Dadu Shin NY Times Sept 2019

Tools for the IDD Palliative Care Journey: Specialized Intellectual/Developmental Disabilities (IDD) Palliative Care Toolkit for Ontario

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Speaker Disclosure of Affiliations, Financial and In-Kind Support

Affiliations:

- I have no relationships with for-profit or not-for-profit organizations.

Financial Support:

- This session/program has not received financial or in-kind support.

Learning Objectives

1. Outline the key elements of the new palliative care framework for individuals with IDD.

2. Use the framework to identify palliative care needs in patients with IDD.

3. Apply the framework and resources to address the palliative care needs of patients with IDD

Question

How comfortable are you in the delivery of IDD specific palliative care?

a) Not comfortable at all
b) Some comfort
c) Comfortable
d) Very comfortable

Observation and Assessment for Dementia and Delirium

https://www.the-ntg.org/ntg-edsd

NTG-EDSD

v.1/2022.3

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID,* can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the cognitive impairment assessment that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.the-ntg.org/ntg-edsd).

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(1) File #: ______________________ (2) Date: ______________________

Name of person: (3) First ______________________ (4) Last: ______________________

(5) Date of birth: ______________________ (6) Age: ______________________

(7) Sex:

	Female
	Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (*check all that apply*)

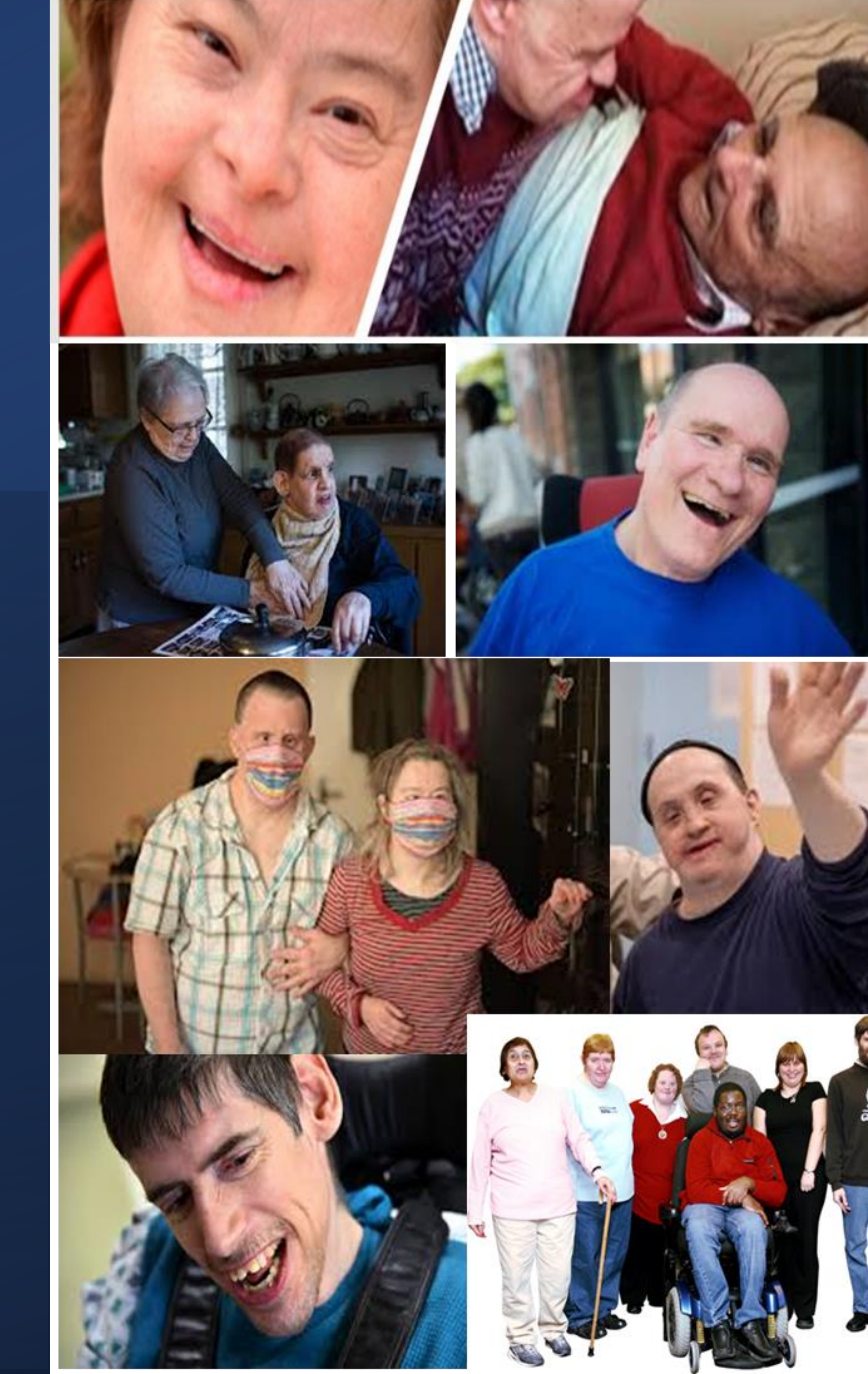
	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:
- □ Lives alone
- □ Lives with spouse or friends
- □ Lives with parents or other family members
- □ Lives with paid caregiver
- □ Lives in community group home, apartment, supervised housing, etc.
- □ Lives in senior housing
- □ Lives in congregate residential setting
- □ Lives in long term care facility
- □ Lives in other: ______________________

Palliative Care

How people die remains the memory of those that live on
-Cicely Saunders

Distinct Palliative Needs of People Living with IDD



Unique Palliative Care Needs

- People living with IDD are not always in family homes; they live in a variety of unique circumstances and settings (e.g., SIL, group/congregate living, etc.,) different to general population (Frances)
- The diverse living arrangements and support needs create challenges that don't exist for the general population.
- Take-home message is that this can be done in Developmental Services, and the goal of this toolkit is to bridge the gap and make the process smoother for everyone.

Inequitable Access to Palliative Care

- People with IDD lack equitable access to quality palliative care
- Most IDD etiologies are life-limiting
- Healthcare disparities result in high use of Emergency Department
- More likely to make 30-day repeat ED visits; late identification and pre-mature death
- PwIDD would benefit from a palliative approach to care, opportunity to positively impact their experiences
  - Provider competency in IDD-focused palliative care
  - Intentional PC Team design combining Developmental Services, Healthcare and PC specialists

(Balogh et al., 2018; Durbin et al., 2019; York et al., 2022)

Recent History
Resulting in a fear of institutional settings
History of Trauma
Being Separated from family

Palliative Care Provider Confidence

- Limited providers with competency in IDD palliative care
- Existing palliative care guidelines and tools not directly transferable to PwIDD
  - Knowledge-to-Action Frameworks requires collaborative practice to meet needs of PwIDD

- Big Dot aims of provincial palliative care strategy not in view
  - Population invisible to PC providers
  - Under-serviced by community-based PC providers
  - Hospital deaths, but preferred death in home with team who knows them best

Question

Do you use any IDD specific palliative care tools in your practice or organization?

a) Yes
b) No
c) Not sure

Role of the IDD Palliative Care Toolkit in Improving Shared Care

IDD PALLIATIVE CARE RESOURCE GUIDE AND TOOLKIT

Executive Summary and Introduction
How to Use this Toolkit

Module A- Essential Conversations

Module B- Domains of Care Needs_Norms of Practice

Module C- CarePathway_HDSF_Integrated Team

Module D- Loss, Grief and Bereavement

Module E- Earlier Identification

Module F- Pain

Module G- Symptom Identification

Module H- Metrics

Glossary of Terms
IDD Specific Tools Summary
Key Resources Link

MODULE B
A PALLIATIVE APPROACH TO CARE
DOMAINS of HOLISTIC CARE/NORMS OF PRACTICE
GUIDANCE

DOMAINS of ILLNESS and BEREAVEMENT ASSOCIATED WITH LIFE-LIMITING ILLNESS/CONDITIONS[1]

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".

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[1]
  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[2,3]
  - 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

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.

