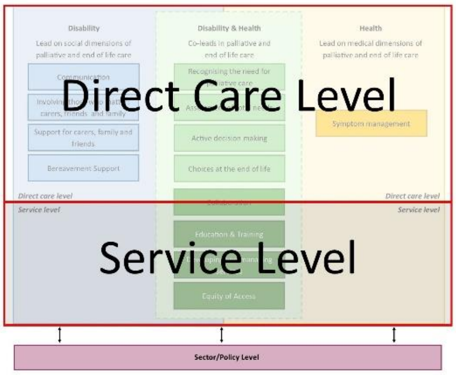
The Framework

The framework consists of:



13 Knowledge Domains

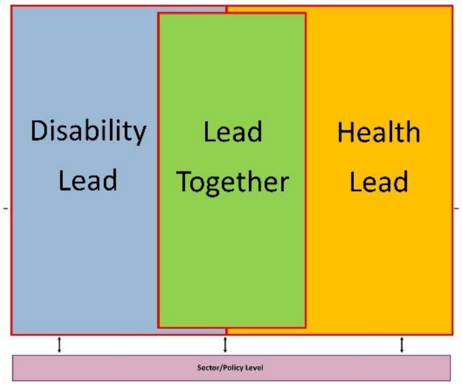
Domains are the topics of knowledge.



Two Levels

- "*Direct Care*" level apply to the knowledge used when supporting an individual.
- "*Service*" level domains apply to the management of organisations and services.

Collaboration is the only knowledge domain that applies to both levels.

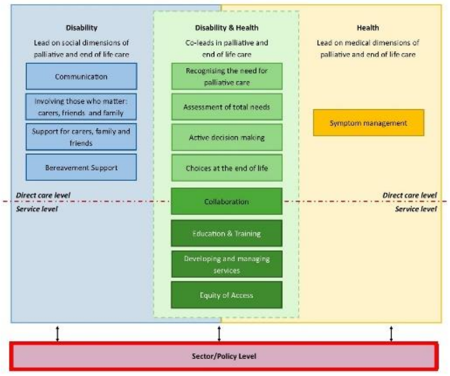


Leads

This is the sector that takes responsibility for coordinating the domain.

- **Disability**- lead the social aspects of palliative and end of life care.
- **Health**- lead the health aspects of palliative and end of life care.
- **Co-lead**- aspects which require working together.

All care providers should be aware of all knowledge domains.



Sector and policy level

This level represents authorities, legislation, government policy, programs, and strategies.

It is included in the framework to acknowledge that practice is influenced by, and will influence, sector and policy level.

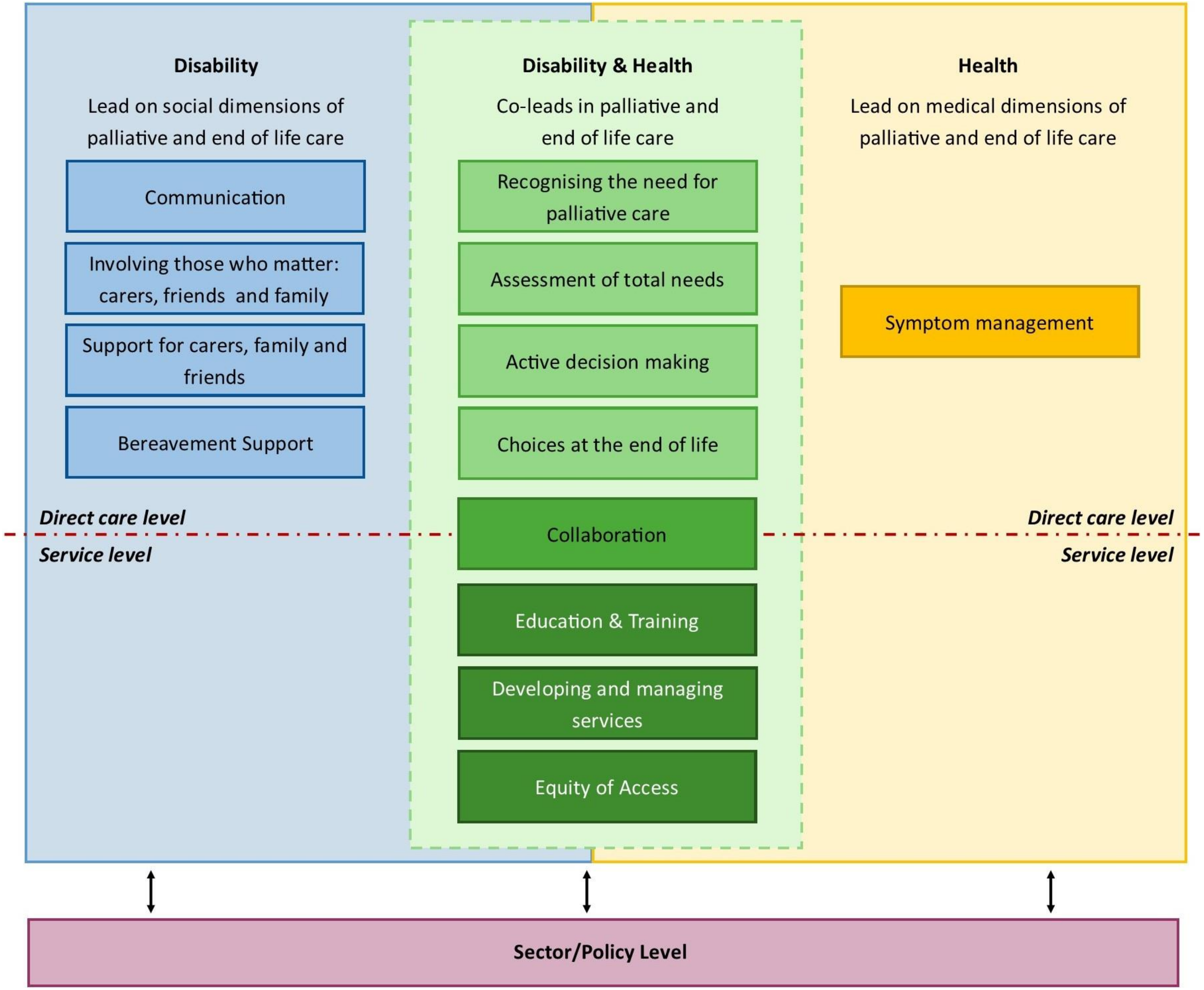
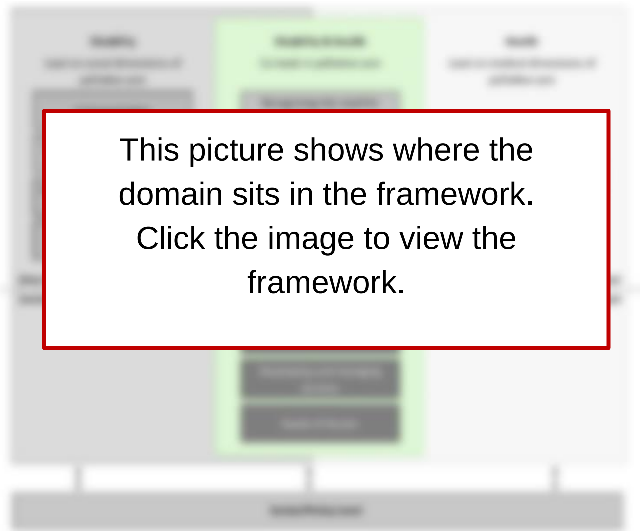


Figure 3: Palliative and end of life care knowledge framework.

