INTELLECTUAL & DEVELOPMENTAL DISABILITIES
PALLIATIVE CARE NETWORK

MODULE A: ESSENTIAL CONVERSTATIONS GUIDANCE

Communicating with the Person with IDD; Advance Care Planning; Goals of Care; Healthcare Consent and Transfer Continuity

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ESSENTIAL CONVERSATIONS GUIDANCE

KNOWLEDGE POINTS:

- *Advance Care Planning*
- *Goals of Care*
- Healthcare Consent
- Capacity
- *Substitute Decision Maker* (e.g., Office of Public Guardian & Trustee)
- Breaking 'Bad News'
- *Supportive Decision Making*

ACTION: "GOOD" PRACTICE STANDARD

Communicating with the person with IDD[i]:

- People with IDD (PWIDD) can vary considerably in their comprehension and understanding of their illness.
- PWIDD may use verbal, symbolic (e.g., signs, pictures), or pre-symbolic (e.g., gestures, facial expressions, body language) means to communicate their needs, will, and preferences.[ii]
- Limitations in the necessary skills for effectively communicating with PWIDD has been a primary concern amongst palliative care providers for some time.[iii, iv]
- There are some basic practices which can help address this challenge.

Setting up the environment:

- Choose times that work for the person (i.e., accommodate their preferred time).
- Ensure the person is wearing their glasses and hearing aids (if applicable).
- Sit face-to-face with the person in a quiet, well-lit environment, away from distractions.
- Involve someone who knows the person well and is trusted by them as a communication support. This person should be able to assist with the interpretation of the person's communication, if necessary. They can also reinforce the person's understanding between visits. ***If a substitute decision maker is deemed necessary, ensure they are present.***
- If the person has a communication book or communication aid, ensure it is used.
- If the person uses sign language, ensure there is someone available to sign with them.
- Allow plenty of time:
    - Do not speak quickly.
    - Give the person ample time to process information and respond.
    - Allow time for the person to express their needs, hopes, wishes, fears and to be included in care, and participate meaningfully in their own care decisions.
    - Booking sufficient time for the conversation(s) is important.

COMMUNICATING WITH THE PERSON WITH IDD

Communicate clearly

Attentively listen and observe

Responsibly address concerns during the healthcare visit

Engaging the patient and others as needed[i]

Ethical Reminder: Essential conversations are not only important for the person with IDD who has a serious illness, but also for people with IDD who live with the person or who care about them.

Communication style:

- Use short, simple sentences.
- Avoid complex or abstract vocabulary; explain things in concrete terms.
- Break information down and provide it in small pieces.
- Repeat information if necessary.
- Use the person's own frame of reference.
- Check for understanding by asking the person to tell you what you have said – ***DO NOT*** simply ask '***Do you understand?***'
- Wherever possible, ***SHOW*** someone something as well as telling them.
- Verbal speech can be supported by:
  - Non-verbal means (e.g., gestures, eye contact, facial expression, signs).
  - Visual aids (e.g., photographs, pictures, symbols).
- Be alert to the person's non-verbal communication. If uncertain, seek assistance from someone who understands their communication well.
- Touch can be very important, especially in the late stages of an illness.
- Providing a simple summary of discussions and information to the person's primary caregiver allows for them to review the information with the individual and ensure understanding.

HEALTHCARE CONSENT

"Presumption of capacity is … a fundamental human right for people with intellectual disability." [iii]

Ethics Pearl: Equitable access to palliative care includes accessible and adaptive communication for the individual person.

RESOURCE LINKS and TOOLS

- Books Beyond Words uses only pictures to help people with IDD understand complex concepts.
- Communicate Care: A Curriculum of Caring for People with Developmental Disabilities is designed to help healthcare professionals effectively care for people with developmental disabilities.
- The DDPCP (Developmental Disabilities Primary Care Program) has a number of resources:
  - Communicate Care provides more detailed information on good practices in communication with a PWIDD in healthcare settings.
  - Adaptive Functioning and Communication for Adults with IDD explains the impact of different levels of intellectual and adaptive functioning on the person's conceptual, communication, social, and practical skills.
- Talking End of Life … with people with intellectual disability (TEL) demonstrates how to teach people with intellectual disability about the end-of-life.
  - Designed for disability support workers, but is also helpful for others including: families, healthcare professionals, and educators. Consists of an online toolkit, modules, videos, and other resources. This resource was created in Australia.