IDD Palliative Care Resource Guide and Toolkit, IDD Palliative Care Network, 2024

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IDDPC Toolkit Is A 3-STEP FRAMEWORK

1. Identify | Screen

2. Observe | Assess

3. Plan | Manage

IDENTIFY & SCREEN

- **Who Would Benefit** from a Palliative Care Approach
- Proactive approach to Early Identification
- Identify Needs using validated screening tools

OBSERVE & ASSESS

- **Holistic Assessment** the person's current and future needs and preferences across all domains of care
- Screen for Pain and Symptoms using IDD validated screening tools
- Explore symptoms and needs across all domains in more detail through history; assessment and physical examination
- Continue to screen regularly for distress and other needs
- Conversation and Consent Tools

PLAN & MANAGE

- **Integrated care** planning to meet current and future needs
- This includes prompt management of symptoms and coordination between IDD sector and Healthcare sector providers into formal collaborative team

Module A: Essential Conversations

Advance Care Planning; Goals of Care; Health Care Consent/ Supported Decision-Making Guidance

Capacity

Breaking Bad News

Supported Decision Making

- Supported Decision Making is a formal process, not just “something nice we do”
- Seeks to use abilities and resources to facilitate participation in decision making
- Acknowledges the dignity and worth of each person we work with and care for

Supported Decision Making Tool

What is the decision?	Who are the right people to assist? Where is the right place?	What's the right way to talk about the decision?	What's the right way to present the information?	How can we assist the person to weigh it up?	How do we hear the person's decision?	How do we support the person to act on their decision?
Be clear about the actual decision.	What knowledge of the person and bias do they bring?	What do we know about the person's preferred way of communicating?	What works best for the person, for example photos, real experiences?	For example, using scales, listing what's important to and for the person, having a short term trial.	What verbal and non-verbal communication will you be looking for?	Who will observe how the person is responding and for how long?
– Assume I can make decisions & involve me – Tell me the truth – Let me make one decision at a time – Give me time to think about it – Ask & understand my preferences – I have the right to learn from trying	– Who I want involved & they want to be involved too help me – Who make sure my voice is heard – People closest to me & know me best – Who have a positive relationship with me – Who I trust & rely on – Who understand me – Who think about problems that might come up	Communicating may be in a way that: – only I use – only people who know me well understand By: – Micro expressions – Vocalizations – Body language – Sign language – Objects or Photos – Drawings or Symbols	– Plain language – In a way I can understand – I may be able to understand only a little bit of information at a time – Visuals – Photos – Videos	– Remember that it's up to me – Let me change my mind How will it affect: – My life and dreams? – What is important to me? – My life now and how could it change? – What good things can happen and what could go wrong?	– Hear me in the way I communicate – Understand what I want – Understand what I say is right for me – Understand why it is important to me – Respect my decision	– Understand what I am trying to achieve – My beliefs – What needs to be put in place – What needs to be completed – What needs to be planned for – Get help from my Family (if involved), My Direct Support Worker and Developmental Specialist Team

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https://waindividualisedservices.org.au/resources/supported-decision-making

IDD – PALLIATIVE CARE APPROACH PROCESS & DECISION-MAKING

STEP 1

DECISION 1

Would the individual benefit from a palliative care approach?

- Life-limiting IDD etiology
- Progressive, life-limiting illness
- Acute serious or life-threatening illness

DECISION 2

Are you aware of their Advanced Care Plan and wishes?

- NO: Conduct ACP conversation
- YES: Ensure ACP recorded in care plan

STEP 2

DECISION 3

Who knows the person best?

- SDM
- CORE TEAM

DECISION 4

AVOID

- Diagnostic overshadowing
- Unintentional bias

DO

- Assume capacity until PROVEN otherwise
- Use Supportive Decision Making
- Dignity in Care Model

STEP 3

WHAT IS THE ILLNESS TRAJECTORY?

- IDD etiology
- Neurodegenerative frailty
- Organ failure
- Cancer

WHAT IS THE STAGE OF ILLNESS?

- Acute, new diagnosis
- Controlled chronic
- Advanced chronic
- End-stage
- End of life

ARE THERE CHANGES?

What is the pattern of decline from baseline?

- Stable progressive decline
- Unstable, erratic decline
- Frequent exacerbations
- Recurrent ER visits/Hospital admission

STEP 4

SCREEN WITH TOOLs to support Earlier ID

- HELP
- SPICT-4 ALL
- GSF
- NTG

SCREEN FOR CHANGES

- NTG (dementia)
- STOP & WATCH
- PALLI-Tool

SCREEN FOR PAIN & SYMPTOMS

- ESAS or 4-Point Scale
- CPS-NAID & DISDAT
- DOLOPLUS
- PACSLAC

SCREEN FAMILY & CAREGIVER EXHAUSTION and SUPPORT NEEDS

- Burden Scale for Family & Caregivers
- FAMCARE
- NCCN Distress Thermometer

STEP 5

SCREEN & ASSESS NEEDS

- All 8 Domains

TEAM COMPOSITION

- Who is the team involved?
- Is the right mix of interdisciplinary team members involved from both IDD and Healthcare?
- CORE TEAM
- EXTENDED TEAM
- PALLIATIVE CARE SPECIALISTS
- If NO, Refer

ASSESSMENT

- Explore Symptoms & Needs in a more detailed assessment
- By most appropriate discipline & provider

STEP 6

GOALS of CARE/ CONSET TOOLS

Ensure results of screening & assessment prompt further discussions about

- wishes, values, hopes, beliefs
- understanding of wellness and any illnesses
- goals for current and future care

Tools to Support

GOC/Consent

- Supportive Decision-Making Tools

These conversations are ongoing and revisited regularly, conducted

- directly with the person living with IDD
- their chosen person(s) who know them best; SDM

OUTCOME

Right care

- for stage of illness

Right Place

- Primary care as appropriate
- Specialist Clinic
- ER/ Hospital as appropriate
- Preferred location EOL

Right Time

- Earlier
- Proactive vs crisis management

Right Team

- Developmental Services Working with Healthcare

Right Communication

- Unimpaired between Developmental Services and Healthcare
- SBAR/SBOR
- Connecting Ontario
- Shared Chart
- Proactive ADP
- GOC with supportive decision making