Knowledge Domains

The following section provides detail about each knowledge domain. The format is as follows:

[Domain Name]



This picture shows where the domain sits in the framework. Click the image to view the framework.

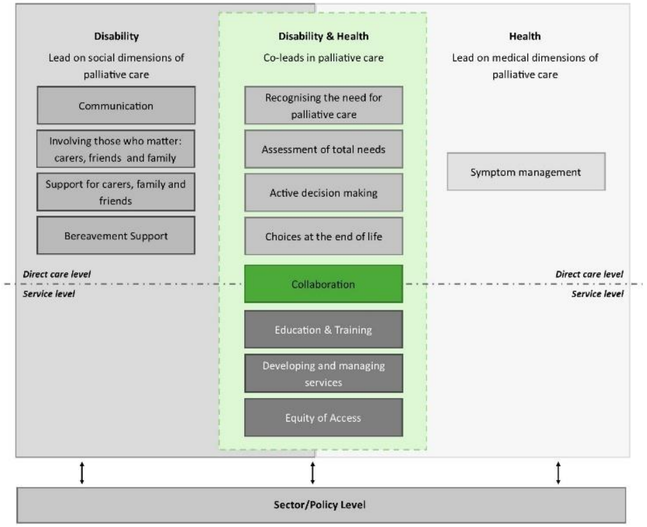
Lead:	The care provider who takes responsibility for the domain.
Level:	Whether domain relates to "Direct Care" or "Service" level.
Norm statements:	Describes the standard of care that should be given to everyone routinely (or "as normal").
Knowledge statements:	Lists what care providers need to know to give the care described in the Norm statements.

Build your knowledge in **[Domain]**:

Available Options	**Related Knowledge Statement**			
		2	**3**	**4**
Example, example text				
Example 2, example text		■		
Example 3, example text			■	
Example 4, example text				■

This table lists the available education, training, and learning resources available to build knowledge.

Collaboration

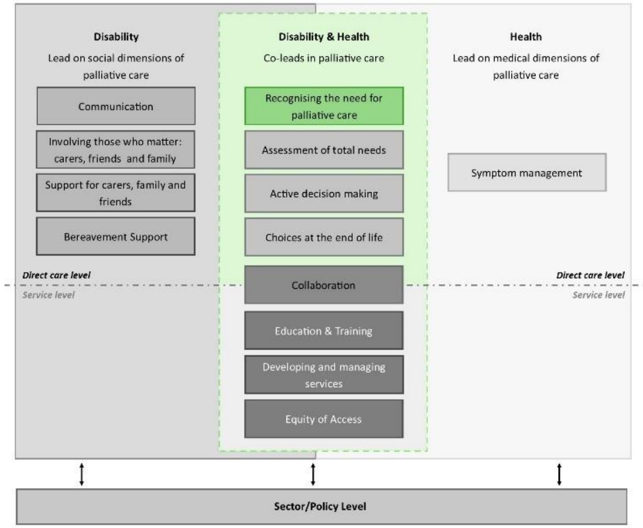


Lead:	Disability & Health
Level:	Direct care & Service
Norm statements:	• Different services need to work together to provide palliative and end-of-life care to people with disability. • Palliative and end-of-life care providers should be identified as early as possible and involved when they are needed. This can include professional services, care providers, carers, and spiritual leaders. • People with disabilities should be able to see medical and nursing professionals when they need to. This includes specialist palliative care services if needed. • Everyone involved should work together and share what they know to help the person with disability.
Knowledge statement: *(direct care)*	1. I understand my role in supporting palliative and end of life care. 2. I know how others in the team can support palliative and end-of-life care. 3. I know about local palliative and end-of-life support services, including specialist services. 4. I know how services work together, and how report and resolve issues if they happen.
Knowledge statement *(service level)*	A. We have policy, procedures and systems that support positive collaboration with other care providers. B. We know and strive to foster collaborative working relationships with other care providers in our local area.

Build your knowledge in **Collaboration**:

Available Options	**Related Knowledge Statement**					
	1	**2**	**3**	**4**	**A**	**B**
Why is this important Talking End of Life with people with intellectual disability (TEL)	🟩					
Cultural Beliefs Talking End of Life with people with intellectual disability (TEL)	🟩					
Managing feelings Talking End of Life with people with intellectual disability (TEL)	🟩					
Your role as a DSP Talking End of Life with people with intellectual disability (TEL)	🟩					
Handy teaching skills Talking End of Life with people with intellectual disability (TEL)	🟩					
Dying Talking End of Life with people with intellectual disability (TEL)	🟩					
The importance of coordination patient care, End of Life Essentials	🟩	🟩				
Topic 1: Multidisciplinary Care, Palliative Care Curriculum for Undergraduates (PCC4U)		🟩				
Enrolled Nurse toolkit Palliative Care Curriculum for Undergraduates (PCC4U)	🟩					
Care Worker toolkit Palliative Care Curriculum for Undergraduates (PCC4U)	🟩					
palliLEARN: Your role in a compassionate community, Palliative Care Queensland	🟩					
PEPA Placement Program of experience in the palliative approach (PEPA)		🟩				
Reverse PEPA Placement Program of experience in the palliative approach (PEPA)	🟩					🟩
Primary Care Toolkit End of Life Directions for Aged Care (ELDAC)		🟩				
Home Care Toolkit End of Life Directions for Aged Care (ELDAC)		🟩				
Dementia Toolkit End of Life Directions for Aged Care (ELDAC)		🟩				
Brisbane and Queensland Communities of Practices, Collaboratives, and peer groups			🟩			🟩
Support for Palliative Care, Brisbane North PHN			🟩			
Your employer/organisation policies, procedures, protocols, and documents				🟩	🟩	🟩

Recognising the need for palliative care



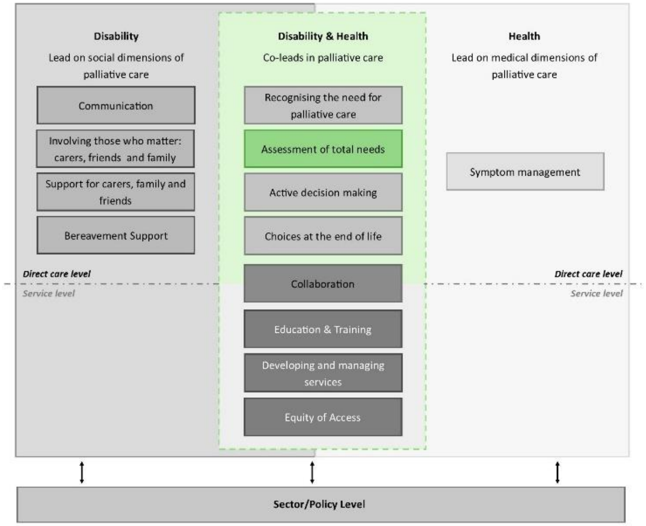
Lead:	Disability & Health
Level:	Direct care
Norm statements:	• Health and social care professionals must be able to tell when people with disability need palliative and end-of-life care. This includes people living at home, in institutional settings, or single and shared community homes. • Care providers must be aware of the signs and symptoms of serious illness, end of life, and the dying phase. • When someone needs palliative care, a person-centred palliative care or end-of-life plan should be put in place. This plan should work together with their existing care plans and goals.
Knowledge statement:	1. I know what palliative and end-of-life care means. I understand the difference, and when each is needed. 2. I can recognise the signs and symptoms of someone at the end of life. 3. I understand my role in supporting palliative and end-of-life care. 4. I know the role of other team members in supporting palliative and end-of-life care. 5. I know how to start providing palliative and end-of-life care. I know how to include this in an individual’s care plan in my work environment.

