INTELLECTUAL & DEVELOPMENTAL DISABILITIES
PALLIATIVE CARE NETWORK

MODULE B: A PALLIATIVE APPROACH TO CARE GUIDANCE

Domains of Holistic Care; Norms of Practice

April 2026

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ACKNOWLEDGEMENTS

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DOMAINS of ILLNESS and BEREAVEMENT ASSOCIATED WITH LIFE-LIMITING ILLNESSES/CONDITIONS[i]

DOMAINS

The palliative approach to care is sensitive to the individual's experience, aiming to positively impact the illness experience by identification, impeccable assessment, and response to needs present and future.

It ensures dignity and quality of living.

The palliative approach to care, also referred to as palliative care, is about the care needed to live well with a life-limiting condition or serious illness. Although palliative care includes end-of-life care, that is not all that it is. Palliative care is beneficial from the start of a life-limiting condition and is not limited only to the time preceding death. Palliative care, simply stated, is the best care for people living with conditions that may shorten a person's life.

To relieve suffering and improve quality of living interprofessional team members must be able to identify and respond to the complex needs that people with intellectual and developmental disabilities (PWIDD), family and their circle of support may face along a life-limiting/serious illness journey. These needs can be categorized into eight equally important domains representing holistic person-centred care.

While palliative care practice refers to the categories of holistic care as "domains of issues" (see Appendix A), this resource adds an adapted version specific for PWIDD named "domains of care: holistic considerations" (see Appendix B). "Issues" may carry negative connotations and stigma for PWIDD and their circle of support. The use of the term "issues" in this section is consistent with existing palliative care terminology. It remains important to understand that it does not refer to problems caused by the person, family, or their circle of support but is referring to the complex care needs that arise from living with life-limiting illnesses/conditions. Where possible the term "issues" has been replaced by the word "needs".

Ethics Pearl: At the heart of good care is respect for the dignity of the person. Dignity is an inherent right of *ALL* human beings. Quality of life is defined by the person themselves and does not *assume* anything about their experience.

KNOWLEDGE POINTS:

- **A palliative care approach** identifies current and potential future needs that require treatment, management, and care planning across all eight domains for holistic care[i]
    1. Disease Management
    2. Physical
    3. Psychological
    4. Social
    5. Spiritual
    6. Practical
    7. End-of-Life Care/Death Management
    8. Loss and Grief

ACTION: "GOOD" PRACTICE STANDARD

- **High quality palliative care** for PWIDD[ii,iii]
  - Is sustainable, accessible, and continuous.
  - Meets the same standards of care for all.
  - Includes *Advance Care Planning*.
  - Ensures the person and their *Substitute Decision Maker (SDM)* understand the *SDM* role.
  - Is delivered earlier (proactively) with timely access to palliative care support.
  - Upholds the person at the center of every decision made.
  - Is individualized, holistic, trauma informed, and dignity conserving.
  - Aligns with the person's hopes, wishes, values, beliefs, and culture.
  - Identifies current needs and plans for the future.
  - Ensures treatments and/or interventions are informed and consented to using principles of *Supported Decision-Making*.
  - Aims to relieve pain and symptoms.
  - Uses communication the person uses and understands best.
  - Provides seamless transitions between stages of illness and care settings.
  - Is provided by an interdisciplinary team of *Developmental Services*, healthcare, and *Palliative Specialist* providers functioning as one team.
  - Involves ongoing discussions regarding goals of care and setting of care, including preferred setting for end-of-life care.
  - Optimizes available supports and access to resources (for the person and *Circle of Support*).
  - Provides education for the person, SDM, family, and circle of support.
  - Leverages cross-training between *Developmental Services*, healthcare providers, and *Palliative Specialists*.
  - Is a measurable quality standard.

Ethical Reminder: Communication with PWIDD needs to be guided by the person in a way that's meaningful for them. This may involve other trusted members of the circle of support and use of adaptive devices.