REPEAT STEPS 3 – 6 All along the illness journey

IDD PALLIATIVE CARE COMMITTEE

DRAFT – IDD PCC TOOLKIT

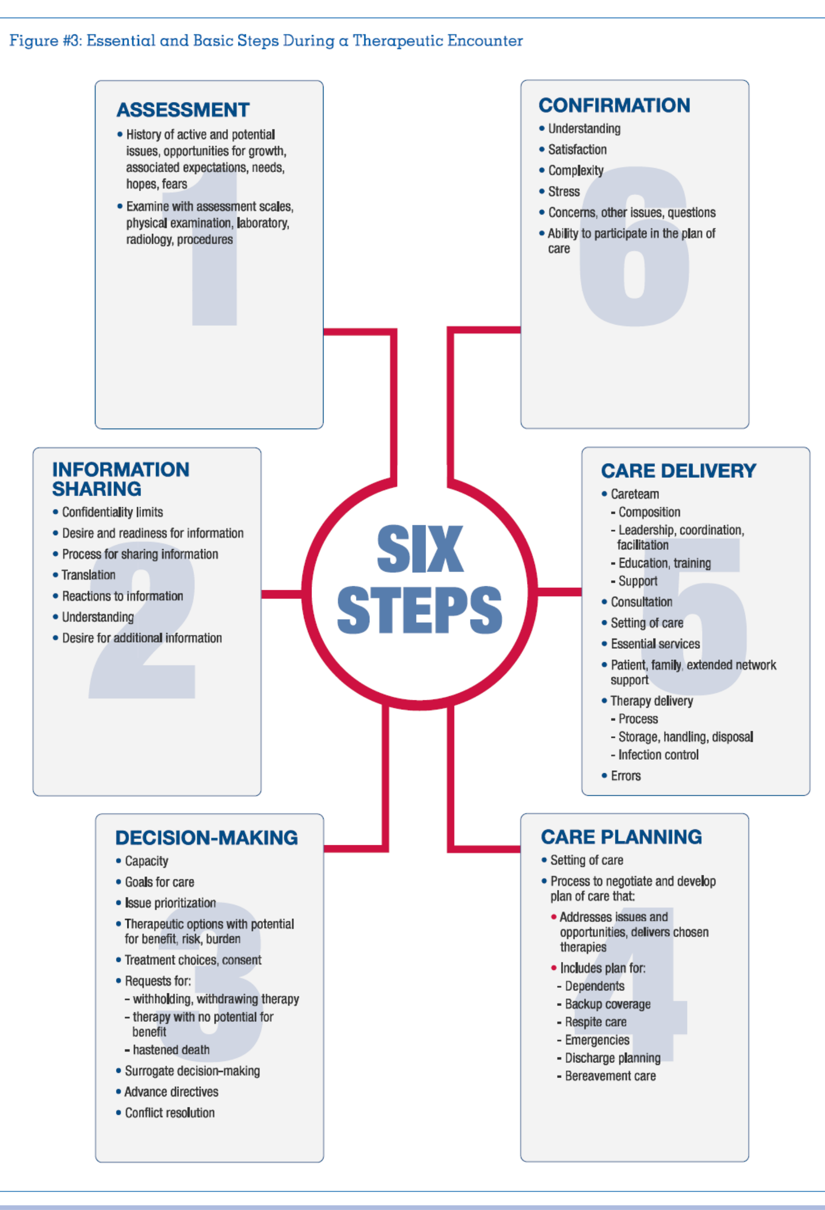
Module B: Norms of Practice

Early ID/ ER Aversion

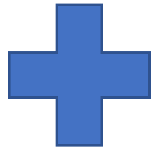
ID & Screen; Observe & Assess & TOOLS

Holistic Comprehensive Assessment

Standards & Norms of Practice



IDD SPECIFIC



PROACTIVE APPROACH TO OBSERVATIONS/ ASSESSMENT

- Recognize who would benefit from a palliative approach to care
- Recognize people with IDD have additional, special, and unique palliative care needs
- Proactive approach to identify; Screen; Observe; Assess; Plan & Manage
- Be alert to the signs of change that may be indicators of decline, serious illness, or transitions toward end of life
- Assess needs across the 8 Domains of issues associated with life-limiting conditions
- Screening and Assessment of Pain and Symptoms requires increased vigilance as may be masked or expressed in unconventional ways e.g. behaviours
- Use Screening Tools validated for use in people with IDD e.g. CPS-NAID
- Assess active and potential issues using a combination of IDD specific and palliative care gold standard Tools
- Avoid 'diagnostic overshadowing', where the symptoms of physical ill-health are attributed to the presence of IDD, putting at risk of late diagnosis, under treatment, and late referrals
- Providers and carers should be informed to recognise pain and symptoms specific to the individual
- Recognize pain and symptom management may be more complex due to the combination of IDD etiology and associated comorbidities and the benefit of timely referrals to specialist teams
- Integration and collaboration between IDD providers who know the person well and healthcare providers is crucial
- Timely referrals and engagement of palliative care expert teams is advised

INFORMATION SHARING

- Avoid assumption unable to understand and participate in directing their care
- Healthcare providers have are to understand the communication of people living with IDD. Leverage IDD providers expertise, and seek cross education opportunities
- Support to communicate their needs whether verbal or non-verbal
- Avoid and explore wishes to protect and withhold information and discussions about health, illness, death and dying
- Process for sharing information, reactions to information, processing information, and confirming understanding may be unique but does not negated the importance of discussing illness, death and dying with the individual directly
- Recognized IDD providers assist in processing "bad news" using special approaches therefore the IDD provider should be included in medical provider conversations
- Families and carers should be given techniques and support in having essential conversations
- When speaking with the person, do not speak quickly, use concrete language, short, simple phrases, the person's own frame of reference, 'chunk' information, allow time to process
- Both IDD and Medical provider teams should have timely and comprehensive access to information in order to ensure continuity of care, including during transitions between care settings (to Home; to Hospital; to Hospice)
- Use of Transfer Form(s)/Check List is advised e.g. Surrey Place Hospital Transfer Form

DECISION MAKING

- Assume capacity to make decisions around care, preferences and treatment, unless demonstrated otherwise
- Include in Advance Care Planning; Goals of Care; Needs/issue prioritization; Therapeutic options and Treatment Choices including consent to withdrawing therapies and understanding when therapies offer no potential for benefit
- End of life decision making is complex, regardless of whether or not the person is living with IDD and therefore not justification to bypass inclusion in decision making
- Enable supportive decision making facilitated by those likely to know him/her best e.g. if family are not directly involved, IDD providers have the longest relationships and know the individual the best
- Identify important relationships ('significant others') Family, partners, friends, Carers (including paid care staff). People with IDD should be involved in identifying these significant others.
- The person's wishes around involving their families at the end of life should be sought and respected
- Family bonds may be crucially important even where these bonds have been broken through lack of contact
- Healthcare providers should recognize and comprehensively involve IDD providers as expert care partners

SIX STEPS

CONFIRMATION

- Is continuous and ongoing part of the therapeutic process by the circle of care
- Understanding, Ability to participate in the plan of care, and desire for additional information
- The plan meets the person living with IDD and family's goals, values, wishes and satisfaction
- Plan of care, implementation, responsiveness, and effectiveness is revisited regularly
- Satisfaction with the process and quality of care provision is sought
- Any concerns, worries, and questions are addressed in a timely manner
- Effective communication across the care team, both written and verbal

CARE DELIVERY

- Apply Dignity Conserving Care practices
- Setting of care preferred by the person living with IDD, where carers known them best
- Care team composition should consist of IDD providers with healthcare providers
- Shared communication platform readily accessible for continuity of care is advised e.g. shared chart or Electronic Health Record (EHR)
- Ensure services to support and care for Family are included
- Ensure access to support circle for both individual/ family e.g. IDD counselling services and maintaining social network with friends who may have special support needs themselves
- Many people with IDD, including those with severe and profound IDD, are at the centre of their family's and carer's life, therefore loss, grief and bereavement experienced is often profound
- IDD providers form deep attachments to the people they support, given the unique nature and length or relationships, and should be supported in their grief when their client is dying
- Encourage healthy grieving rituals for closing the therapeutic relationship e.g. conducting Honor Guards, attending funerals, conducting memorials

PERSON DIRECTED CARE PLANNING

- Have the right to life and recognition of the value of their lives; Assumptions of inability to tolerate or adhere to treatment should be avoided
- Closely integrated care teams of both IDD providers and Healthcare providers should be the norm
- Incorporate palliative care experts due to unique and complex needs
- Inclusion in Advance Care Planning should take place as early as possible. A record of wishes, values, hopes, choices and preferences for end of life care, funeral wishes and wills should be incorporated
- Where the individual considers home is the preferred care location whenever possible, including end-of-life care with the appropriate wrap around of services and providers in order to avoid distress and decompensation.
- Early identification of changes may assist avoidable ER transfers/Hospital admission and therefore the associated distress and decompensation
- Address current needs and anticipate future needs, including potential palliative care emergencies
- Estimating the last year of life and/or transition to end of life stage should be identified as early as possible in the care pathway. Observing for indicators of status transitions/decline should be included in Individual Support Plans (ISPS)
- Transitions between care settings be aware of common language differences e.g. "transition" has a different meaning in the IDD sector from healthcare

Module C: Care Pathway & Cross Sector Collaborative Care Model

INTER-COLLABORATION TEAM APPROACH

PROVIDER & SYSTEM NAVIGATION

TRANSITIONS BETWEEN CARE SETTINGS (HOME TO ER; HOSPITAL TO HOME, ETC.)

CARE TEAM COMMUNICATION

Collaborative Practice is Necessary for Success

Healthcare providers need DS providers experienced in IDD to guide practice

DS providers need healthcare/palliative providers experience to guide Early ID; Pain and Symptom ID

Early ID – enables time for informed choices/preferences

Pain and Symptom ID leads to management – resolves allowing unethical suffering

IDD – PALLIATIVE CARE - COLLABORATIVE CARE TEAM COMPOSITION

Team evolves as needs change, as illness progresses, acute events, exacerbations, or emergencies that may occur