Build your knowledge in **Recognising the need for palliative care**:

Available Options	**Related Knowledge Statement**				
	1	**2**	**3**	**4**	**5**
Understanding care at the end of life, Queensland Health Care at the end of life	🟩				
New to Palliative care, CareSearch	🟩				
What is palliative care?, CareSearch	🟩				
Understanding the palliative care needs of intellectually disabled people, CareSearch	🟩				
Palliative Care: Getting Started, Centre for Palliative Care	🟩				
Primary Care Toolkit, ELDAC	🟩			🟩	
Home Care Toolkit, ELDAC	🟩			🟩	
Dementia Toolkit, ELDAC	🟩			🟩	
Information for Indigenous health workers wanting to know about palliative care, IPEPA	🟩				
Module 1: Principles, PCC4U	🟩	🟩			
Module2: Communication, PCC4U	🟩				
Module 3: Assessment, PCC4U	🟩				
Module 4: Optimisation, PCC4U	🟩				
palliLEARN: What is palliative care, Palliative Care Queensland	🟩				
Last Aid, Palliative Care Queensland	🟩				
Learning Guide for Allied Health Professionals, PEPA	🟩				
Learning Guide for Disability Support Workers, PEPA	🟩				
Learning Guide for Medical Practitioners, PEPA	🟩				
Learning Guide for Nurses, PEPA	🟩				
Dementia Specific Training for Careworkers, The Advance Project	🟩				
Pathway 4: When the person is dying CarerHelp		🟩			
Pathway 2: Caring for a person who is finishing up, CarerHelp		🟩			
End of Life Symptoms, CareSearch		🟩			

Available Options	**Related Knowledge Statement**				
	1	**2**	**3**	**4**	**5**
Dying, a normal part of life, End of Life Essentials		🟩			
Recognising the end of life, End of Life Essentials		🟩			
Caring for mob at the end of their life, IPEPA		🟩			
Dying, Talking End of Life with people with intellectual disability (TEL)		🟩	🟩		
Death, Talking End of Life with people with intellectual disability (TEL)		🟩			
Enrolled Nurse toolkit, PCC4U			🟩		
Care Worker toolkit, PCC4U			🟩		
palliLEARN: Your role in a compassionate community, Palliative Care Queensland			🟩	🟩	
Reverse PEPA Placement, PEPA			🟩		
Why is this important, Talking End of Life with people with intellectual disability (TEL)			🟩		
Cultural Beliefs, Talking End of Life with people with intellectual disability (TEL)			🟩		
Managing feelings, Talking End of Life with people with intellectual disability (TEL)			🟩		
Your role as a DSP, Talking End of Life with people with intellectual disability (TEL)			🟩		
Handy teaching skills, Talking End of Life with people with intellectual disability (TEL)			🟩		
The importance of coordination patient care, End of Life Essentials				🟩	
Topic 1: Multidisciplinary Care, PCC4U				🟩	
PEPA Placement, PEPA				🟩	
Your employer/organisation policies, procedures, protocols, and documents					🟩

Assessment of total needs

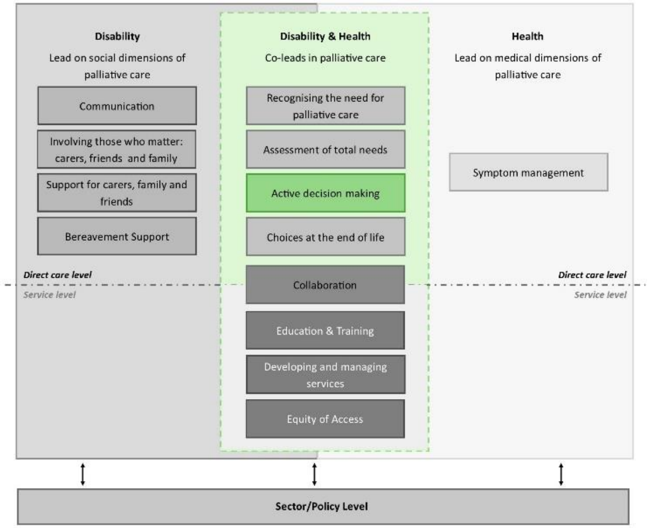


Lead:	Disability & Health
Level:	Direct care
Norm statements:	• People with disabilities have the same palliative and end-of-life needs as everyone else. These include physical, emotional, social, and spiritual needs. • A person's physical, psychological, social, cultural, and spiritual needs must be regularly assessed. We should also document and evaluate them, and review how well these needs are being met. • People with disability may need extra support to meet their needs because of their disability or changes in their health. Everyone involved in the person's care should work together to address this. • People with disability should have equity of access to support for their needs. This includes access to counselling services that fit their needs. It also includes maintaining social connections and friendships.
Knowledge statement:	1. I understand that everyone has physical, emotional, social, cultural, and spiritual needs. People with disability may need extra support to have their needs met. 2. I understand how needs are assessed, recorded, addressed, monitored, and reviewed in my organisation. 3. I understand my role in assessing, addressing, and watching over needs. 4. If a person's palliative needs are not documented or recognised, I know who can help with this.

Build your knowledge in **Assessment of total needs**:

Available Options	**Related Knowledge Statement**			
	1	**2**	**3**	**4**
Living with a terminal illness, Queensland Health Care at the end of life	🟩			
Primary Care Toolkit, ELDAC	🟩			
Home Care Toolkit, ELDAC	🟩			
Dementia Toolkit, ELDAC	🟩			
What do people with serious illness need? IPEPA	🟩			
Module 1: Principles, PCC4U	🟩			
Module2: Communication, PCC4U	🟩		🟩	
Module 3: Assessment, PCC4U	🟩		🟩	
Enrolled Nurse toolkit, PCC4U	🟩			
Care Worker toolkit, PCC4U	🟩			
Cultural Beliefs, Talking End of Life with people with intellectual disability (TEL)	🟩		🟩	
Last Aid, Palliative Care Queensland	🟩			
Your employer/organisation policies, procedures, protocols, and documents		🟩		🟩
Module 4: Optimisation, PCC4U			🟩	
palliLEARN: Palliative Caring: planning in 5 steps, Palliative Care Queensland			🟩	
Managing feelings, Talking End of Life with people with intellectual disability (TEL)			🟩	
Dementia Specific Training for Careworkers, The Advance Project			🟩	
Dementia Specific Training for Clinicians and Managers, The Advance Project			🟩	

Active decision making

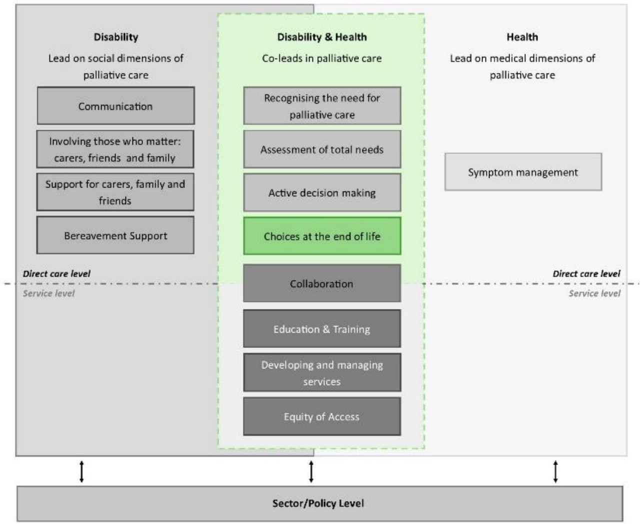


Lead:	Disability & Health
Level:	Direct care
Norm statements:	• Palliative and end-of-life care decisions are complex. • People with disability should have support to be part of palliative care and end-of-life decisions. This includes support and advocacy to allow people to speak for themselves. • Different places have different laws about who can make decisions. Care providers should know and follow national laws and laws in their area. • We should assume that people with disability can make decisions unless there is proof that they can't.
Knowledge statement:	1. I understand capacity, self-determination, agency, and advocacy in decision making. 2. I am aware of the relevant laws and rules. 3. I understand how to support people with disability to make decisions about palliative and end-of-life care.

