

Pan-Canadian Palliative Care Framework Consultation Submission

The Down Syndrome Association of Ontario (DSAO) is a charitable organization composed of 19 local Down syndrome associations from across the province of Ontario. Together, we coordinate the efforts to raise awareness, educate, and encourage the inclusion of people with Down syndrome and their families across Ontario.

The DSAO thanks Health Canada for the opportunity to provide input into this important project, the development of a National Framework for Palliative Care.

People with intellectual disabilities make up 1-3% of the population, and are increasingly living into old age. This means that, like the rest of the population, many people with Down syndrome and other intellectual disabilities will require a period of palliative care at the end of their lives.

As noted by Tuffrey-Wijne in her article “Palliative Care and Intellectual Disabilities”:

The palliative care needs of people with intellectual disabilities are, in essence, the same as those of the general population. Who wouldn’t want to die a death that is free of pain and other symptoms, or spend time with their family or friends, or be listened to and involved when choices and decisions are made about their care and treatment? (Tuffrey-Wijne, 2017)

While the palliative care needs of this population may be the same as those of the general population, “they often present with unique issues, challenges, and circumstances that make it more difficult to meet those needs. Therefore, they need focused consideration.” (Tuffrey-Wijne, 2015)

There are some medical considerations that are specific to those with Down syndrome, such as an elevated risk of leukemia among children, and much higher incidence - and earlier onset - of dementia in older adults. However, for the purposes of this consultation submission we would like to focus on four main areas to be addressed in the Framework to benefit not just those with Down syndrome and their families, but all Canadians with intellectual disabilities:

- 1. Equity in access to palliative care services**
- 2. Maximized comfort**
- 3. Improved training and/or collaboration**
- 4. Improved bereavement and grief supports**

1. Equity in access to palliative care services

There is growing evidence in Europe, where much of the study of palliative care for those with intellectual disabilities is being carried out, that people with intellectual disabilities face significant barriers in accessing palliative care services. (Overview Report, Care Quality Commission) This poorer quality of care at end of life is often a result of providers not understanding or fully considering their needs. (People with Learning Disabilities, Care Quality Commission)

Provincial Health Care Consent laws are widely misunderstood in many provinces, even among social services and healthcare professionals, leading to staff making decisions around advanced care planning, consents, and substitute decision making at their own discretion rather than with the involvement of the individual with intellectual disabilities.

Intellectual disabilities, including Down syndrome, are a spectrum, and each person's autonomy needs to be respected and their cognitive abilities considered and accommodated for on an individual basis. Otherwise, assumptions are made and individuals who should be at the centre of their own planning are instead sidelined.

Some adjustments are needed to ensure equitable access (Tuffrey-Wijne, 2017):

- Giving people information that is tailored to their communication needs (such as easy-to-read materials and pictures – consider the Books Beyond Words series noted in the Resource Section),
- Addressing the individual directly rather than speaking about them as if they are not there,
- Allowing more time,
- Involving family and other care givers,
- Providing staff training (see point 3),
- Accessing expertise about intellectual disability when needed.

2. Maximized Comfort

In England, the Palliative Care for People with Learning Disabilities (PCPLD) Network has produced a handbook of best practices, "Delivering high quality end of life care for people who have a learning disability." (See Resource Section) This guide identifies several "ambitions" for service providers, one of which is "Maximizing comfort and wellbeing." This section includes several goals, including:

- **Helping the person with intellectual disabilities to understand their illness and symptoms.**
 - Understanding what is happening helps the individual cope better with changes (including new living arrangements or symptoms) and new treatments, self-report changes in their symptoms or new symptoms, and reduces fear of the unknown.
 - Family members and staff will need to prepare to have these conversations, consider the context of the individual to find stories to draw on to help understanding, and feel supported themselves in order to have these conversations.
- **Relieving psychological distress and improving wellbeing.**
 - Maintaining connections and normality.
 - Responding to the messages the person is sending through their behaviour. All behavior is communication, and one should never assume that if a person with an intellectual disability cries, shouts, or behaves in an unusual way that it is because of their disability. They may be communicating hunger, fatigue, fear, pain, or new symptoms.
 - Establishing a baseline is crucial to identifying distress. Consider the Disability Distress Assessment Tool (DisDAT).
- **Carrying out an effective and appropriate person-centred pain assessment.**
 - Ways of assessing pain for the general population may need to be adapted for people with an intellectual disability. People who have an intellectual disability such as Down syndrome may have difficulty describing and reporting their pain.
 - "Diagnostic Overshadowing" often occurs when service providers and care givers attribute a behavior to a person's intellectual disability rather than investigating potential illnesses and symptoms.
 - Evidence demonstrates that people with an intellectual disability are less likely to receive pain relief than people in the general population with the same condition, which is an unacceptable level of inequity, and can be overcome with appropriate pain assessments in place. (PCPLD Network)

- Ensuring that a person's usual 'pain behaviour' or non-verbal communication is understood is helpful. There are a number of tools that can support health professionals in identifying pain in people with a communication difficulty.

