



# Working together with the person & their team

This information is for health professionals involved in the provision of palliative care for a person with intellectual disability and the people that support them

## **Why is it important to work together with a person with intellectual disability and their team during palliative care?**

- People with intellectual disability encounter significant barriers in accessing palliative care that meets their needs.
- People with intellectual disability are often not supported to be involved in discussions or making decisions about their care.
- Supporters (e.g., family, carers, paid disability support) are also not always appropriately engaged or supported to fulfil their roles.
- It is important to work collaboratively with the person with intellectual disability, their supporters, and other health professionals that all bring different knowledge and skills that can be best utilised when everyone works together.
- A person with intellectual disability should be the focus, with different members of their team working towards the person's preferences.

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

The following guiding principles 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**



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



**Palliative care is person-centred and holistic**



**Access to quality care is equitable**



**Dying, death and grief are recognised as part of life**



**Care is well-coordinated and integrated**



**Care is high quality and evidence-based**

## Practice tips

- Communication and assessment may take longer. **Allocate longer appointment times, if needed.**
- Ask the person with intellectual disability and their supporters about communication preferences and needs, including use of alternative communication needs. **Ensure communication needs and preferences are met and provide information in an accessible format.**
- People with intellectual disability report that they find it easier to communicate with professionals if they feel comfortable and trust them. **Spend time building rapport and trust and provide continuity with team members where possible.**
- The person with intellectual disability should be the focus and recognised as being capable of expressing preferences and directing care. Different team members should work towards the person's goals and provide support as needed. **Work collaboratively with the person with intellectual disability and their chosen supporters when developing care plans to meet the person's goals, needs and wishes for palliative and end of life care.**
- Ask the person with intellectual disability and their supporters about how to make the person comfortable. **Identify opportunities for reasonable adjustment of spaces where people receive palliative care (e.g., adjusting lights or sounds for people with sensory needs, or identifying personal comfort items). If completed by the person, read the planning sheet in the resource [Preparing for palliative care](#) to identify the person's preferences.**

- People with intellectual disability may have multiple people supporting them, including family, carers, friends, paid disability support, and other health professionals. **Use the planning sheet [Working together with my team](#) to identify if and how the person with intellectual disability would like their team involved in their palliative care.**
- Supporters of the person may have different needs and roles. **Clarify roles and responsibilities of supporters when determining goals of palliative care.**
- Supporters may have little or no experience supporting a person at end of life. **Educate supporters to help them fulfil their roles.**
- Collaboration requires communication. **Ensure clear communication and documentation of end of life care plans with those providing care and support, including how plans are to be implemented.**
- **If available in your health district or network, contact the specialist intellectual disability health service for advice.**

For more information and resources visit the [National Toolkit for health professionals on improving palliative care for people with intellectual disability](#).

This document 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.