NORMS OF PRACTICE[i,iv]

Norms of practice guide organizations to standardize the palliative approach to care. All programs should strive to achieve the norms of practice. This is important where palliative care is delivered by various providers from *Developmental Services* and healthcare sectors uniting as one interdisciplinary care team, legislated by two Ministries (Ministry of Children, Community and Social Services and Ministry of Health).

The palliative care norms of practice is a 3-step process[v]:

1. **Identify and Screen** using appropriate tools
2. **Observe and Assess** based on role scope of practice
3. **Plan and Manage** based on the assessed needs identified

The aim is to identify who would benefit from a palliative approach to care earlier using a proactive, rather than reactive, approach. A proactive approach allows for the time needed to be responsive and seamless in care delivery. This includes care through the stages of illness, transitions between care settings, and as the care team evolves to meet the person's needs. The approach aims to avoid repeat crises, emergency transfers/hospital admissions, while also preparing in advance for end-of-life.

NORMS OF PRACTICE

1. Identify & Screen
2. Observe & Assess
3. Plan & Manage

Ethical Reminder: The 'standard of care' is the *minimum* of care that is expected. PWIDD may require increased specialized care to realize equitable palliative care.

KNOWLEDGE POINTS:

A palliative care approach is beneficial during the entire illness journey – through each stage of illness. Whether a new diagnosis, chronic stage, advanced stage, or progressing to end-of-life, the goal is to ensure the right care is provided in the right place, at the right time, by the right team who use the right communication (5 Rs).

- **Right Care** includes primary wellness checks, chronic/chronic progressive illness management, pain and symptom management, end-of-life care, and meeting practical, psychological, social, and spiritual needs.
- **Right Place** is the person's preferred care setting. It may be their home, a clinic, hospital, in-patient palliative care unit, long-term care home, or community-based palliative care residential hospice. The care setting should enable *Developmental Services* supports to continue being highly involved.
- **Right Time** recognizes changes from baseline that may be warning of a health concern or health status decline early to meet the changing needs of the person. This requires understanding and proactively considering the distinct needs of the person to ensure a timely care response.
- **Right Team** is interdisciplinary and formally unites *Developmental Services* with medical healthcare providers as one team (professional care team).
- **Right Communication** acknowledges the personhood of PWIDD first. Communication is in the manner the person communicates and understands best. It uses plain language principles free of medical jargon – extending to family, the *Circle of Support*, and the professional care team involved in care delivery.

Ethics Pearl: Implementing the 5 Rs for PWIDD requires tailoring our approach to the individual person.

ACTION: "GOOD" PRACTICE STANDARD

Norms of Practice follows a 3-step process: Identify and Screen; Observe and Assess; Plan and Manage[v]

1. IDENTIFY and SCREEN

► **Identify who would benefit from a palliative approach to care. Those people living with:**

- IDD conditions.
- Life-limiting chronic conditions (comorbidities) that progress over time e.g. frailty, neurodegenerative conditions, organ failure illnesses, and cancer.
- Serious illness events that result in repeat ER visits and/or hospital admissions.

► **Screen for needs in all eight domains for holistic person-centred care (See Appendix A and B)**

- Screening should address all domains to identify active concerns and potential needs, including how the needs/concerns impact the person, family, and circle of support.
- Screening must incorporate tools appropriate and specific for use with PWIDD.

2. OBSERVE and ASSESS

► **Use the results from the Identification and Screening steps to inform those needs that should be thoroughly explored by assessment**