TEAM MEMBERS	CHRONIC ILLNESS STAGE	ADVANCED CHRONIC ILLNESS STAGE	END-STAGE ILLNESS STAGE	END OF LIFE STAGE
CARE SETTING	**Home/ Congregate living (preferred setting)**	**Home/ Congregate living (preferred setting)** **Long-term Care** **ER/ Hospital for acute event/exacerbation**	**Home/ Congregate living (preferred setting)** **Long-term Care** **ER/ Hospital for acute event/exacerbation**	**Home/ Congregate living (preferred setting)** **24/7 in residence hospice** **Palliative Care Unit (PCU)**
DEVELOPMENTAL SERVICE PROVIDER	**CORE TEAM MEMBERS** Person living with IDD, Family, SDM/Chosen person to assist with decision making with: o Direct Support Care Team (DSP, DSW, CSW) o Supported Living Services Supervisor/Manager **EXTENDED TEAM MEMBERS** o Special programs (e.g., respite, day programs) o Service Coordination o Therapists (Behavioral, Occupational, Physical) o Social Worker	**CORE TEAM MEMBERS** Person living with IDD, Family, SDM/Chosen person to assist with decision making with: o Direct Support Care Team (DSP, DSW, CSW) o Supported Living Services Supervisor and Manager **EXTENDED TEAM MEMBERS** o Special Services (e.g., Community Networks of Specialized Care, Complex Care Coordinators) o Therapists (Behavioral, Occupational) o Psychiatrists; Psychologists, Social Workers o Speech-Language Pathologists o Service Coordination (Family Support Workers, SWs) o Special programs (e.g., respite, day programs) o Bioethicist as appropriate	**CORE TEAM MEMBERS** Person living with IDD, Family, SDM/Chosen person to assist with decision making with: o Direct Support Care Team (DSP, DSW, CSW) o Transitional 1-to1 Support Staffing o Supported Living Services Supervisor and Manager **EXTENDED TEAM MEMBERS** o DS Special Services (e.g., Community Networks of Specialized Care, Complex Care Coordinators) o Therapists (Behavioral, Occupational) o Psychiatrists; Psychologists, Social Workers o Speech-Language Pathologists o Service Coordination (e.g., Family Support Workers, SWs) o Bioethicist as appropriate	**CORE TEAM MEMBERS** Person living with IDD, Family, SDM/Chosen person to assist with decision making with: o Direct Support Care Team (DSP, DSW, CSW) o Supervisor; Manager **EXTENDED TEAM MEMBERS** o DS Special Services (e.g., Community Networks of Specialized Care; Complex Care Coordinators) o DS Social Workers for grief and bereavement care o Bioethicists as appropriate
HEALTHCARE or PALLIATIVE CARE PROVIDER	**CORE TEAM** o MRMP (Primary Care MD; NP) o Specialized IDD Health Care Providers o Pharmacists **EXTENDED TEAM MEMBERS** o Care Coordinators; Case Managers o Specialists Care (neurology, psychiatry, cardiology, respirology, renal, geriatrics, acute care/ER, etc.) o Nurses; PSWs o Allied Health professionals, (e.g., dietitians, physical, occupational, recreational therapists)	**CORE TEAM** o MRMP (Primary Care MD; NP) o Specialized IDD Health Care Providers o Pharmacists **EXTENDED TEAM MEMBERS** o Care Coordinators; Case Managers o Specialists Care (neurology, psychiatry, cardiology, respirology, renal, geriatrics, acute care/ER, etc.) o Nurses; PSWs o Allied Health Professionals, (e.g., dietitians, physical, occupational, recreational therapists)	**CORE TEAM** o MRMP (Primary Care MD; NP) o Specialized IDD Health Care Providers o Pharmacists **EXTENDED TEAM MEMBERS** o Care Coordinators; Case Managers o Specialists Care (neurology, psychiatry, cardiology, respirology, renal, geriatrics, acute care/ER, etc.) o Nurses; PSWs and Allied Health Professionals, (e.g., dietitians, physical, occupational, recreational therapists) **PALLIATIVE SPECIALISTS** o Palliative Physician/NP (tertiary, home visiting) o Palliative Nurses (RN, RPN), PSWs o PPSMCs (Pain & Symptom Management Consultants) o Hospice (Intake, Inpatient, Outreach, Community programs, volunteers) o Grief & Bereavement Care; Spiritual Care	**CORE TEAM** o MRMP (Primary Care MD; NP) **EXTENDED TEAM MEMBERS** o HCCSS Care Coordinator o Respiratory Therapist **PALLIATIVE SPECIALISTS** o Physician (home visiting, PCU) o Palliative Nurse Practitioners (HCCSS home-visiting) o Pharmacist/ HCCSS Pharmacy provider o End-of-life home-visiting nursing team o End-of-life home-visiting PSW support o Hospice (Inpatient or Community) o PPSMCs (Pain & Symptom Management Consultants)

DRAFT – IDD PCC TOOLKIT

ORGANIZATIONAL POLICY & PROTOCOL GUIDANCE

- Palliative Approach to Care
- Pain Care Policy
- End of Life Policy
- Expected Death in the Home/DNR/ Coroner

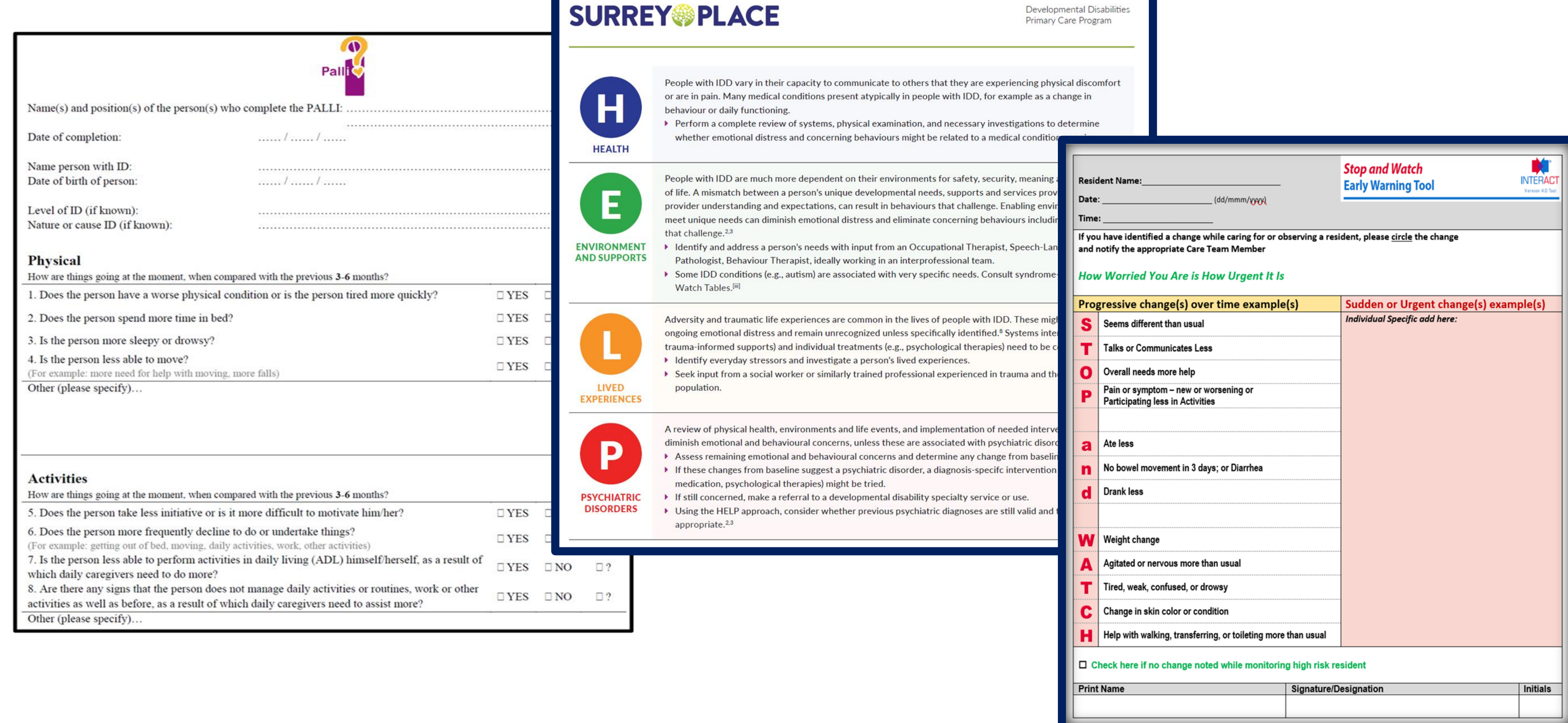
Module D: Grief and Bereavement

KEY CONSIDERATIONS

LINKING TO GUIDES & RESOURCES

CONGREGATE LIVING LOSS FOR ALL

Module E: Earlier Identification



Palli

Name(s) and position(s) of the person(s) who complete the PALLI: ....

Date of completion: ...... / ...... / ......

Name person with ID: ....
Date of birth of person: ...... / ...... / ......

Level of ID (if known): ....
Nature or cause ID (if known): ....

Physical
How are things going at the moment, when compared with the previous 3-6 months?

1. Does the person have a worse physical condition or is the person tired more quickly? ☐ YES
2. Does the person spend more time in bed? ☐ YES
3. Is the person more sleepy or drowsy? ☐ YES
4. Is the person less able to move? ☐ YES
(For example: more need for help with moving, more falls)

Other (please specify)...

Activities
How are things going at the moment, when compared with the previous 3-6 months?