Build your knowledge in **Active decision making**:

Available Options	**Related Knowledge Statement**		
	1	**2**	**3**
Advance care planning, Queensland Health Care at the end of life	🟩	🟩	
People living with a disability, Queensland Health Care at the end of life	🟩	🟩	
End of life law for clinicians website, End of Life Law for Clinicians	🟩	🟩	
End of Life Law for Medical Practitioners and Medical Students, End of Life Law for Clinicians	🟩	🟩	
End of Life Law for Nurses, End of Life Law for Clinicians	🟩	🟩	
End of Life Law for other health professionals, End of Life Law for Clinicians	🟩	🟩	
Asking the right questions, Queensland Health Shared Decision Making	🟩		
Value-based healthcare, Queensland Health Shared Decision Making	🟩		
The La Trobe Support for Decision Making Practice Learning Resource, La Trobe University	🟩	🟩	🟩
Medico-legal elements of advance care planning, Advance Care Planning Australia		🟩	
Support for family members and carers, Queensland Health Care at the end of life		🟩	
Module 1: Principles. PCC4U		🟩	
Legal information and your rights, Queensland Government: People with Disability		🟩	
Why is this important,Talking End of Life with people with intellectual disability (TEL)			🟩
Your role as a DSP, Talking End of Life with people with intellectual disability (TEL)			🟩
Dying, Talking End of Life with people with intellectual disability (TEL)			🟩
Bequeathing, Talking End of Life with people with intellectual disability (TEL)			🟩
Funeral Wishes, Talking End of Life with people with intellectual disability (TEL)			🟩

Choices at the end of life



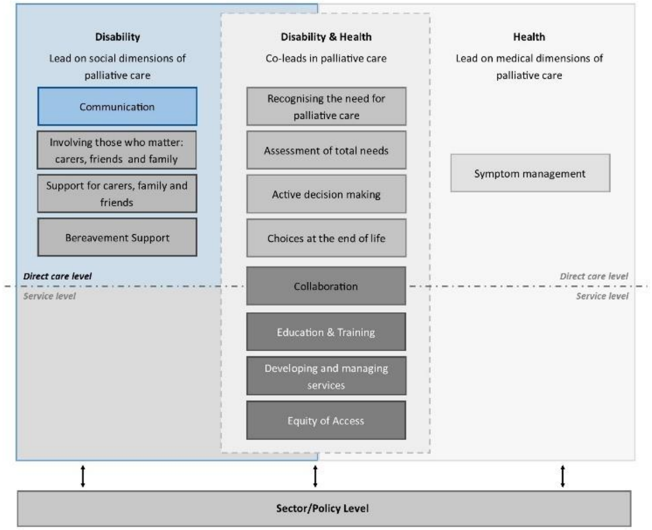
Lead:	Disability & Health
Level:	Direct care
Norm statements:	• People with disabilities should have the chance to plan their care in advance. This can be before the need for palliative care arises. • All care providers should have access to existing advance care plans. • When a person with disability needs end-of-life care, a palliative care plan should be made to meet their care needs. The person's wishes should be part of the plan and followed by the care providers. • People with disability should be involved in discussions and decisions about end-of-life care, funeral wishes, and wills. • If families are not usually responsible for funerals, care providers should recognise their role and give them support as needed.
Knowledge statement:	1. I understand the difference between advance care planning and after-death planning. 2. I understand the official documents used for planning advance care. 3. I know my role in advance care planning and after-death planning. 4. I know how to have conversations and support people to make and record their choices. 5. I know how to access records of choices about advance care and after-death plans in my organisation. I know how these are shared with others involved in the person’s care.

Build your knowledge in **Choices at the end of life**:

Available Options	**Related Knowledge Statement**				
	1	**2**	**3**	**4**	**5**
Advance Care Planning is for everyone, Advance Care Planning Australia	🟩		🟩		🟩
Advance care planning and dementia, Advance Care Planning Australia	🟩				
Advance care planning and My Health Record for carers, Advance Care Planning Australia	🟩				🟩
Medico-legal elements of advance care planning, Advance Care Planning Australia	🟩				
Advance care planning, Queensland Health Care at the end of life	🟩	🟩	🟩	🟩	
Primary Care Toolkit, ELDAC	🟩				
Home Care Toolkit, ELDAC	🟩				
Dementia Toolkit, ELDAC	🟩				
Managing affairs after death, Queensland Health: Loss and bereavement	🟩		🟩		
Tips for Careworkers: Advance Care Planning, palliAGED	🟩		🟩		
Module 1: Principles, PCC4U	🟩				
palliLEARN: What matters most to me? Palliative Care Queensland	🟩				
Care when dying, Talking End of Life with people with intellectual disability (TEL)	🟩		🟩	🟩	
Organ and tissue donation, Talking End of Life with people with intellectual disability (TEL)	🟩		🟩	🟩	
Bequeathing, Talking End of Life with people with intellectual disability (TEL)	🟩		🟩	🟩	
Funeral Wishes, Talking End of Life with people with intellectual disability (TEL)	🟩		🟩	🟩	
Support for family members and carers, Queensland Health Care at the end of life		🟩			
My Care My Choices: Advance Care Planning, Statewide Office of ACP		🟩	🟩		🟩
Planning for the Future: People with Disability, Department of Social Services			🟩		
Your role as a DSP, Talking End of Life with people with intellectual disability (TEL)			🟩		
Dementia Specific Training for Careworkers, The Advance Project			🟩	🟩	
Dementia Specific Training for Clinicians and Managers, The Advance Project			🟩	🟩	
Pathway 3: Preparing for Dying, CarerHelp				🟩	

Available Options	**Related Knowledge Statement**				
	1	**2**	**3**	**4**	**5**
Advance Care Planning, Clinical Excellence Queensland				🟩	
Care Companion: A patient decision aid for people with life limiting illness, Clinical Excellence Queensland				🟩	
Tips for Careworkers: Talking about Dying, palliAGED				🟩	
Module2: Communication, PCC4U				🟩	
Topic 2: Australian Indigenous Peoples, PCC4U				🟩	
palliLEARN: How to have conversations about dying and grief, Palliative Care Queensland				🟩	
Why is this important, Talking End of Life with people with intellectual disability (TEL)				🟩	
Dying, Talking End of Life with people with intellectual disability (TEL)				🟩	
Death, Talking End of Life with people with intellectual disability (TEL)				🟩	
Last Aid, Palliative Care Queensland				🟩	
Your employer/organisation policies, procedures, protocols, and documents					🟩