- Observations made by the professional care team of *Developmental Services Direct Support Workers (DSWs)* are the foundation to all assessment(s). *DSWs* intuition ('trusting your gut') is encouraged. If something 'feels off' there likely is a concern and should prompt further exploration and assessment.
- Assessment(s) depends on the type of need or concern and is conducted by the appropriate provider and discipline (*Developmental Services*, healthcare, *Palliative Specialist*).
- Assessment must utilize communication the person uses and understands best.
- *DSWs* are important as communication partners/translators for the person who uses non-verbal behaviour(s) as their language.
- For emergency, hospital or clinic-based assessments, ensure the primary *DSW* – who knows the person best – remains present for translation, reassurance, and for the person to feel safer.
- *Community Network of Specialized Care (CNSC) Healthcare Facilitators* and *Complex Support Coordinators* should be referred to for PWIDD with high support and complex care needs. Referrals are made through *Developmental Services Ontario (DSO)*.
- Healthcare providers must utilize a trauma informed approach during assessment due to high incidence of PWIDD's experience of institutional, intergenerational, and medical trauma.
- Assessment incorporates use of IDD specific tools e.g. HELP, CPS-NAID, DISDAT, NTG-EDSD, PALLI-Tool, SPICT-4-ALL. (See Module C and Module E for tools)
- Assessment includes actual and anticipated health related needs, associated expectations, hopes, and fears.
- Use the results of any assessment to prompt *Essential Conversations* (See Module A) as part of *Advance Care Planning*, *Health Care Consent*, and treatment decisions using *Supported Decision-Making* to inform *Goals of Care* and *Care Planning* (both current and future) from a capabilities approach lens.
- Refer to appropriate providers to meet the needs in all eight domains for holistic person-centred care (*Developmental Services*, healthcare, *Palliative Specialists*).

- Continue to screen, observe, and assess regularly for needs or changes from baseline. (See Module E)

3. PLAN and MANAGE

Plan and manage any current and possible future needs identified during the assessment. This includes proactive, timely, and responsive referrals to the most appropriate providers to ensure seamless continuity of care. (See Module C for information on various teams)

▶ **Planning should include at a minimum:**

- *Advance Care Planning*.
- Care of the family and circle of support.
- Education to equip the care team to skillfully meet the palliative care needs of PWIDD.
- Prompt management of pain and symptoms.
- Coordination with other care providers on the interdisciplinary care team:
    - ***Developmental Services*, healthcare, *Palliative Care Specialist* providers**
- Essential steps of a therapeutic encounter. (See Appendix C)

▶ **Information Sharing**

- PWIDD have a range of communication needs that must be recognised and taken into consideration in the manner the person understands and communicates best.
- PWIDD prefer their communication partner/non-verbal behaviour translator to be involved in all healthcare encounters to feel safer. This will be the *DSW* when there is no family to include.
- For healthcare providers to better understand the person who is an atypical communicator – whether the person's language is verbal, non-verbal, behaviours or micro-gestures – include the person's communication partner/non-verbal behaviour translator at each healthcare visit/encounter.
- Information shared must be accessible and tailored to the person's communication needs. This can include allowing more time and involving their chosen and trusted people who amplify the person's voice and provide translation for atypical, non-verbal communicators to resolve PWIDD's report of being made to feel "invisible" in healthcare settings.
- Create channels for close communication between *Developmental Services* and healthcare delivering direct care.
- It is recommended to use a standardized information sharing form for health and/or hospital visits, e.g. "My Hospital Form" or "About My Health Form." (See Resource Links and Tools section)

▶ **Decision Making**

- *Advance Care Planning* should utilize tools designed for PWIDD. (Module A)
- Capacity is assumed for PWIDD until proven otherwise regardless of atypical communication (verbal or non-verbal).
- *Supported Decision-Making* models are good practice for PWIDD, where their most trusted/chosen person – who knows them best – and *SDM* support their decision-making.
- Need(s) prioritization is informed directly by the person.

- *Goals of Care* decisions, treatment choices, benefits, burdens, risks, and end-of-life decision-making should utilize principles of plain language in a manner the person understands best.
- Diagnostic overshadowing and unconscious bias are avoided when considering withdrawal or withholding of treatments. Quality of life is what the person says it is.