HEALTHCARE CONSENT: INVOLVING THE PERSON WITH IDD IN DECISIONS REGARDING THEIR CARE

- Every person has the right to participate in decisions concerning their own medical treatment.
- PWIDD have the right to be accommodated to demonstrate their capacity to make a certain healthcare decision.[v]
- The United Nations' Convention on the Rights of Persons with Disabilities recognizes the right of people with disabilities to have the necessary supports to realize their equal standing with others before the law.[vi]
- Regardless of the severity of the person's disability, there are ways to support their participation in these essential conversations.[vii]

Ethics Pearl: PWIDD are entitled to the same respect and consideration afforded everyone else. If they understand and appreciate the consequences of their decision, regardless of how they communicate this, they are capable.

ACTION: "GOOD" PRACTICE STANDARD

- DO NOT assume that the patient with IDD lacks the capacity to participate in decisions.[viii]
- Identify and provide any accommodations the patient may need to support their active participation in the care decision at hand.
- Consider including someone who knows the patient very well (e.g., paid or unpaid primary caregiver) who could help the patient to respond to the healthcare provider who is assessing their decision-making capacity.
- When supporting someone with severe or profound IDD, an emotionally involved support network is needed to properly represent the expressed wishes and goals of the person.[vii]
- Once you've made the necessary accommodations, assess the person's capacity to make the decision at hand and, if necessary, involve the person's *Substitute Decision Maker (SDM)*.
    - If the individual is unable to meet the capacity requirements, they will require an *SDM*, according to the SDM hierarchy outlined in the Health Care Consent Act (Ontario).
    - If no person in the hierarchy is willing or available, the Public Guardian and Trustee will be their *SDM*.
- In Ontario, *Supported Decision-Making* does not have a legal framework. Regardless, the principles of supportive decision making should be incorporated in *Health Care Consent*, *Advance Care Planning*, and *Goals of Care*.
- In cases where the person with IDD has capacity to appoint a Power of Attorney for personal care, or they want to have support in decision making, they should have the opportunity to identify their preferred person.

Ethics Pearl: Ethics encompasses principles, virtues, values, as well as legislation and standards of practice, which are the *minimum* of ethical care.

RESOURCE LINKS and TOOLS

- The DDPCP has developed a guide for Canadian healthcare providers who assess legal capacity of adults with IDD:
  - Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities
- Action guide to understanding legal capacity and supported decision making

ADVANCE CARE PLANNING WITH THE PERSON WITH IDD

- Caregivers often avoid including the person with IDD in end-of-life activities and discussions for fear that they may become upset or psychologically harmed.[ix] This avoidance can potentially exacerbate the grief experienced by the person with IDD.[x]
- It is recommended that PWIDD undergoing life-phase changes, such as the transition into palliative care, receive early preparation.[xi]
- The person does not have to pass a legal capacity test to contribute to this process.[xii]
- The role of the person in *Advance Care Planning* discussions is to express their wishes and preferences.[xiii]
- *Advance Care Planning* clarifies the persons hopes, wishes, values, goals, fears, and preferences regarding future healthcare.

ADVANCE CARE PLANNING

"People with IDD should have all the necessary support, including advocacy, in order to enable their involvement in End-of-Life decision making." [viii]

Ethical Reminder:
Open communication should happen early and be ongoing so trust can be established and maintained.