Communication

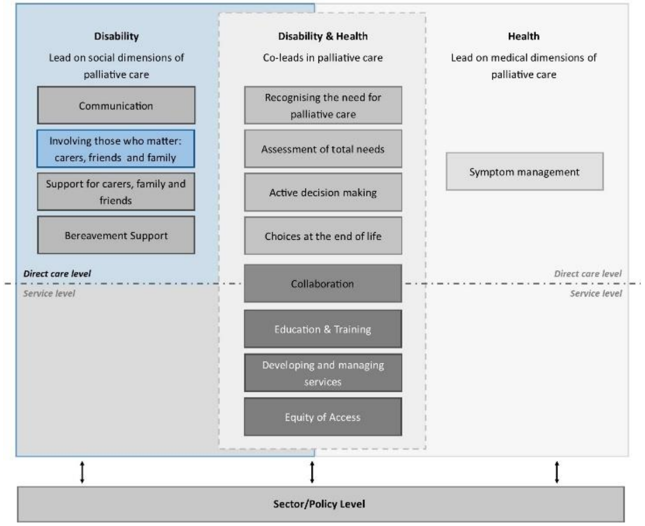


Lead:	Disability
Level:	Direct Care
Norm statements:	• People with disability may have a range of communication needs. These communication needs should be understood and met as needed. • Care providers have a responsibility to understand the communication of people with disability. They should get communication training if needed. • People with disability should have support to communicate their needs, whether they are verbal or non-verbal. • Care providers should have access to documents about the person’s wishes, including any advance care plans and after-death plans.
Knowledge statement:	1. I understand the importance of communication between a person and the people providing care. 2. I understand that people with disability may need specific support with their communication needs. 3. I am aware of ways to support communication, like getting support from carers who know the individual well.

Build your knowledge in **Communication**:

Available Options	**Related Knowledge Statement**		
	1	**2**	**3**
Tips for Careworkers: People with Disability – Communication, palliAGED	■	■	■
Module2: Communication, PCC4U	■		
Module 4: Optimisation, PCC4U	■		
Topic 2: Australian Indigenous Peoples, PCC4U	■		
Better Communication, Queensland Government: People with Disability	■	■	■
Talking with your healthcare provider, Queensland Health: Shared Decision Making	■		
Value-based healthcare, Queensland Health: Shared Decision Making	■		
Why is this important, Talking End of Life with people with intellectual disability (TEL)	■		
Handy teaching skills, Talking End of Life with people with intellectual disability (TEL)		■	■
Loss, grief, and mourning, Talking End of Life with people with intellectual disability (TEL)		■	
Asking the right questions, Queensland Health: Shared Decision Making			■
Julian's Key Health Passport, Queensland Health: Shared Decision Making			■

Involving those who matter: Carers, family, and friends.

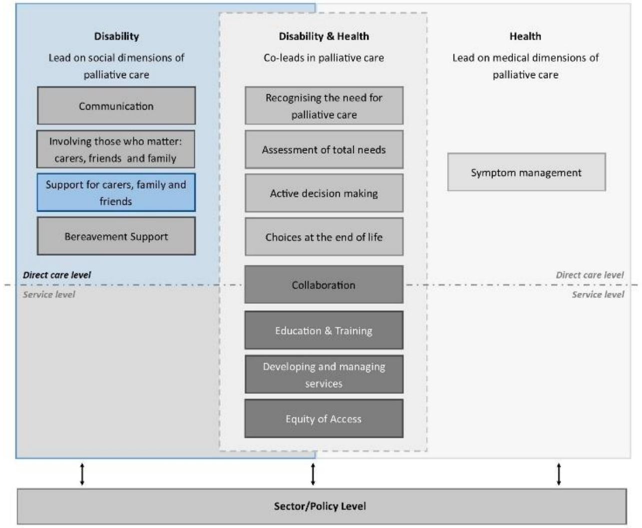


Lead:	Disability
Level:	Direct Care
Norm statements:	• People with disability should be involved in identifying their important relationships or 'significant others'. This can include family, partners, friends, carers, and care providers. • Significant others should be encouraged to take part in palliative and end-of-life care if they wish. • The person's closest carers are likely to know the person best. For some people with disability, their family have often been their carers for many years or decades. Care providers should respect and involve the carers as expert care partners. • Care providers should acknowledge and respect the important family bonds of the person with disability. • Care providers should listen to and document the person's wishes about involving or not involving their families. • Including significant others is especially important for children and young people, who mostly live within a family unit.
Knowledge statement:	1. I understand the importance of listening to and respecting a person's choices about involving their family and significant others. 2. I know how to identify important relationships for an individual and how to support their involvement.

Build your knowledge in **Involving those who matter: Carers, family, and friends**:

Available Options	**Related Knowledge Statement**	
	1	**2**
Module 4: Optimisation, PCC4U	■	
Talking with your healthcare provider, Queensland Health: Shared Decision Making	■	
Ryan's Rule, Queensland Health: Shared Decision Making	■	
Dying, Talking End of Life with people with intellectual disability (TEL)	■	■
Funeral Wishes, Talking End of Life with people with intellectual disability (TEL)	■	

Support for carers, family, and friends

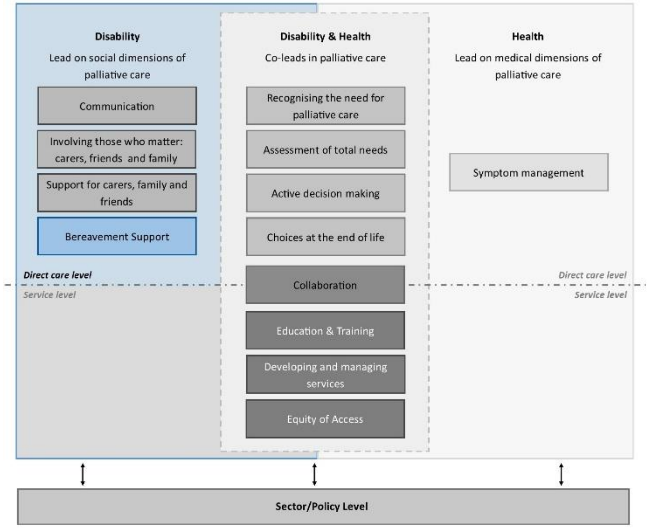


Lead:	Disability
Level:	Direct Care
Norm statements:	• Families and carers (including care providers) are often deeply affected when someone with disability goes through changes in their condition or reaches the end of life. They should be supported in their caring role. • Carers and families may feel anticipatory grief before the person with disability reaches the end of their life. They should be supported. • Many people with disability are central to their family's and carer's life. The death of someone with disability is often a significant loss for those around them. • Care providers may form strong attachments to the people they support. They should also be supported, including training on self-care.
Knowledge statement:	1. I understand that palliative and end-of-life care involves caring for both the individual and those around them. 2. I understand that grieving can start before death for both the person and their significant others. 3. I understand how to identify needs and provide support to significant others. 4. I am aware that self-care is an important part of caring. I know of various self-care activities that may work for me.