► **Care Planning**

- PWIDD participate in their plan of care to the extent they wish, along with their *Circle of Support*.
- The plan of care is to meet the person's needs, hopes, wishes, resolve fears, deliver chosen therapies, and medication administration considerations.
- Includes preferred setting for care, whether home (private, family home, congregate living), clinic, hospital/hospital-based palliative care unit (PCU), palliative care community-based hospice, or LTCH.
- Includes plan for backup coverage, respite care, emergencies, dependents, and pets.
- For PWIDD living in congregate living homes, transfers from healthcare settings/discharge planning must include the direct care *Development Services* provider.
- Refer to and include *CNSC Healthcare Facilitators* and *Complex Support Coordinators* for PWIDD with high support and complex care needs.
- End-of-life care planning must include education for the development services provider organization/direct support team on:
    - Home and Community Support Services (HCCSS) Expected Death Protocols (EDP/EDITH).
    - Rationale for when the plan of care does not include CPR.
    - Healthcare provider use of DNR-C forms.
    - End-of-life palliative physician/nurse use of Symptom Response Kits (SRK).
- Include loss, grief, and bereavement care.

► **Care Delivery**

- Confirm care team composition and best communication channels across the interdisciplinary professional team of *Developmental Services*, healthcare and *Palliative Specialists* involved. Secondary level palliative care specialists are required due to medical complexity.
- The *Developmental Services* care team includes supported living home management team (supervisor, manager, director) as key players to ensure care coordination.
- Reciprocal education and training support between *Developmental Services*, healthcare, and *Palliative Specialist* providers is essential to positively impact the person, family, and *Circle of Support* illness experience.
- Special attention to pain and symptom management is imperative given high incidence and complexity of pain in PWIDD. (See Module F)

► **Confirmation**

- Effective care team function and seamless care coordination.
- Satisfaction with care, support, and future care planning.
- Confirmation should include:
    - Understanding of illness.
    - Understanding of what to expect as illness progresses.

- What to watch for, when to be concerned.
- Understanding therapy/treatment option(s).
- Chosen therapies have met the identified need(s).
- Who to contact with concerns.
- Expected response time.

Ethics Pearls: Good practice is good ethics; through an ethical approach respecting autonomy, doing good, avoiding harm, and being just.

"Any clinical act is an ethical act, as you're making a judgment about the good you want to do."
– Dr. Elizabeth Peter, former Dean of Nursing, University of Toronto