ACTION: "GOOD" PRACTICE STANDARD

ADVANCE CARE PLAN (ACP)

- *ACPs* are typically developed for end-of-life care but are important to have for any serious healthcare event when the *SDM* will need to make decisions. The key is to focus on what the person would want and not the *SDM*'s own opinion or wishes.
- *Advance Care Planning* should occur before a person is diagnosed with a life-limiting illness. This planning can take place anywhere along the life journey.
    - *Advance Care Planning* is a process of multiple conversations to help a person and their *SDM* prepare for future health care decisions.
- Any *ACP* needs to be evaluated and updated regularly. This should occur after transitions in care or changes to the person's functional or health status. Include the person's *Circle of Support* in these reviews.
- Whether discussing *Advance Care Planning* with a person with IDD or helping them cope with the serious illness and expected death of a loved one or housemate, resources adapted for a person with IDD can be helpful.
- Enquiring about the life story of a person with IDD (including awareness of loss and trauma) informs us about what they find meaning in and what is important to them (e.g., how they find peace and quiet, who they like to have around them, what activities they like, and how they respond to change).

RESOURCE LINKS and TOOLS

- Regardless of the setting in which palliative care is going to be provided, if the treatment plan includes no CPR, in Ontario the DNR confirmation (DNR-C) form must be completed. This form provides direction to emergency responders (i.e., paramedics and firefighters) in the community regarding a person's resuscitation status.
- The following tool (from Ireland) can be used to facilitate *Advance Care Planning* with people with IDD:
    - Accessible Planning Tool: Glancing Back Planning Forward

- Books Beyond Words (UK) has some particularly relevant resources:
  - Am I Going to Die
  - Getting on With Cancer
  - Going into Hospital
- Advance Care Planning: A Guide for Caregivers of Adults with Intellectual and Developmental Disabilities
- The Victoria and Stuart Project: End of life care planning with people with intellectual disabilities (UK) codesigned a toolkit for end-of-life care planning with people with IDD. The toolkit was informed by the experience of PWIDD, developmental support staff, and healthcare professionals and includes modules, videos, and other resources.
- Understandable is the private website of Dr. Nic McKenzie, an experienced disability professional and researcher in New Zealand. Many of the materials on the website have been developed with the contribution of PWIDD.
  - My plan for a good life, right to the end
  - Supporting People with Learning Disabilities to Develop their Advance Care Plans
  - Advance Care Planning Policy Development – Guidance for Disability Service Providers
- Improving palliative care – Toolkit for people with intellectual disability and supporters (Australia)
  - Preparing for palliative care (Plain English information sheet for PWIDD)
  - Preparing for palliative care (Easy to read information sheet for PWIDD)
  - Working together with my team (Plain English planning sheet)
  - Working together with my team (Easy to read planning sheet)
- Living Well: Thinking and planning for the end of your life (Helen Sanderson Associates; UK)
- End of Life Planning: A guide for staff teams

GOALS OF CARE AND TREATMENT PLANNING WITH THE PERSON WITH IDD

- In striving for the best quality of life, as defined by the person, the discussion should centre around what's important to them and brings them joy and purpose. Ensure involvement of all people who can provide important insights regarding the individual and their care needs.
- Review the Communicating with the Person with IDD section for tips and strategies.
- Involve someone who knows the person well and is trusted by them as a communication support.
- These conversations are fluid and as the person's illness progresses, they should be revisited as necessary.

ACTION: "GOOD" PRACTICE STANDARD

GOALS OF CARE (GOC)

- If the person with IDD has an *ACP*, it should be reviewed and inform the goals of care discussion, as applicable.
- If you need to inform the person of a new life-limiting illness, broach the conversation gradually rather than delivering bad news in a single discussion.[xiv]
    - Do not assume that PWIDD do not want to, or cannot, discuss death. Some individuals will want to talk about death, and some will not. Allow them to choose.
- The Serious Illness Conversation Guide[xv] provides advice on what these discussions should include:
    - Set up the conversation (as described above in this module).
    - Assess illness understanding and information preferences.
    - Share prognosis.
    - Explore key topics (e.g., goals, fears and worry, trade-offs, sources of strength).
    - Close the conversation (e.g., summarizing and making a recommendation).
    - Document these conversations and share them with key clinicians and other stakeholders.
- Keep the following practice in mind:
    - Reflect on your own biases and perspectives and consider asking the following:
        - *What do I need to know about you [or your family member] as a person to give you the best care possible?*[xvi]
        - *Do unto patients as they would want done unto themselves.*[xvi]

GOALS OF CARE AND TREATMENT PLANNING

Reflect on your own biases and perspective and consider asking:

What do I need to know about you [or your family member] as a person to give you/them the best care possible?