Build your knowledge in **Support for carers, family, and friends**:

Available Options	**Related Knowledge Statement**			
	1	**2**	**3**	**4**
Support for family members and carers, Queensland Health Care at the end of life	■		■	
Tips for Careworkers: Supporting Families, palliAGED	■		■	
Module 4: Optimisation, PCC4U	■	■	■	
Care when dying, Talking End of Life with people with intellectual disability (TEL)		■		
CarerHelp website, CarerHelp			■	
Self-care room, ELDAC				■
Tips for Careworkers: Self-Care, palliAGED				■
Module2: Communication, PCC4U				■
palliLEARN: Self- Care, Palliative Care Queensland				■
Cultural Beliefs, Talking End of Life with people with intellectual disability (TEL)				■
Managing feelings, Talking End of Life with people with intellectual disability (TEL)				■

Bereavement Support

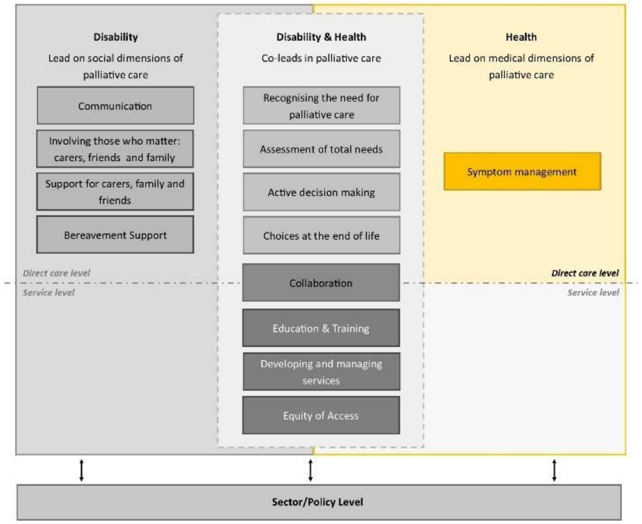


Lead:	Disability
Level:	Direct Care
Norm statements:	• People with disability experience loss and grief, just like everyone else. • People with disability are at higher risk of complicated grief. Those who support them should be aware that complicated grief reactions might happen. • Care providers should know about mainstream and specialist bereavement services. They should be able to refer people with disability to services if they are needed. • People with disability should be supported to go to funerals of people they knew, if they choose to go.
Knowledge statement:	1. I know about grief and bereavement. I understand different types of grief, including complicated grief. 2. I know about local services and support for grief and bereavement. 3. I know how to help people with disability to find support for grief and bereavement when they need it.

Build your knowledge in **Bereavement Support**:

Available Options	**Related Knowledge Statement**		
	1	**2**	**3**
Primary Care Toolkit, ELDAC	■		
Home Care Toolkit, ELDAC	■		
Dementia Toolkit, ELDAC	■		
Introduction to Bereavement Support and Brief Contact, Grief Australia	■		
Guiding Clients Through Palliative Care, Grief Australia	■		
Grief counselling and support, Queensland Health: Loss and bereavement	■	■	
Module 4: Optimisation, PCC4U	■		
Managing feelings, Talking End of Life with people with intellectual disability (TEL)	■		■
Loss, grief, and mourning, Talking End of Life with people with intellectual disability (TEL)	■		■
Living with a terminal illness, Queensland Health Care at the end of life		■	
Module 4: Optimisation, PCC4U			■
Death, Talking End of Life with people with intellectual disability (TEL)			■

Symptom management

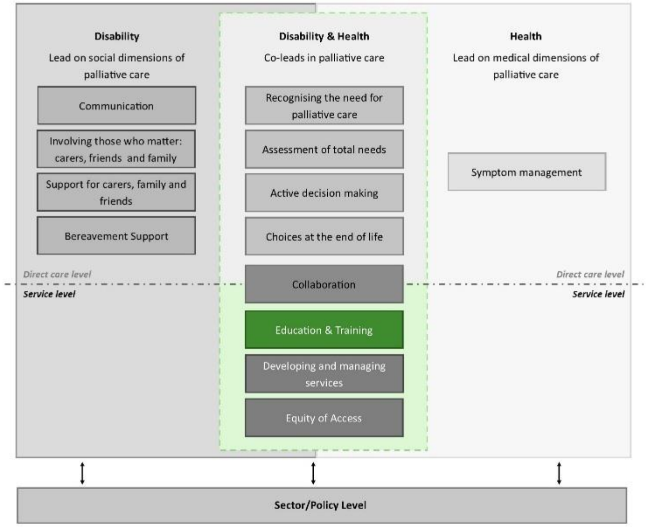


Lead:	Health
Level:	Direct Care
Norm statements:	• Symptom management is very important in palliative and end of life care. • Assessing pain and other symptoms can be more difficult for people with disability. Symptoms may be masked or shown in unusual ways. This can include behavioural changes such as behaviour which may be seen as ‘challenging’, or withdrawal. • Care providers should be aware of ‘diagnostic overshadowing.’ This is when physical symptoms of illness are mistaken as part of the person’s disability. This means their symptoms might not be treated or managed. • Carers and care providers should be supported to recognise symptoms, including pain. • Care providers should be aware that managing symptoms in people with disability can be complex because they might have other health issues too. • It is crucial for the people who know the person well and experts to work together to manage symptoms for people with disability.
Knowledge statement:	1. I understand that symptom assessment and management may be more complex in people with disability. 2. I understand the idea of diagnostic overshadowing and other biases that can affect symptom management. 3. I understand the importance of supporting the people around the individual with disability to recognise and respond to their symptoms. 4. I am aware of available services and supports for symptom management.

Build your knowledge in **Symptom management**:

Available Options	**Related Knowledge Statement**			
	1	**2**	**3**	**4**
Understanding the palliative care needs of intellectually disabled people, CareSearch	🟨			
Module 3: Assessment, PCC4U	🟨			
Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland Summary of recommendations, The Public Advocate	🟨	🟨		
Intellectual Disability, CareSearch		🟨		
Exploratory Analysis of Barriers to Palliative Care: Issues Report on People with Disabilities, Australian Government Department of Health		🟨		
Pathway 4: When the person is dying, CarerHelp			🟨	
Symptoms and Medicines, palliAGED			🟨	
Ryan's Rule, Queensland Health: Shared Decision Making			🟨	
Medicines from the PBS Prescriber's bag for Terminal Phase Symptoms, CareSearch				🟨
Brisbane North PHN region specific resources, Brisbane North PHN				🟨
Specialist Palliative Care Services Available to Adult in the Brisbane North PHN region, Brisbane North PHN				🟨

Education and Training

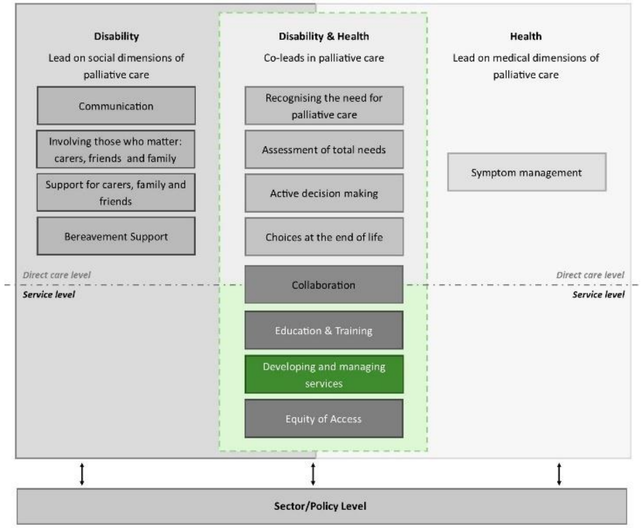


Lead:	Disability & Health
Level:	Service level
Norm statements:	• Care provider training: all workers who support people with disability should get palliative and end-of-life care training. • Death education for people with disability: people with disability should be included in information and discussions about illness, dying, and death throughout their lives. These discussions could happen in any setting. Carers, family, and friends should be supported to encourage these discussions.
Knowledge statement:	1. We train care providers to support people with disability in palliative and end-of-life care. 2. We educate people with disability and their significant others about palliative and end-of-life care. We encourage open conversations about dying. We offer advice, referrals, and support material when needed.