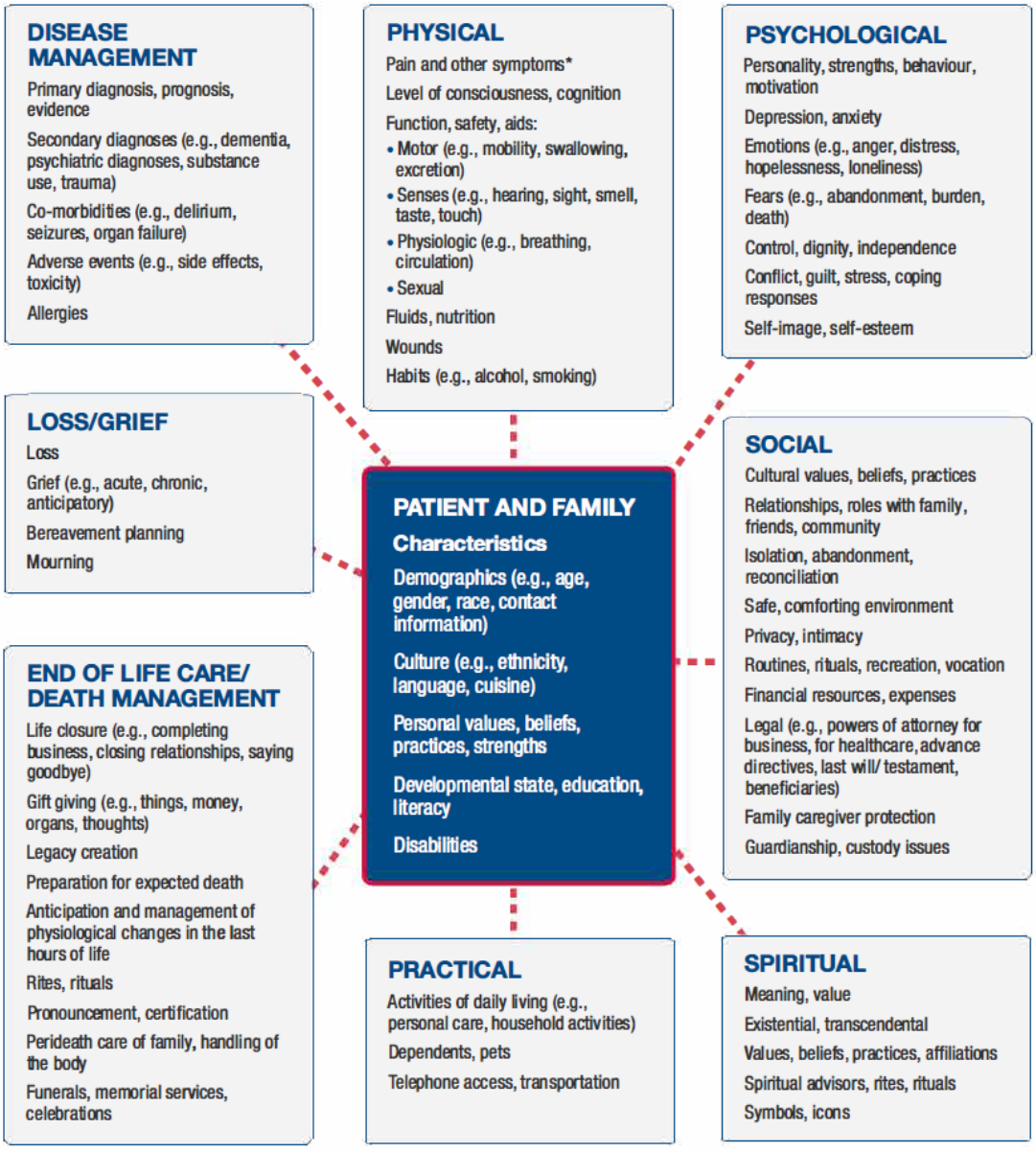
RESOURCE LINKS and TOOLS

IDD Specific

- Consensus Norms for Palliative Care of People with Intellectual Disabilities, European Association for Palliative Care (EAPC) Taskforce on People with Intellectual Disabilities (2015)
- Palliative Care for People with Learning Disabilities Network and Resources (PCPLD)
- Health Watch Tables, Developmental Disabilities Primary Care Initiative (2011), Surrey Place, Toronto
- Canadian Consensus Guidelines on Primary Care for Adults with Intellectual and Developmental Disabilities (2018)
- Developmental Services Ontario (DSO) and PASSPORT Funding
- Community Networks of Specialized Care
- Health Care Access Research and Developmental Disabilities (H-CARDD)
- Communicate Care, Guidance for Person Centred Care of Adults with Intellectual and Developmental Disabilities
- My Hospital Form
- About My Heath Form
- Trauma informed care
- Dignity conserving care