3. Improved training and/or collaboration

People with intellectual disabilities like Down syndrome are often under-referred to specialist palliative care because of a limited understanding of its role and a lack of collaboration. Professionals often also lack knowledge about and confidence in their ability to meet the needs of people with an intellectual disability who require palliative care. (Dunkley) Many caregivers of people with intellectual disabilities are extremely uncomfortable even talking about death, dying, and grief, so the topic is often avoided altogether, much to the detriment of the person with intellectual disabilities.

In order to provide the best end of life care, there is a need for training among those who work in palliative care on how to best support those with intellectual disabilities, and for training among those who specialize in intellectual disabilities on how to provide/when to refer for palliative care.

The authors of the literature review "The challenges of providing palliative care for people with intellectual disabilities" recommended staff development in the following areas (Dunkley):

- Staff confidence,
- Collaborative working between professionals,
- Empowerment of people with intellectual disability to be involved in decisions about their end-of-life care.

As noted earlier, a clearer understanding of Health Care Consent laws, substitute planning, and advanced care planning is needed, with improved coordination between health care and social service sectors. This will lead to earlier and better engagement of palliative care resources and services as well as a better end of life experience for individuals with intellectual disabilities and everyone involved in their care.

The literature review also notes that:

Further research is needed to examine the most effective way of capturing the perspectives of those with intellectual disability and of enabling people with intellectual disability to access and engage with health surveillance, cancer screening, and palliative care services. (Dunkley)

4. Improved bereavement and grief supports

Individuals with intellectual disabilities experience the emotional response of bereavement when loved ones die. Yet the emotional impact that bereavement has on the lives of people with intellectual disabilities often goes unrecognized and unacknowledged, and their ability to publicly mourn is widely unsupported. (Mason)

It is not unusual for society to fail to recognize the emotional lives of people with intellectual disabilities or believe in their ability to emotionally grasp the finality of death. (Mason) Expressions of grief are often labelled as challenging behavior and are considered an effect of the intellectual disability rather than the emotional state. This view has been challenged and it has been demonstrated that people with intellectual disabilities respond to bereavement and loss in essentially the same way as anyone else. However, it is still common "for people with intellectual disabilities not to be told when a loved one has died, to be left out of the rituals of grief and bereavement, and to be excluded from the opportunity to say their final goodbyes."

(Mason) This often comes from a desire to protect the individual from sadness and grief, called ‘benevolent exclusion.’

Euphemisms about death are unhelpful to people with intellectual disabilities. Again, the Books Beyond Words series can be helpful in sensitively telling people what has happened using plain language. Down’s Syndrome Scotland also has easy-read publications for learning more about the process of death.

In order to support people with intellectual disabilities well through bereavement and grief, staff need to be trained, family members need to be educated, and resources need to be available to share information appropriately and honestly with the individual who is experiencing loss.

Conclusion

Inclusion of these four considerations in the development of the National Palliative Care Framework will help improve the end of life experience for individuals living with Down syndrome and other intellectual disabilities. Again, we appreciate the opportunity to have the interests of those living with Down syndrome considered in this consultation process.

Resources:

[“A different ending: Addressing inequalities in end of life care, Overview Report.”](#) 2016. Care Quality Commission, England.

[“A different ending: Addressing inequalities in end of life care, People with Learning Disabilities.”](#) 2016 Care Quality Commission, England.

Books Beyond Words

[“Delivering high quality end of life care for people who have a learning disability.”](#) PCPLD Network, England.

Disability Distress Assessment Tool (DisDAT).

[“Let’s Talk About Death.”](#) 2012. Down’s Syndrome Scotland.

Dunkley, Susie and Rachel Sales. [“The challenges of providing palliative care for people with intellectual disabilities: a literature review.”](#) 2014. International Journal of Palliative Nursing.

Mason, Victoria and Sandra F Dowling. [“Bereavement In The Lives Of People With Intellectual Disabilities.”](#)

Tuffrey-Wijne, Irene. [“Palliative Care and Intellectual Disabilities.”](#) Intellectual Disability and Health, University of Hertfordshire. 2012, updated in 2017.

Tuffrey-Wijne, Irene and Dorry McLaughlin. [“Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe.”](#) April 2015. European Association for Palliative Care (EAPC) Taskforce on People with Intellectual Disabilities.