Build your knowledge in **Education and Training**:

Available Options	**Related Knowledge Statement**	
	1	**2**
Care at end of life: Education and training framework, Clinical Excellence Queensland	🟩	
Palliative Care Curriculum for Undergraduates (PCC4U) website and resources, PCC4U	🟩	
Your employer/organisation policies, procedures, protocols, and documents	🟩	🟩
Handy teaching skills, Talking End of Life with people with intellectual disability (TEL)		🟩

Developing and managing services

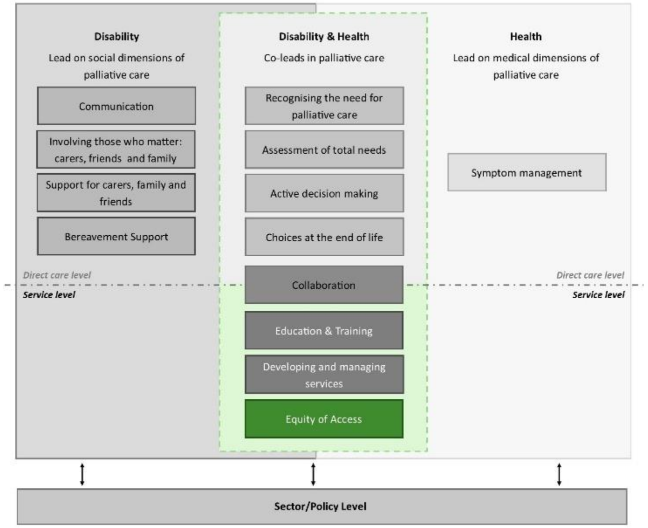


Lead:	Disability & Health
Level:	Service level
Norm statements:	• Service leaders and staff should be aware of laws and regulations on palliative and end-of-life care. • Policies, procedures, and process around support plans addressing palliative and end of life care practices are regularly updated. • People who manage their own support arrangements should regularly plan for the continuity of their care. • Services should not only focus on a good life. Services should also create processes that support people with disability to experience a good death.
Knowledge statement:	1. We have a policy and procedure to support palliative and end-of-life care for people with disability. 2. Our care providers are trained to have respectful conversations about palliative and end-of-life care for people with disability in line with their scope of practice. 3. We have procedures to meet our statutory reporting requirements (for example, the Queensland Coroner). 4. We are aware of services and support in the region to support palliative and end-of-life care.

Build your knowledge in **Developing and managing services**:

Available Options	**Related Knowledge Statement**			
	1	**2**	**3**	**4**
End of Life Directions for Aged Care (ELDAC) programs, ELDAC	🟩			
Indigenous Program of experience in the palliative approach (IPEPA), IPEPA	🟩			
National Consensus Statement: Essential elements for safe and high-quality paediatric end-of-life care, The Australian Commission on Safety and Quality in Health Care	🟩			
National Consensus Statement: Essential elements for safe and high-quality end-of-life care, The Australian Commission on Safety and Quality in Health Care	🟩			
National Palliative Care Standards for All Health Professionals and Aged Care Services (non-specialist), Palliative Care Australia	🟩			
National Palliative Care Standards for specialist palliative care services, Palliative Care Australia	🟩			
National Safety and Quality Health Service Standards, The Australian Commission on Safety and Quality in Health Care	🟩			
Palliative and end of life care strategy, Queensland Health	🟩			
Planning for the Future: People with Disability, Department of Social Services	🟩			
The National Palliative Care Strategy, Department of Health and Aged Care	🟩			
Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland Summary of recommendations, The Public Advocate	🟩			
Why succession planning matters: A resource for families to plan for the future, CRU	🟩			
Your employer/organisation policies, procedures, protocols, and documents	🟩	🟩		
Brisbane and Queensland Communities of Practice, Collaboratives, and peer groups		🟩		
End of Life Law for Clinicians website, End of Life Law for Clinicians			🟩	
Support for Palliative Care, Brisbane North PHN				🟩

Equity of access



Lead:	Disability & Health
Level:	Service level
Norm statements:	• People with disability should have equity of access to palliative care services and supports. • Care providers should make sure that people with disability can access palliative care services, by referring them to these services when they need them. • Services may need to change so that people with disability have access to them. Palliative care services should make changes when needed to enable people with disability to access their services and support.
Knowledge statement:	1. We have policies and procedures in place so that people with disability have equitable access to palliative and end of life care. 2. We are aware of palliative care services and support in the region, and we know how to refer people to them.

Build your knowledge in **Equity of access**:

Available Options	**Related Knowledge Statement**	
	1	**2**
Exploratory Analysis of Barriers to Palliative Care: Issues Report on People with Disabilities, Australian Government Department of Health	■	
National Consensus Statement: Essential elements for safe and high-quality paediatric end-of-life care, The Australian Commission on Safety and Quality in Health Care	■	
National Consensus Statement: Essential elements for safe and high-quality end-of-life care, The Australian Commission on Safety and Quality in Health Care	■	
National Palliative Care Standards for All Health Professionals and Aged Care Services (non-specialist), Palliative Care Australia	■	
National Palliative Care Standards for specialist palliative care services, Palliative Care Australia	■	
National Safety and Quality Health Service Standards, The Australian Commission on Safety and Quality in Health Care	■	
Palliative and end of life care strategy, Queensland Health	■	
The National Palliative Care Strategy, Department of Health and Aged Care	■	
Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland Summary of recommendations, The Public Advocate	■	
Your employer/organisation policies, procedures, protocols, and documents	■	
Support for Palliative Care, Brisbane North PHN		■

Resources to support specific populations

Aboriginal and Torres Strait Islander people

- PCC4U Topic 2: Australian Indigenous Peoples
- CarerHelp
    - Pathway 1: Getting prepared for caring for someone who is very sick
    - Pathway 2: Caring for a person who is finishing up
    - Pathways 3: Grief and after caring
- Exploratory Analysis of Barriers to Palliative Care Issues Report on Aboriginal and Torres Strait Islander Peoples, Australian Government Department of Health
- Indigenous Program of experience in the palliative approach (IPEPA)
    - First Nations health professionals' toolkit
    - Cultural Safety toolkit
    - Caring for mob at the end of their life
    - Information for Indigenous health workers wanting to know about palliative care
    - A palliative approach to care for Aboriginal and Torres Strait Islander professions
    - What do people with serious illness need?
    - Cultural Considerations: providing end-of-life care for Aboriginal and Torres Strait Islander peoples
- palliAGED: Tips for Careworkers: First Australians – Communication

People from culturally and linguistically diverse backgrounds

- Advance Care Planning Australia
    - Advance Care Planning is for everyone
    - Multicultural perspectives on Advance Care Planning
- Living with a terminal illness- multicultural, Queensland Health Care at the End of Life
- CarerHelp resources in other languages, CarerHelp
- End of life care for diverse communities, End of Life Essentials
- Exploratory Analysis of Barriers to Palliative Care – Issues Report on People from Culturally and Linguistically Diverse Backgrounds, Australian Government Department of Health
- Topic 4: Culture- Centred Care, PCC4U
- Cultural Beliefs, Talking End of Life with people with intellectual disability (TEL)

People who identify as LGBTQIA+

- LGBTIQ+ Health Australia's Palliative Care Project
    - Online modules
- Queensland council for LGBTI Health- training and consultancy
- Exploratory Analysis of Barriers to Palliative Care Issues Report on People Who Identify as Lesbian, Gay, Bisexual, Transgender, or Intersex, Australian Government Department of Health

Children

- Living with a terminal illness- young people, Queensland Health Care at the End of Life
- Paediatric end of life care, End of Life Essentials
- National Consensus Statement: Essential elements for safe and high-quality paediatric end-of-life care, The Australian Commission on Safety and Quality in Health Care
- Topic 3: Caring for children, PCC4U.
- palliLEARN: Talking to children about dying, Palliative Care Queensland.