5. Does the person take less initiative or is it more difficult to motivate him/her? ☐ YES
6. Does the person more frequently decline to do or undertake things? ☐ YES
(For example: getting out of bed, moving, daily activities, work, other activities)
7. Is the person less able to perform activities in daily living (ADL) himself/herself, as a result of which daily caregivers need to do more? ☐ YES ☐ NO ☐ ?
8. Are there any signs that the person does not manage daily activities or routines, work or other activities as well as before, as a result of which daily caregivers need to assist more? ☐ YES ☐ NO ☐ ?

Other (please specify)...

SURREY PLACE

Developmental Disabilities
Primary Care Program

H — HEALTH
People with IDD vary in their capacity to communicate to others that they are experiencing physical discomfort or are in pain. Many medical conditions present atypically in people with IDD, for example as a change in behaviour or daily functioning.
- Perform a complete review of systems, physical examination, and necessary investigations to determine whether emotional distress and concerning behaviours might be related to a medical conditio…

E — ENVIRONMENT AND SUPPORTS
People with IDD are much more dependent on their environments for safety, security, meaning … of life. A mismatch between a person's unique developmental needs, supports and services prov… provider understanding and expectations, can result in behaviours that challenge. Enabling envir… meet unique needs can diminish emotional distress and eliminate concerning behaviours includi… that challenge.[2,3]
- Identify and address a person's needs with input from an Occupational Therapist, Speech-Lan… Pathologist, Behaviour Therapist, ideally working in an interprofessional team.
- Some IDD conditions (e.g., autism) are associated with very specific needs. Consult syndrome-… Watch Tables.[iii]

L — LIVED EXPERIENCES
Adversity and traumatic life experiences are common in the lives of people with IDD. These mig… ongoing emotional distress and remain unrecognized unless specifically identified.[8] Systems inte… trauma-informed supports) and individual treatments (e.g., psychological therapies) need to be c…
- Identify everyday stressors and investigate a person's lived experiences.
- Seek input from a social worker or similarly trained professional experienced in trauma and th… population.

P — PSYCHIATRIC DISORDERS
A review of physical health, environments and life events, and implementation of needed interv… diminish emotional and behavioural concerns, unless these are associated with psychiatric disor…
- Assess remaining emotional and behavioural concerns and determine any change from baseli…
- If these changes from baseline suggest a psychiatric disorder, a diagnosis-specifc intervention… medication, psychological therapies) might be tried.
- If still concerned, make a referral to a developmental disability specialty service or use.
- Using the HELP approach, consider whether previous psychiatric diagnoses are still valid and … appropriate.[2,3]

Stop and Watch
Early Warning Tool
INTERACT

Resident Name: __________
Date: __________ (dd/mmm/yyyy)
Time: __________

If you have identified a change while caring for or observing a resident, please circle the change and notify the appropriate Care Team Member

How Worried You Are is How Urgent It Is

	Progressive change(s) over time example(s)	Sudden or Urgent change(s) example(s)
S	Seems different than usual	*Individual Specific add here:*
T	Talks or Communicates Less	
O	Overall needs more help	
P	Pain or symptom – new or worsening or Participating less in Activities	
a	Ate less	
n	No bowel movement in 3 days; or Diarrhea	
d	Drank less	
W	Weight change	
A	Agitated or nervous more than usual	
T	Tired, weak, confused, or drowsy	
C	Change in skin color or condition	
H	Help with walking, transferring, or toileting more than usual	

☐ Check here if no change noted while monitoring high risk resident

Print Name	Signature/Designation	Initials

SPICT-4ALL

- Encouraged to be used for education for

DS providers who typically are not clinical

- Carers and family members can often see that a person is getting less well with one or more health problems

- Aims to make it easier for everyone to recognize and talk about signs overall health may be declining so that those people and their carers get better coordinated care and support

- Uses non-medical words that makes sense to everyone and is similar to the SPICT tool for health professionals

- It can be used to help ask about more help from a doctor, a nurse or another professional

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

- Less able to manage usual activities and getting worse.
- Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

- Unable to dress, walk or eat without help.
- Eating and drinking less; difficulty with swallowing.
- Has lost control of bladder and bowel.
- Not able to communicate by speaking; not responding much to other people.
- Frequent falls; fractured hip.
- Frequent infections; pneumonia.

Nervous system problems (eg Parkinson's, MS, stroke, motor neurone disease)

- Physical and mental health are getting worse.
- More problems with speaking and communicating; swallowing is getting worse.
- Chest infections or pneumonia; breathing problems.
- Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

- Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.
- Very poor circulation in the legs; surgery is not possible.

Lung problems

- Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.
- Needs to use oxygen for most of the day and night.
- Has needed treatment with a breathing machine in the hospital.

Kidney problems

- Kidneys are failing and general health is getting poorer.
- Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

- Worsening liver problems in the past year with complications like:
  - fluid building up in the belly
  - being confused at times
  - kidneys not working well
  - infections
  - bleeding from the gullet
- A liver transplant is not possible.

Other conditions

- People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

What we can do to help this person and their family.

- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

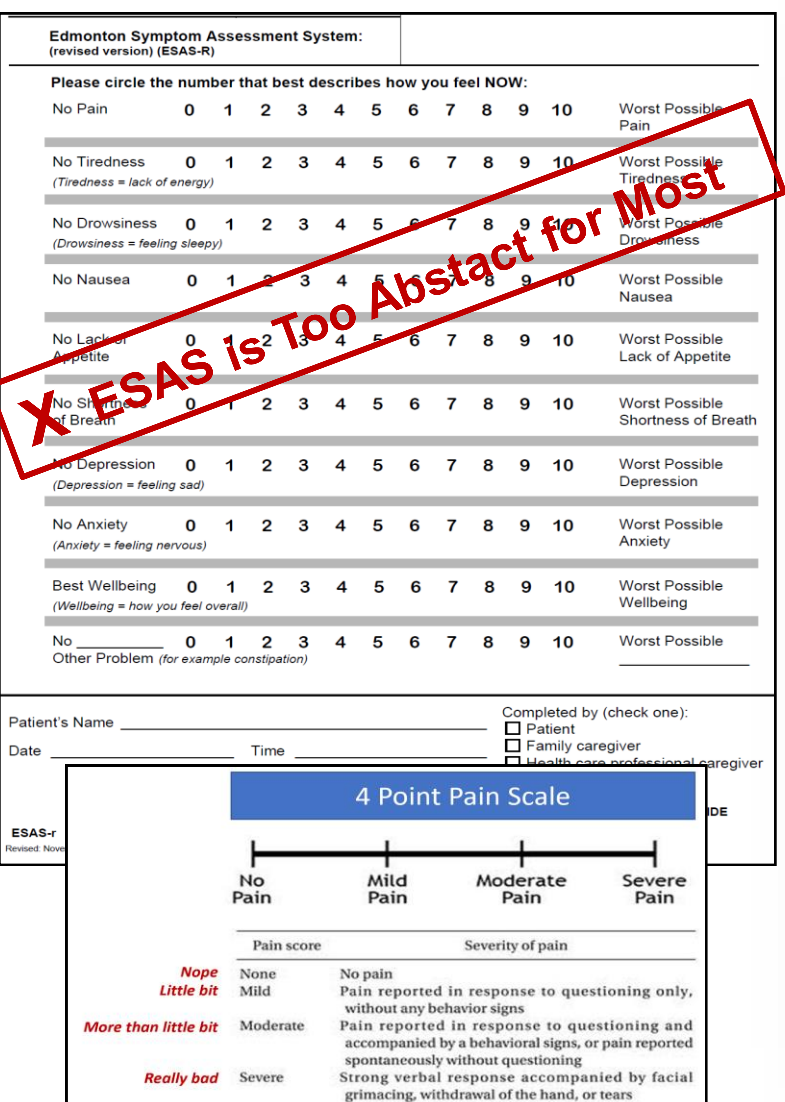
SPICT-4ALL™, June 2017

Module F: PAIN

Pain in People Living with IDD

- Unidentified, neglected, diagnostically overshadowed and untreated pain
- Chronic pain is a significant problem

Pain Screening



Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness (*Tiredness = lack of energy*)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness (*Drowsiness = feeling sleepy*)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression (*Depression = feeling sad*)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety (*Anxiety = feeling nervous*)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing (*Wellbeing = how you feel overall*)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No ______ Other Problem (*for example constipation*)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible ______