Do unto patients as they would want done unto themselves.

Ethical Reminder:

It is important to keep the person's history in mind during all interactions to avoid re-traumatization. Trauma-informed care approaches are essential for people with IDD. This requires inclusion of their Circle of Support (including their direct support worker).

RESOURCE LINKS and TOOLS

- The Serious Illness Conversation Guide outlines the key steps in goals of care discussions:
  - Serious Illness Conversation Guide
- Resources from the College of Physicians and Surgeons of Ontario:
  - Decision-Making for End-of-Life Care (policy)
  - Advice to the Profession: End-of-Life Care
  - Guide for Patients and Caregivers

TRANSFER AND CONTINUITY

- PWIDD often prefer to be surrounded by familiar people and things and appreciate the care they can get in their own home (including group homes).[xvi] Unfortunately, it is not always possible for them to receive the care they need in their usual environment.
- If the person with IDD wants to live somewhere other than where the caregivers, healthcare providers, or relatives deem appropriate, respect for their autonomy must be considered.[xvii]
- A key factor affecting the end-of-life experience for PWIDD is the location where they die; most preferring to do so in a familiar environment (e.g., home) and with the people they consider family and loved ones.[xviii, xix]
- When the person's needs exceed the capacity of their care staff (e.g., in the group home), this may necessitate transfer into a different environment (e.g., residential hospice, palliative care unit) and/or as needed, alternative spaces (e.g., long-term care).
- A change in environment can be especially stressful for PWIDD because of the importance of routine and familiarity (of both surroundings and people).[xx] This stress can be exacerbated if the new setting is not familiar with caring for PWIDD.
- If the caregivers (e.g., family, *Developmental Services Team*), primary care, and the *Palliative Care Specialists* start a collaborative process, a co-designed care plan can be helpful.[xviii]

TRANSFER AND CONTINUITY

Many older PWIDD have experienced significant trauma; some of this involving past institutionalization.

"Transitions to hospital or to other accommodation settings can trigger their memories, exacerbate their trauma and heighten their vulnerability." [xvi]

ACTION: "GOOD" PRACTICE STANDARD

Supporting a patient with IDD in the hospital:

- Identify the people who know the person with IDD best, are best able to communicate with them, and best able to relay their wishes.
- If a primary caregiver (paid or unpaid) accompanies the patient, this person can be a valuable support in helping the person with IDD communicate symptoms and their *Goals of Care* to the care team.
- The primary caregiver can also help communicate the proposed treatment plan to the person with IDD.
- PWIDD may be accompanied by a specialized form containing key information regarding their medical and communication needs and suggested accommodations.
- It is important that the care team understand how the individual communicates, including behaviours that indicate distress, pain, and needs.
- PWIDD may rely on non-verbal, verbal, and/or augmentative forms of communication.
- Refer to the practice points and resources provided in the *Communicating with the Person with IDD* section (above).

Implementation of the DNR-C form (Ontario):

- Regardless of the setting in which palliative care is going to be provided, if the treatment plan states that no CPR is to be given, the DNR-C form must be completed.
- This form directs the actions of paramedics and firefighters and must be signed by one of the following healthcare practitioners:
    - Physician (MD)
    - Registered Nurse (RN)
    - Nurse Practitioner/Registered Nurse (Extended Class) (RN (EC))
    - Registered Practical Nurse (RPN)
- Is a durable and portable document, meaning that the form follows the person across care settings.
- Form has no expiry date but is not necessarily permanent. Can change based on person's condition and wishes and be revoked at any time.
- First responders may require the original, but form may be photocopied once signed.
- To access the form, fill a Form Order Request at https://forms.mgcs.gov.on.ca/dataset/014-0350-93 and email the completed form to OSSDistribution@ontario.ca.