Foundation

This framework is built on the *Disability and Palliative Care Intersectoral Partnership Framework* [1].

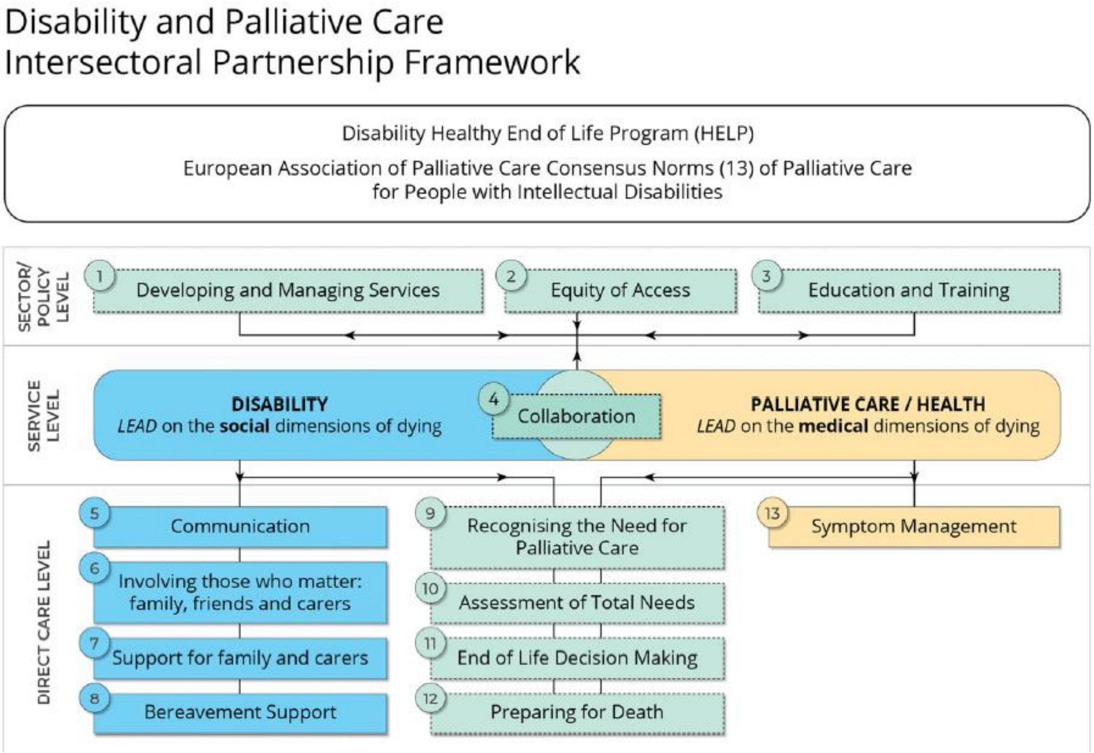


Figure 4: Disability and Palliative Care Intersectoral Partnership Framework (Grindrod, 2021)

The Norm Statements in this framework come from the European Association of Palliative Care *Consensus Norms of Palliative care for People with Intellectual Disabilities*[4]. The statements have been broadened in this framework to include all types of disability.

Useful Links

NDIS

- NDIS
- NDIS Quality and Safeguard Commission

Queensland Legislation

- Medicines and Poisons Act 2019
- Human Rights Act 2019

Queensland Coroner

- Deaths of people with a disability: Coroner Court of Queensland factsheet

My Aged Care

- My Aged Care website

Voluntary Assisted Dying (VAD)

- Voluntary Assisted Dying (VAD) education module for healthcare workers *Although titled for healthcare workers, it is appropriate for all care providers.
- Voluntary Assisted Dying (VAD) – information for GPs
- Voluntary assisted dying in aged care: Roles and obligations of personal care workers
- QUT End of Life Law- Voluntary Assisted Dying

Peak Bodies in Queensland

- For Palliative Care- Palliative Care Queensland
- For a list of disability sector peak bodies in Queensland see Peak Body Supports page on the Queensland Government Website.

PallConsult

- PallConsult is a statewide end of life care support service for clinicians.
- Palliative and End of life care Framework- last 12 months of life. Outlines clinical processes and care considerations in all settings.
- PallConsult Resources

References

1. Grindrod, A. (2021) Dying with disability: a disability and palliative care intersectoral partnership framework. *Research and Practice in Intellectual and Developmental Disabilities*, 8:2, 138-151, DOI: 10.1080/23297018.2021.1943500
2. World Health Organisation (2023) *International classification of functioning, disability, and health (ICF)*. Access via https://icd.who.int/dev11/l-icf/en
3. Palliative Care Queensland (no date) *Compassionate Communities are…* Accessed via https://palliativecareqld.org.au/compassionate-communities-are/
4. Tuffrey-Wijne, I. and McLaughlin, D. (2015) *Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe: EAPC White Paper.* European Association for Palliative Care (EAPC) Taskforce on People with Intellectual Disabilities. Accessed via https://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/eapc-white-paper-id_full-version_april-2015.pdf

Appendix 1: Commonly used acronyms

ACP	Advance Care Planning
AHPRA	Australian Health Practitioner Regulation Agency
CRU	Community Resource Unit
DOHAC	Department of Health and Aged Care
EAPC	European Association for Palliative Care
ELDAC	End of Life Directions for Aged Care
EOL	End of Life
GP	General practitioner
HHS	Hospital and Health Service
IPEPA	Indigenous Program of Experience in the Palliative Approach
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Services
OACP	Office of Advance Care Planning
OPG	Office of The Public Guardian
PCA	Palliative Care Australia
PCC4U	Palliative Care Curriculum for Undergraduates
PCQ	Palliative Care Queensland
PEPA	Program of Experience in the Palliative Approach
QAMH	Queensland Alliance for Mental Health
QDN	Queenslanders with Disability Network
VAD	Voluntary Assisted Dying

Living and dying well for people with disability:
palliative and end of life care knowledge framework
Version 1

Released 28 February 2024

Help improve this resource

This resource is part of a suite under active development.

We want to hear from you about your experience with using these resources.

- How can this resource be improved?
- Do you have any suggestions for other support material that would be helpful?

You can provide feedback anonymously through this online survey (https://myvoice.brisbanenorthphn.org.au/embeds/projects/86905/survey-tools/102536).

Alternatively, email the project team on community.care@brisbanenorthphn.org.au

This resource is supported by funding from the Department of Health and Aged Care under the Greater Choice for At Home Palliative Care measure.

www.brisbanenorthphn.org.au

Level 1, Market Central
120 Chalk Street, Lutwyche QLD 4030
PO Box 845 Lutwyche QLD 4030
t 07 3630 7300

Partners 4 Health Ltd (ABN 55 150 102 257), trading as Brisbane North PHN