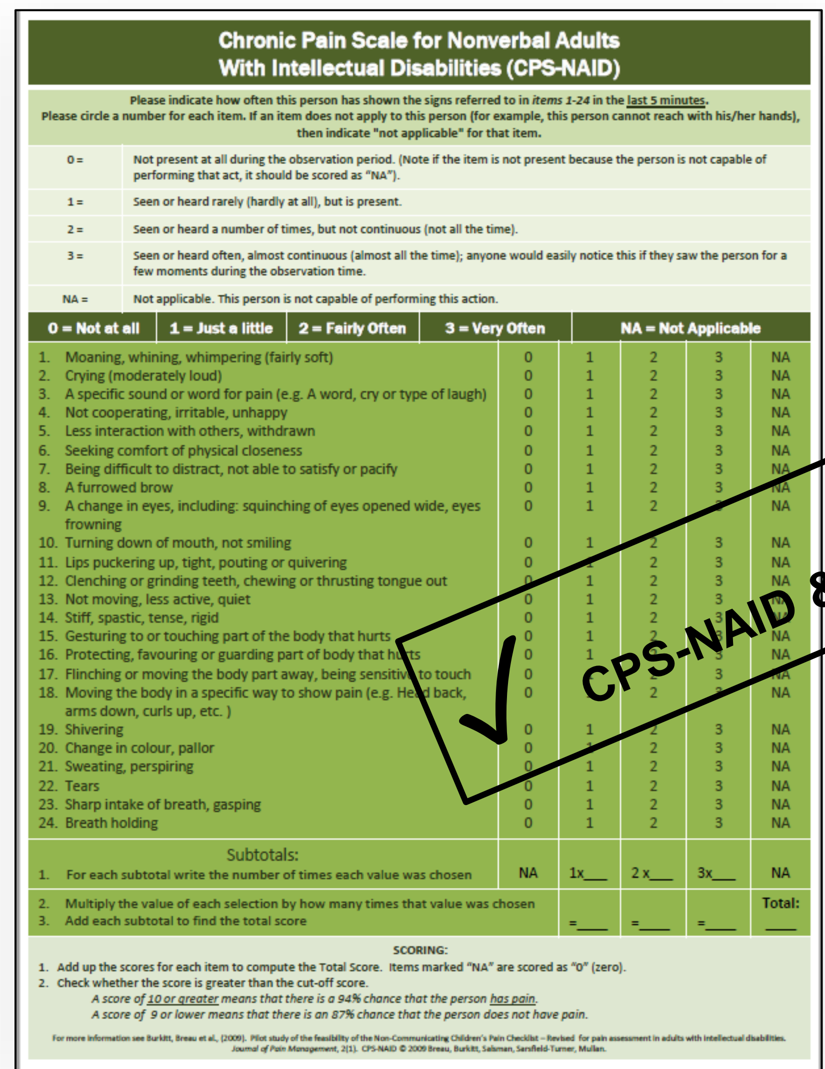
Patient's Name ______________
Date ____________ Time ____________

Completed by (check one):
☐ Patient
☐ Family caregiver
☐ Health care professional caregiver

ESAS-r

4 Point Pain Scale

	Pain score	Severity of pain
Nope	None	No pain
Little bit	Mild	Pain reported in response to questioning only, without any behavior signs
More than little bit	Moderate	Pain reported in response to questioning and accompanied by a behavioral signs, or pain reported spontaneously without questioning
Really bad	Severe	Strong verbal response accompanied by facial grimacing, withdrawal of the hand, or tears



Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Please indicate how often this person has shown the signs referred to in *items 1-24* in the last 5 minutes. Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands), then indicate "not applicable" for that item.

0 =	Not present at all during the observation period. (Note if the item is not present because the person is not capable of performing that act, it should be scored as "NA").
1 =	Seen or heard rarely (hardly at all), but is present.
2 =	Seen or heard a number of times, but not continuous (not all the time).
3 =	Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time.
NA =	Not applicable. This person is not capable of performing this action.

	0 = Not at all	1 = Just a little	2 = Fairly Often	3 = Very Often	NA = Not Applicable
1. Moaning, whining, whimpering (fairly soft)	0	1	2	3	NA
2. Crying (moderately loud)	0	1	2	3	NA
3. A specific sound or word for pain (e.g. A word, cry or type of laugh)	0	1	2	3	NA
4. Not cooperating, irritable, unhappy	0	1	2	3	NA
5. Less interaction with others, withdrawn	0	1	2	3	NA
6. Seeking comfort of physical closeness	0	1	2	3	NA
7. Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA
8. A furrowed brow	0	1	2	3	NA
9. A change in eyes, including: squinching of eyes opened wide, eyes frowning	0	1	2	3	NA
10. Turning down of mouth, not smiling	0	1	2	3	NA
11. Lips puckering up, tight, pouting or quivering	0	1	2	3	NA
12. Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA
13. Not moving, less active, quiet	0	1	2	3	NA
14. Stiff, spastic, tense, rigid	0	1	2	3	NA
15. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
16. Protecting, favouring or guarding part of body that hurts	0	1	2	3	NA
17. Flinching or moving the body part away, being sensitive to touch	0	1	2	3	NA
18. Moving the body in a specific way to show pain (e.g. Head back, arms down, curls up, etc.)	0	1	2	3	NA
19. Shivering	0	1	2	3	NA
20. Change in colour, pallor	0	1	2	3	NA
21. Sweating, perspiring	0	1	2	3	NA
22. Tears	0	1	2	3	NA
23. Sharp intake of breath, gasping	0	1	2	3	NA
24. Breath holding	0	1	2	3	NA
Subtotals: 1. For each subtotal write the number of times each value was chosen	NA	1x___	2 x___	3x___	NA
2. Multiply the value of each selection by how many times that value was chosen 3. Add each subtotal to find the total score		=___	=___	=___	Total: ___

SCORING:
1. Add up the scores for each item to compute the Total Score. Items marked "NA" are scored as "0" (zero).
2. Check whether the score is greater than the cut-off score.
   A score of 10 or greater means that there is a 94% chance that the person has pain.
   A score of 9 or lower means that there is an 87% chance that the person does not have pain.

For more information see Burkitt, Breau et al., (2009). Pilot study of the feasibility of the Non-Communicating Children's Pain Checklist – Revised for pain assessment in adults with intellectual disabilities. Journal of Pain Management, 2(1). CPS-NAID © 2009 Breau, Burkitt, Salsman, Sarsfield-Turner, Mullan.

Distress and Discomfort Assessment Tool v22 DisDAT

Please take some time to think about and observe the individual under your care, especially their appearance and behaviours when they are both content and distressed. Use these pages to document these.

We have listed words in each section to help you to describe the signs and behaviours. You can circle the word or words that best describe the signs and behaviours when they are content and when they are distressed.

Your descriptions will provide you with a clearer picture of their 'language' of distress.

COMMUNICATION LEVEL * Ring their level when	well	unwell
This individual is unable to show likes or dislikes	Level 0	Level 0
This individual is able to show that they like or don't like something	Level 1	Level 1
This individual is able to show that they want more or have had enough of something	Level 2	Level 2
This individual is able to show anticipation for their like or dislike of something	Level 3	Level 3
This individual is able to communicate detail, qualify, specify and/or indicate opinions	Level 4	Level 4

* This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association).

FACIAL SIGNS

Appearance

What to do	Appearance when content	Appearance when distressed
Ring the words that best fit the facial appearance. Add your words if you want.	Passive Laugh Smile Frown Grimace Startled In your own words:	Passive Laugh Smile Frown Grimace Startled In your own words:

Jaw or tongue movement

What to do	Movement when content	Movement when distressed
Ring the words that best fit the jaw or tongue movement. Add your words if you want.	Relaxed Drooping Grinding Biting Rigid Shaking In your own words:	Relaxed Drooping Grinding Biting Rigid Shaking In your own words:

Appearance of eyes

What to do	Appearance when content	Appearance when distressed
Ring the words that best fit the appearance of the eyes. Add your words if you want.	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils In your own words:	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils In your own words:

