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Survey Monkey questionnaire

- ✓ Quick Response or QR Code on handout;


OR



- ✓ Survey Monkey web link on handout:
<https://www.surveymonkey.com/r/CNSC-PalliativeCare>

- ✓ Community Networks website to access survey link: www.community-networks.ca

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- AN INTERACTIVE TUTORIAL -

**Palliative/ End-of-Life Care and
People with Developmental
Disabilities**

March 24, 2015

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Learning Objectives

Participants will be able to:

1. Define the philosophy underlying the palliative approach as it applies to caring for people with a life limiting illness.
2. Name some of the challenges facing people with a developmental disability receiving palliative care services in different types of living environments.
3. Describe, using a holistic approach, how to provide the best support to someone nearing the end of life, describing the caregiver's role throughout the stages of palliative care.
4. Identify people who could be part of the palliative care team including key community partnerships, roles and responsibilities.

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Learning Objectives #1 & 4

- Define the philosophy underlying the palliative approach as it applies to caring for people with a life limiting illness.
- Identify people who could be part of the palliative care team, including key community partnerships, roles and responsibilities.

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The greatest human freedom is
to live and die according to one's
own desires and beliefs

Lynn Keegan and Carole Ann Drick

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Why do we need this presentation?

- People with disabilities are living longer and aging.
- Life expectancy of a person with a developmental disability is within 5 years of a person without a disability.
- We recognize that people with a developmental disability face some unique barriers to end-of-life choices.
- We help people plan their lives...why would we not help people plan around the end of their life?

Definition of Hospice Palliative Care

- Hospice Palliative Care aims to relieve suffering and improve the quality of living and dying.
- HPC strives to help patients and families to address physical, psychological, social, spiritual, and practical issues, and their associated expectations, needs, hopes and fears. It helps them prepare for and manage self-determined life closure and the dying process, and cope with loss and grief during the illness and bereavement.
- HPC aims to treat all active issues, prevent new issues from occurring, promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization

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The CHPCA: A Model to Guide Hospice Palliative Care, 2007

Why a Palliative Approach to Chronic Disease Management?

- In 2007, 37% of Canadians reported that they had been diagnosed by a physician as having a chronic condition or illness.

CHPCA Fact Sheet – Hospice Palliative Care in Canada, April 2010 Page 2 of 12

- 1 in 3 Ontarians lives with one or more chronic diseases. Of those, almost 4 of 5 over the age of 65 have one chronic disease, and of those, about 70% suffer from two or more.

HPCO Fact Sheet, 2012

- Seniors make up the fastest-growing age group. In 2003, an estimated 4.6 million Canadians were 65 years of age or older, a number that is expected to double in the next 25 years
- Chronic diseases account for 70% of all deaths.
- Only 2.9% of all deaths are sudden; most of us will die over a longer trajectory.

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Why a Palliative Approach to Chronic Disease Management?

- When a person is diagnosed with a life-limiting/threatening condition such as Congestive Heart Failure, Parkinson's, COPD, Dementia, Advanced Age with Frailty, etc, a discussion should be had with regards to the possible and/or expected course of the disease.
- This approach shifts and changes as the person's health status changes and encompasses the total individual, respecting their right to informed consent.
- The goal is to identify the strengths the person brings to the challenges in managing and coping with a chronic illness and facilitates the transitioning through the stages of the disease to the end-of-life.

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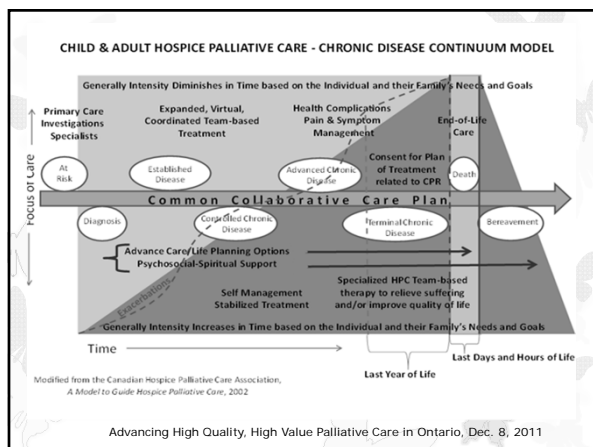
Palliative Approach Assessment

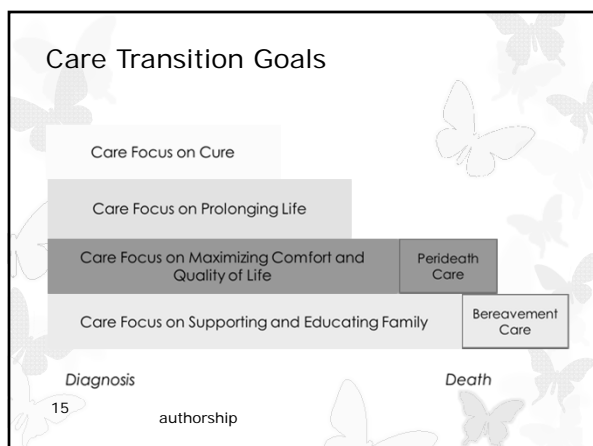
1. Would you be surprised if the person died within the next year?
2. Have there been hospital admissions recently?
3. Are there distressing physical or psychological symptoms?
4. What are the goals of care? What is the person's/family's understanding of the disease processes, prognosis, and treatment options?
5. Are there significant social or spiritual concerns affecting daily life? (Limited social support)
6. Has the person and family (if applicable) participated in advance care planning?
7. Has resuscitation been discussed?