APPENDIX A[i]: DOMAINS OF ISSUES ASSOCIATED WITH ILLNESS AND BEREAVEMENT

Figure #1: Domains of Issues Associated with Illness and Bereavement



* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

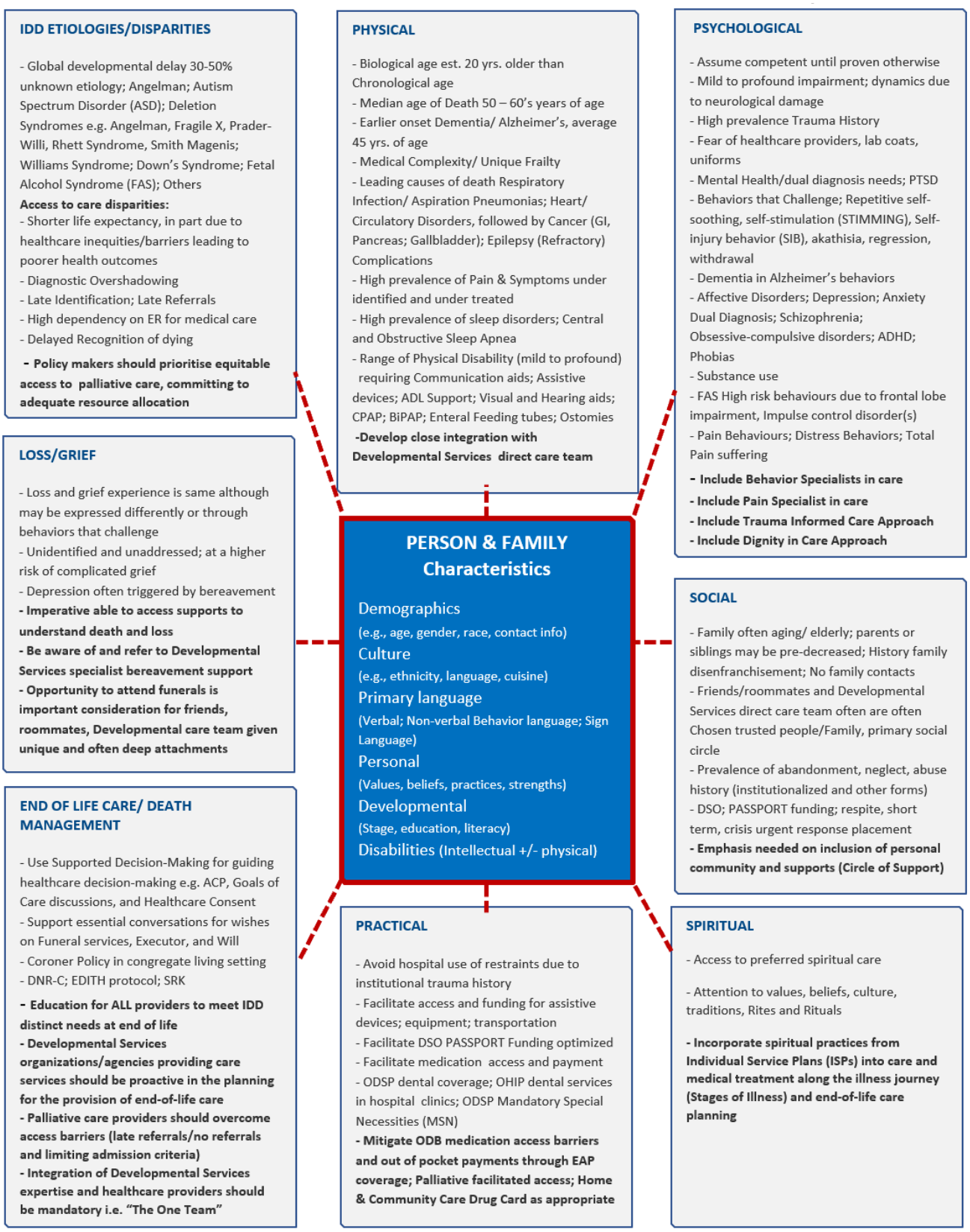
Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

From Canadian Hospice Palliative Care Association. (2013). *Domains of Issues associated with illness and bereavement.* A model to guide hospice palliative care: Based on national principles and norms of practice, p. 5