Ethical Reminder: In cases of expected death, where CPR has been discussed and the decision made not to proceed with resuscitative measures, this treatment needs to be upheld, and the wishes of the person respected. This affirms both the autonomy and the dignity of the person.

Preparing to transition the Person with IDD to palliative care:

Successful transitions in care planning and outcomes require a collaborative approach with all sectors of healthcare. Regardless of the present and proposed settings of care, the best outcomes will be assured if the developmental sector, primary care, and palliative care sectors work together to plan, implement, and update services as changes occur.

The resources and supports available to family and PWIDD in *Supported Independent Living (SIL)* or independent living environments will vary depending on the region. It may or may not be possible to move someone from *SIL* to a higher support group living situation with the same agency. Acknowledging that services maybe be fragmented or not uniformly available, it is important to include care providers with knowledge of local resources in the planning and implementation of care. This fragmentation of resources may mean that PWIDD may need to plan for transition to another setting of care if their needs can't be met in their preferred place.

Ethical Reminder: All transitions in care, including discharge planning, require collaboration with the person's circle of support and should include DS sector and the person's direct support worker.

Below are some recommendations to guide the important work of transitions in care planning.

- Transition or transfer between care settings, in addition to preparing the person with IDD and their family, should include the person's *Circle of Support* (e.g., their relatives, friends, previous care staff and fellow residents), especially if these people can pay regular visits.
- Consider connecting the people in the person with IDD's *Circle of Support* to hospice services that make home visits.
- When the person with IDD's needs exceed the capacity of the group home, transfer into a palliative care setting may occur (losing the context of staff who are comfortable and competent):
    - Involve the group home staff in the transition.

- To the person's home:
    - For the healthcare sector:
        - Whether the person with IDD lives in a group home or family home, ensure consultation with the home and community care palliative team prior to discharge to help arrange a thoughtful planned approach to care.
        - Ensure that staff or family are provided with the education and resources necessary to facilitate care in their home.
        - It is important to understand which skills *Direct Support Workers (DSWs)* in the developmental sector have and which they do not have.
        - *DSWs* cannot administer IVs; nor are they able to administer all medications.
        - *DSWs* are skilled in supporting communication with the person with IDD.
    - For the developmental service sector:
        - Establish a concrete plan, including collaboration with the home and community care palliative team, before the person returns home.
        - Once the person with IDD is identified as benefiting from a palliative approach to care, request a care conference (including family and *Developmental Services* staff support as applicable). If the person is in acute care, ideally the case conference occurs prior to discharge.
        - Consider potential future care needs, including transfer to a residential hospice, palliative care unit, or hospital, if necessary.
        - Continue to stay connected with the home and community care support services palliative team and reassess routinely.
            - They can provide various supports.
        - Make connections with the palliative care health care providers in the community.
        - Access the necessary training for staff.
        - Assess the home environment and any adaptations that may be required to support changing care needs (e.g., mobility devices, lifts, etc.).
        - Create the associated policies and procedures to support provision of palliative care (e.g., DNR, Edith protocol, etc.)
        - Medication for end-of-life; palliative care and PRN sheets.
        - Review with the person whom they would like to have visit them and the conditions of such visits.
        - Planning for death: If death is expected, complete the Expected Death in the Home (EDITH) protocol.

- To a palliative care setting (e.g., residential hospice, palliative care unit, alternative space, and/or a long-term care setting):
    - For the healthcare sector:
        - Give as much notice as possible to the family and/or *Developmental Services Care Team* so they can prepare the person with IDD for transition.
        - Try to minimize the number of transfers when creating a plan.
        - Arrange a care conference with the person's *Circle of Support* shortly after admission.

