

# Intellectual and Developmental Disability Palliative Care Resource Guide and Toolkit

## A Knowledge-to-Action Guide for Developmental Services, Healthcare, and Palliative Care Providers

### SCOPE

This guide focuses on a palliative care approach for adult people with intellectual and developmental disabilities (PWIDD). It is intended to guide all care settings across the continuum of care, stages of serious/and life-limiting illnesses and illness trajectories for Core, Extended, and Palliative Specialists care teams.

**Figure 1.**

*Collaborative Care Team, Adapted to include Developmental Services<sup>i</sup>*



The palliative approach to care is the highest quality holistic care for people living with the challenges of life-limiting illness/conditions.

Awareness of baseline, vigilant observation and a proactive approach for future planning should stimulate screening with appropriate tool(s) and assessment(s) by the most appropriate member(s) of the interdisciplinary collaborative team.

***The Intellectual and Developmental Disability (IDD) Palliative Care (PC) Resource Guide and Toolkit encompasses foundational knowledge-to-action for an IDD specific palliative approach. Ethical principles and practices are also integrated throughout each module, highlighting that good care is good ethics. The Toolkit incorporates IDD specific tools for Supported Decision Making and Earlier Identification of:***

- ***Needs/changes to direct care action(s)***

- *Health decline from baseline (acute, post exacerbation event, ER transfer or hospital admission) to enable responsive and proactive care and care planning*
- *Pain and symptoms present in need of management*
- *Approaching end-of-life phase to enable responsive care provision “Right Care; Right Place; Right Time; Right Team; Right Communication”*
- *Loss; Grief and Bereavement support needs*

## HOW TO USE THIS TOOLKIT

The Toolkit is intended to be a IDD specific supplement to the [Ontario Palliative Care Toolkit](#).<sup>ii</sup>

It incorporates prevailing practices (good practice) in IDD palliative care approaches from:

- [Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe, European Association for Palliative Care \(EAPC\)](#)<sup>iii</sup>
- [Delivering high quality end of life care for people who have a learning disability: Resources and tips for commissioners, service providers and health and social care staff, NHS England](#)<sup>iv</sup>
- [Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines](#)<sup>v</sup>

Along with the gold standard evidence informed palliative care norms of practice from:

- [A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, Canadian Hospice Palliative Care Association](#)<sup>vi</sup>
- [Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action](#)<sup>vii</sup>

This Toolkit blends gold standards and evidence-informed palliative care norms of practice to establish IDD palliative norms of practice for cross-sectoral collaboration in IDD shared care. It is intended as a knowledge-to-action guideline that encompasses:

1. **KNOWLEDGE Points: Foundational knowledge to inform provider palliative care approach**
2. **ACTION Points: “Good Practice” for care delivery and skill building**
3. **IDD specific palliative care tools**
4. **Composition of the Collaborative Care Team which must include Developmental Services direct care team *with* Healthcare/Palliative Specialists as “one team”**
5. **ETHICS PEARLS: Ethics principles, virtues, and values applied to our work**
6. **ETHICAL REMINDERS: Reminders of how to implement ethics into practice**

The reader will note within the developmental services sector the preferred term and common language is “good practice”.

Formal care providers should be familiar with the Ontario Palliative Care Toolkit<sup>ii</sup> blending the strengths with this IDD specific supplement to advance high quality palliative care for PWIDD.

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## REFERENCES

- <sup>i</sup> Ontario Palliative Care Network (2019, April). *Palliative Care Health Services Delivery Framework, Recommendations for a Model of Care to Improve Palliative Care in Ontario, Focus Area 1: Adults Receiving Care in Community Settings*. <https://www.ontariohealth.ca/content/dam/ontariohealth/documents/palliative-adult-care-community-setting.pdf>
- <sup>ii</sup> Ontario Health (2026, Jan 06). *Palliative Care Toolkit*. <https://www.ontariohealth.ca/clinical/palliative/toolkit>
- <sup>iii</sup> Tuffrey-Wijne, I., McLaughlin, D. & European Association for Palliative Care (EAPC) Taskforce on People with Intellectual Disabilities (2015, April). *Consensus Normal for Palliative Care of People with Intellectual Disabilities in Europe: EAPC White Paper*. [https://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/eapc-white-paper-id\\_full-version\\_april-2015.pdf](https://www.learningdisabilityanddementia.org/uploads/1/1/5/8/11581920/eapc-white-paper-id_full-version_april-2015.pdf)
- <sup>iv</sup> Palliative Care for People with Learning Disabilities Network (n.d.). *Delivering high quality end of life care for people who have a learning disability: Resources and tips for commissioners, service providers and health and social care staff*. <https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf>
- <sup>v</sup> Sullivan, W.F., Diepstra, H., Heng, J., Ally, S., Bradley, E., Casson, I., Hennen, B., Kelly, M., Korossy, M., McNeil, K., Abells, D., Amaria, K., Boyd, K., Gemmill, M., Grier, E., Kennie-Kaulbach, N., Ketchell, M., Ladouceur, J., Lepp, A., ... Witherbee, S. (2018, April). Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Canadian Family Physician*, 64(4), 254-279. <https://www.cfp.ca/content/64/4/254>
- <sup>vi</sup> Canadian Hospice Palliative Care Association (2013). *A Model to Guide Hospice Palliative Care*. Ottawa, ON: Canadian Hospice. <https://www.chpca.ca/wp-content/uploads/2024/07/norms-of-practice-eng-web.pdf>
- <sup>vii</sup> *Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action* (2011, December). <https://neltoolkit.mao.ca/sites/default/files/Advancing%20High%20Quality,%20High%20Value%20Palliative%20Care%20in%20Ontario.pdf>