APPENDIX B: DOMAINS OF CARE: HOLISTIC CONSIDERATIONS FOR PEOPLE LIVING WITH IDD

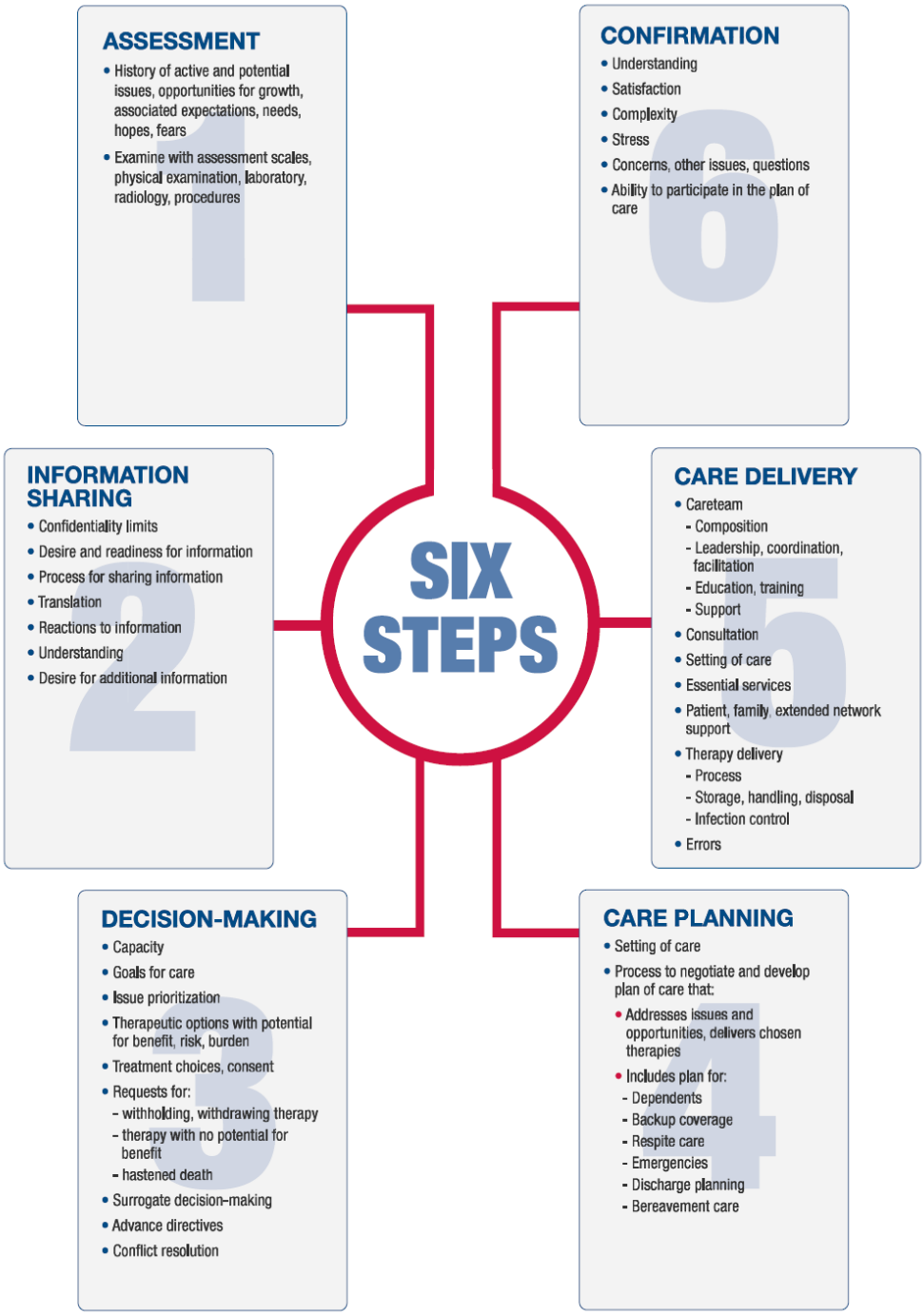


Adapted from Canadian Hospice Palliative Care Association. (2013). *Domains of Issues associated with illness and bereavement.* A model to guide hospice palliative care: Based on national principles and norms of practice, p. 5

APPENDIX C[i]

APPENDIX C[1]: NORMS OF PRACTICE/ESSENTIAL STEP OF THERAPEUTIC ENCOUNTER

Figure #3: Essential and Basic Steps During a Therapeutic Encounter



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[v] Ontario Palliative Care Network. (n.d.). *Palliative care toolkit*. Retrieved from https://www.ontariopalliativecarenetwork.ca/resources/palliative-care-toolkit