        - To enhance continuity of care, collaborate with their previous care team. This may include family, *Developmental Services* staff, etc.
        - Review the person's documentation (which may be provided as a binder). Refer to the section below for a description of typical contents.

    - For the developmental sector:
        - If the person is offered a bed in a palliative care setting, it can happen quickly. Once a bed offer is made, an immediate commitment to the room is often required and transfer is often within a day. Being prepared to share important information about the person with IDD with the new care team is helpful and can ease the transition.
        - Consider preparing a document (or binder) that incorporates the person with IDD's important contacts (including decision makers), previous health information, current care needs, their personal plan, behaviour support plan (if applicable), communication strategies, likes, dislikes, and triggers.
        - Preparing for a move to long-term care may seem like a lengthy process; however, the move itself often feels sudden.

RESOURCE LINKS and TOOLS

- Decision-making about the best place of palliative care for people with intellectual disabilities
    - Includes a decision-making chart (pp.19-20) which can be used as an aid in reaching these decisions.
- COVID-19 Hospital Transfer Form for Patients with Intellectual and Developmental Disabilities
- Ensure personal clinician to clinician information transfer
- Hospital discharge checklist
- Do Not Resuscitate Confirmation Form (Presentation)
- *Transitioning to Long-Term Care* (see Appendix A)

APPENDIX A
TRANSITIONING TO LONG-TERM CARE

This tip-sheet offers guidance for families and professional caregivers supporting adults with intellectual and/or developmental disabilities preparing to move into a long-term care home. It provides suggestions of important information to share, what to bring on moving day and strategies for communicating with the long-term care home.

Preparing for a move to long-term care may seem like a lengthy process, however, the move itself often feels sudden. Once a bed offer is made, it is common for the long-term care home to require an immediate commitment to the room and to request a move-in date be scheduled within a few days. Being prepared to share important information with the long-term care team about the person moving in is helpful and can ease the transition.

Consider preparing the following information to share:

- A brief life story.
- Most recent Individualized Support Plan or Person Directed Plan, if applicable.
- Previous medical assessments or reports.
- Information on mobility: type of assistance required; any mobility aids used.
- Other assistive devices used: hearing aids, glasses, dentures.
- Information on any prescheduled appointments.
- Current medications in original labelled containers or blister packs.
- Likes: music, TV shows, movies, hobbies, interests, foods, etc.
- Dislikes: foods, specific triggers, fears, etc.
- Comfort strategies: what helps the person when they are sad, mad, or afraid.
- Information on how the person communicates: language(s) they speak, communication aids - any strategies that may be helpful to share.
- Religious, spiritual, or cultural considerations.
- Support strategies: social stories, visual schedules, Behaviour Support Plan, if applicable.
- Current hygiene routines and type of assistance required.
- List of decision makers and contacts: *Substitute Decision Maker*, Power of Attorney or Public Guardian and Trustee, if applicable.
- Relevant legal information.
- Relevant financial information - consider Passport Funding.
- Information on advance care planning.
- Room décor & set up - consider setting up the room to be similar to their current bedroom.
- Inventory list of items moving in - items will be labelled upon admission.

Communication:

- Many long-term care homes have Social Work Counsellors who provide support during admission and transition to the home.
- Post-admission care conferences occur approximately 6 weeks after admission and provide an opportunity to formally connect with the new care team. The care conference will often include a review of assessments and care plans and include care team feedback on how the person is adjusting to their new environment. The care conference is a great opportunity to provide information on any developmental services supports that may remain in place or to explain the person's discharge from developmental services supports.
- If developmental services supports are unable to remain involved, consider advocating that the individual be referred to volunteer services for support and friendly visiting.
- Ensure that the recreation team has been activated and that the person is being encouraged to participate in recreational programs.
- Explore any specialized supports available that may be of interest to the person such as art or music therapy.
- Consider Passport Funding and how this may be used to support a person in long-term care. Ensure that the funds will continue to be appropriately managed for the person if they are unable to manage the funds themselves. Consider using Passport Funding to arrange for 1:1 support and ongoing community participation.

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