BODY OBSERVATIONS: SKIN APPEARANCE

What to do	Appearance when content	Appearance when distressed
Ring the words that best fit the describe the skin. Add your words if you want.	Normal Pale Flushed Sweaty Clammy In your own words:	Normal Pale Flushed Sweaty Clammy In your own words:

https://ddprimarycare.surreyplace.ca/guidelines/general-health/pain-and-distress/

https://www.wamhinpc.org.uk/sites/default/files/Dis%20DAT_Tool.pdf

Pharmacology Guidance & Considerations

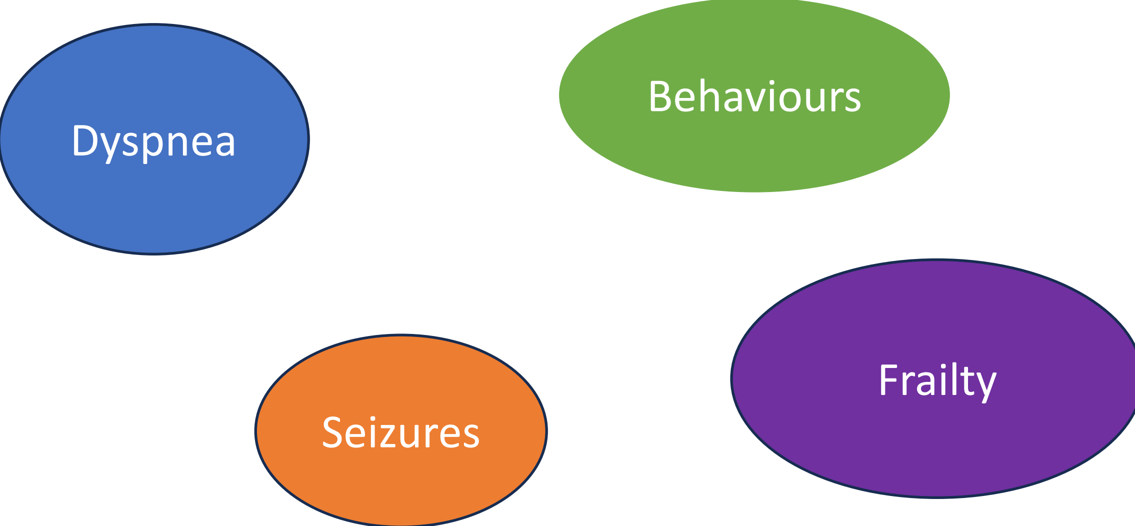
IDD considerations

Linking pain & symptom guides

End of Life order sets

Module G: Symptom Management

Symptom ID and Screening



Head and neck symptoms[7,8] (bulbar)

- Impaired speech
- Excess saliva
- Difficulty swallowing
- Lack of emotional control

Respiratory symptoms[7]

- Shortness of breath
- Restricted breathing
- Difficulty sleeping

Upper body symptoms[7-9]

- Hand weakness
- Limited range of motion
- Upper body muscle spasms
- Trouble with dressing/hygiene
- Impaired handwriting
- Difficulty preparing food

Lower body symptoms[8,9]

- Frequent tripping
- Difficulty on stairs
- Weak feet

Mood Screening

Glasgow Depression Scale for people with a Learning Disability (GDS-LD)

In the last week . . .

1 Have you felt sad?
  Have you felt upset?
  Have you felt miserable?
  Have you felt depressed?
2 Have you felt as if you are in a bad mood?
  Have you felt bad-tempered?
  Have you felt as if you want to shout at people?
3 Have you enjoyed the things you have done?
  Have you had fun?
  Have you enjoyed yourself?
4 Have you enjoyed talking to people and being with other people?
  Have you liked having people around you?
  Have you enjoyed other people's company?
5 Have you made sure you have washed yourself, worn clean clothes, brushed you teeth
  Have you taken care of the way you look?
  Have you looked after your appearance?
6 Have you felt tired during the day?
  Have you gone to sleep during the day?
  Have you found it hard to stay awake during the day?
7 Have you cried?
8 Have you felt you are a horrible person?
  Have you felt others don't like you?
9 Have you been able to pay attention to things (such as watching TV)?
  Have you been able to concentrate on things (like television programmes)?
  What is your favourite [television programme]? Are you able to watch it from start
10 Have you found it hard to make decisions?
  Have you found it hard to decide what to wear, or what you would like to eat, or do
  Have you found it hard to choose between two things? [Give concrete example if required.]

APPENDIX 2

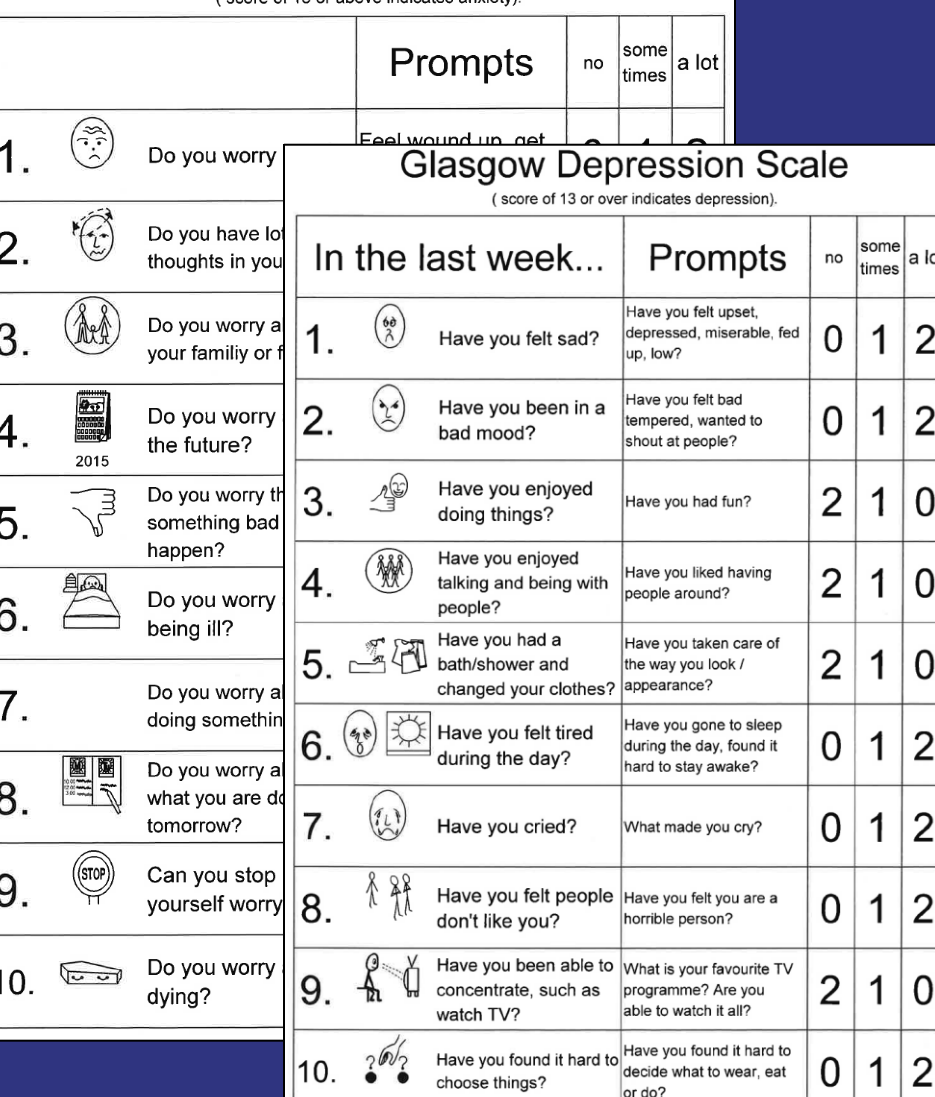
Carer Supplement to the Glasgow Depression Scale for people with a Learning Disability (GDS–CS)

What is the name of the person you look after? ________
[referred to as 'X' in the following questions]
What is your relationship to X? ________
The following questions ask about how you think X has be
answer. Please circle the answer you feel best describes X in

In the last week . . .

1 Has X appeared depressed?
2 Has X been more physically or verbally aggressive than usual?
3 Has X avoided company or social contact?
4 Has X looked after his/her appearance?
5 Has X spoken or communicated as much as he/she used to?
6 Has X cried?
7 Has X complained of headaches or other aches and pains?
8 Has X still taken part in activities which used to interest him/her?
9 Has X appeared restless or fidgety?
10 Has X appeared lethargic or sluggish?
11 Has X eaten too little/too much?
  If no problem, score 0. (A positive answer to either question means it should be scored. Please tick whic
  response is relevant, beside the question.)
12 Has X found it hard to get a good night's sleep? Please also tick which one of the following options is releva
  Has X had difficulty falling asleep when going to bed at night? ☐
  Has X been waking in the middle of the night and finding it hard to get back to sleep again? ☐
  Has X been waking very early in the morning and finding it hard to get back to sleep? ☐
13 Has X been sleeping during the day?
14 Has X said that he/she does not want to go on living?
15 Has X asked you for reassurance?
16 Have you noticed any change in X recently? Please explain what changes you have noticed, in either mood
  behaviour________

Thank you for answering these questions.



Glasgow Anxiety Scale.
(score of 15 or above indicates anxiety).

		Prompts	no	some times	a lot
1.	Do you worry	Feel wound up, get			
2.	Do you have lot thoughts in you				
3.	Do you worry a your familiy or f				
4.	2015 Do you worry the future?				
5.	Do you worry th something bad happen?				
6.	Do you worry being ill?				
7.	Do you worry a doing somethin				
8.	Do you worry a what you are do tomorrow?				
9.	Can you stop yourself worry				
10.	Do you worry dying?				

Glasgow Depression Scale
(score of 13 or over indicates depression).

In the last week...		Prompts	no	some times	a lot
1.	Have you felt sad?	Have you felt upset, depressed, miserable, fed up, low?	0	1	2
2.	Have you been in a bad mood?	Have you felt bad tempered, wanted to shout at people?	0	1	2
3.	Have you enjoyed doing things?	Have you had fun?	2	1	0
4.	Have you enjoyed talking and being with people?	Have you liked having people around?	2	1	0
5.	Have you had a bath/shower and changed your clothes?	Have you taken care of the way you look / appearance?	2	1	0
6.	Have you felt tired during the day?	Have you gone to sleep during the day, found it hard to stay awake?	0	1	2
7.	Have you cried?	What made you cry?	0	1	2
8.	Have you felt people don't like you?	Have you felt you are a horrible person?	0	1	2
9.	Have you been able to concentrate, such as watch TV?	What is your favourite TV programme? Are you able to watch it at all?	2	1	0
10.	Have you found it hard to choose things?	Have you found it hard to decide what to wear, eat or do?	0	1	2

(Cuthill et al., 2018)

Module H: Metrics

- Incorporate OPCN/ HQO metrics
- Quality measures of success
- Caregiver Voice Survey

Developmental Service Agencies

Developmental Service Agencies, Resources and Links

HCCARD (Health Care Access Research and Developmental Disabilities)

- Multidisciplinary research team led out of CAMH Azrieli Adult Neurodevelopmental Centre that
- studies and monitors the health and healthcare of adults with IDD.
- Provides online resources for PWIDD and their caregivers as well as toolkits/ best practices/ tips for healthcare providers to improve access and health outcomes.
- https://www.camh.ca/en/professionals/professionals--projects/hcardd

OPADD/ CRPADD (Ontario Partnership on Aging & Developmental Disabilities/ Central Region Partnership)

- OPADD is an informal partnership of service providers across sectors dedicated to enriching the quality of life for older adults with IDD.
- Ontario regional committees, including Central Region share common values to improve cross-sector communication, advocacy and engagement with a goal to identify service gaps/ trends/needs and to build system capacity across sectors (e.g. DS and LTC).
- https://pclkw.org/crpadd-resources/

Surrey Place

- Greater Toronto agency providing a wide range of services and programs to children and adults with IDD, autism and visual impairments.
- Provide training, consultation and assessment to outside partners/ organizations.
- Extensive online resource library for families and professionals including articles, recordings and tool kits in multiple areas of care.
- ***Developmental Disabilities Primary Care Program (DDCP) P***rimary care guidelines, tools and templates for medical professionals.
- https://www.surreyplace.ca/ https://ddprimarycare.surreyplace.ca/

DSO (Developmental Services Ontario)

- Access point for all adult developmental services funded by the Ministry of Children, Community and Social Services (MCCSS). Individuals with IDD are eligible for services at the age of 18. There are nine DSO locations across Ontario.
- https://www.dsontario.ca/

Concluding Remarks Reflection & Evaluation

Thank You!

INTELLECTUAL & DEVELOPMENTAL DISABILITIES
PALLIATIVE CARE NETWORK

SURREY PLACE

PPSMC
PALLIATIVE CARE PAIN & SYMPTOM MANAGEMENT CONSULTATION

COMMUNITY LIVING
Toronto

LU ME NUS
lumenus
Community Services

vita
community living services
mens sana
families for mental health

NEW VISIONS TORONTO

Christian Horizons

HOME AND COMMUNITY CARE SUPPORT SERVICES
Ontario

Reena

meta
high quality supports

MONTAGE
SUPPORT SERVICES
Live your dream

Kerry's Place
Autism Services
Services en autisme

Mary Centre
Building a Good Life

Hospice
NORTHWEST SERVICES
ST. JOSEPH'S CARE GROUP

NORTH OF SUPERIOR
HEALTHCARE GROUP

Key Resources and Links

- Canadian Hospice Palliative Care Association (CHPCA)
  - CHPCA Home Page
  - A Model to Guide Hospice Palliative Care
- Developmental Disabilities Primary Care Program (DDPCP) DDPCP Home Page:
  - Adaptive Functioning and Communication in Adults with Intellectual and Developmental Disabilities: Fact Sheet
  - Communicate CARE: Guidance for person-centred care of adults with intellectual and developmental disabilities
  - Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities
  - Health Watch Table: Angelman Syndrome (AS)
  - Health Watch Table: Down Syndrome
  - H.E.L.P. Tool When Behaviours Communicate Distress from Anthony Levinson on Vimeo.
  - Publication Canadian Family Physician special issues 1 (Vol 64: S1-78, April 2018) and 2 (Vol 65, S1-66) on Primary care of adults with intellectual and developmental disabilities: HELP for behaviours that challenge in adults with intellectual and developmental disabilities
- Health Care Access Research and Developmental Disabilities (H-CARDD)
  - H-CARDD Home Page
  - Prevalence of adult Ontarians with developmental disabilities higher than expected
  - Aging Profiles of Adults With and Without Developmental Disabilities
- Health Quality Ontario (HQO):
  - HQO Quality Standards related to Palliative Care
  - HQO Quality Standard: Palliative Care
  - HQO Quality Standard: Palliative Care Recommendations for Adoption

Key Resources and Links

- IDD Advocacy
  - People First of Ontario, https://www.peoplefirstofcanada.ca/
  - https://reaction4inclusion.com/2016/11/people-first-ontario-website-a-provincial-movement-of-self-advocates/
  - https://www.youtube.com/channel/UCO0Jw-fSMDt0uq4k2BAiBNQ
  - IRIS Institute (Toronto) https://irisinstitute.ca/resource/implementation-blueprint-for-community-based-pilots-for-supporting-decision-making
  - Palliative Care for People with Learning Disabilities (PCPLD) PCPLD Home Page
  - Delivering High Quality End of Life Care for People who have a Learning Disability
- Ontario Palliative Care Network (OPCN) OPCN Home Page
  - Declaration of Partnership and Commitment to Action: Advancing High Quality, High Value Palliative Care in Ontario (December 2011)
  - Framework on Palliative Care in Canada
  - The Ontario Palliative Care Competency Framework
  - OPCN Palliative Care Toolkit
  - OPCN Palliative Care Health Services Delivery Framework
- Surrey Place
  - https://ddprimarycare.surreyplace.ca/tools-2/general-health/capacity-for-decision-making/
  - https://www.surreyplace.ca/resources/webinar-advance-care-planning-for-adults-with-developmental-disabilities-during-covid-19/

Key Resources and Links

- Web-based Diagnostic Information:
  - Alcohol Effects on a Fetus
  - Cerebral palsy in under 25s: assessment and management
  - Down's Syndrome Association Annual Health Check Information for GPs
  - Fragile X syndrome and FMR1-Related Disorders: Information for Health Care Providers
  - Fragile X Syndrome Medical Issues: Birth to Adolescence
  - Understanding Hydrocephalus in Adults
  - Rett Syndrome
  - Smith-Magenis Syndrome
- Web-based Reports Related to Palliative Care for People with IDD:
  - Consensus norms for palliative care of people with intellectual disabilities in Europe: EAPC White Paper
  - Decision-making about the best place of palliative care for people with intellectual disabilities: a guide for care staff and healthcare professionals providing palliative care for people with intellectual disabilities
  - Living and dying with dignity: the best practice guide to end-of-life care for people with a learning disability
- Web-based Resources, Others:
  - interRAI Comprehensive Assessment Instruments
  - Standardized Mortality Ratios (SMR) Calculator
- Western Australia's Individualised Services (WAIS) ca
  - https://waindividualisedservices.org.au/resources/supported-decision-making
  - Involving people with intellectual disabilities in end-of-life decisions. Available at: https://youtu.be/zNPl_dXgbKA

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