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People aren't palliative...
the care they would benefit from is!!!

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Why are we planning?

- Planning for end-of-life care is an on-going activity in a person's life and should begin well in advance of a terminal illness.
- The plan may change with the passage of time, based on the current state of health and life experiences.
- Person centered care planning can support 'aging in place'

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Palliative Care Team Members

- | | |
|--|---------------------------|
| • Individual | • Family physician |
| • Family/caregivers | • Dietitian |
| • Friends/housemates | • Occupational Therapist |
| • Palliative care coordinator | • Physiotherapist |
| • Nurse practitioner | • Social worker |
| • Nursing staff (ie. home care or other) | • Pharmacist |
| • Palliative care physician | • Music therapist |
| • Bereavement coordinator | • Massage therapist |
| • Speech and language pathologist | • Respiratory therapist |
| | • Chaplain/spiritual care |
| | • Hospice/volunteers |

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Settings where people die

People have the right to choose where to die.

- Residential hospice
- Long term care facility and hospital
- At home
- Residential group home

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*We must consider that death is not
always "an incident"...only to be
investigated and documented on a
form.*

It is the final passage of one's life...

Leigh Ann Creaney Kingsbury, MPA, Gerontologist
InLeadS, Inc. Consulting and
Training;
Author, People Planning
Ahead

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*"Life should end as
beautifully and naturally as
coming into the world".*

Dee Brightstar

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Learning Objective 2

Name some of the challenges facing
people with a developmental disability
receiving palliative care services in
different types of living environments.

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Potential Challenges for the Person and Their Supports

This can be a troubling time for people and their support network as they navigate through how a diagnosis impacts their life.

Challenges may arise in three key areas of their life:

- Personal (emotional impact, relationships, quality of life)
- Medical (pain management, comfort, complex needs)
- Environmental (living arrangements, adaptive aids, support hours)

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Personal Challenges

- Understanding the impact on life moving forward
 - Is plain language being used? Does the person understand how things will change?
- Level of Family Involvement and Relationships
 - People we support do not always have family involvement. Who will help make decisions and be there for the person in their time of need?
 - How can the person be supported to maintain friendships and relationships?

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Personal Challenges

- Spiritual Considerations
 - What is important to the person? How do we ensure it is respected?
- Leisure and Community Participation
 - How will the person be supported to enjoy the things and activities that bring him/her joy?
- Employment and Volunteering
 - How will these areas of a person's life be affected? How can they be supported to stay connected if this is important to them?

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Medical Challenges

- Diagnosing Complex Medical Conditions
 - Symptoms may be atypical. How does the person convey pain? How do we know something is wrong?
- Access to Medical Care
 - Does the person have a doctor? Are they eligible for any supports in their home? Do they have any fears that may make it hard to get help?
- Changing abilities and declining skills
 - Is the person safe in their home? Are there supports available if needed? Can they manage their own medical care?

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Environmental Challenges

- Living Arrangements
 - Does the person live with their family? Independently? Group home?
 - What is the impact on the people around them?
- Physical Environment
 - Will their home meet their changing needs?
 - Do they need any adaptive devices?
- Staff Support
 - Are the supports they receive meaningful and sufficient?
 - Do the people around them want to be part of their journey?

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Communication

- Communication skills pose a major barrier
 - Expressing pain or distress effectively
 - Expressing emotional feelings
 - Understanding complicated concepts (eg. treatment planning)
 - Understanding abstract concepts (eg. grief, death)

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Communication Strategies

- Carefully consider the person's ability to understand
- Allow plenty of time
- No assumptions – no evidence that people with I/DD need less information on death and dying
- Picture cues and books
- Provide honest and simple answers
- Concrete communication vs abstract

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Case study #1: Cathy

- Cathy is a 31-year-old woman who is an active member in a local theatre group.
- She shares an apartment with her boyfriend of 5 years.
- Cathy has been battling a terminal lung disease, and the recent prognosis is that she has 3 months to live.
- She receives 3 hours a day of staff support, and nurses visit once a day.
- Cathy is blind and has a developmental disability.
- She is struggling with her prognosis and having difficulty understanding the serious nature of her illness.
- Cathy has no family to support her, only her boyfriend.

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Case study #1: Cathy

Questions

1. How might Cathy be supported to understand her illness and make plans?
2. Who might be valuable to be involved in Cathy's life?
3. What might quality of life look like for Cathy in the next three months?

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Learning Objective #3

Describe, using a holistic approach, how to provide the best support to someone nearing the end of life, describing the caregiver's role throughout the stages of palliative care.

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Advance Care Planning

"Advance Care Planning can often make a positive difference to the outcome of difficult life transitions and crises, and for end of life care"

(Primary care of adults with developmental disabilities, Canadian Consensus Guidelines)

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What is Advanced Care Planning?

- Opening a discussion
 - Values
 - Who needs to support you
 - Fears
 - Invasive treatments
 - CPR
- Sharing wishes with caregivers
- Assigning a Substitute Decision Maker (SDM)
- Documentation of your plan
- Revisit plan annually or when health changes occur

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Who Needs Advance Care Planning?

Making personal choices is basic to a person's sense of identity and well being

- Recent study – 100% of us will die
- Everyone's journey will be different
- EVERYONE should have an Advance Care Plan
 - MUST for capable adults with advanced stage illness
 - SHOULD for capable adults with chronic illness
 - IDEAL to discuss with healthy capable adult

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When??

NOW!

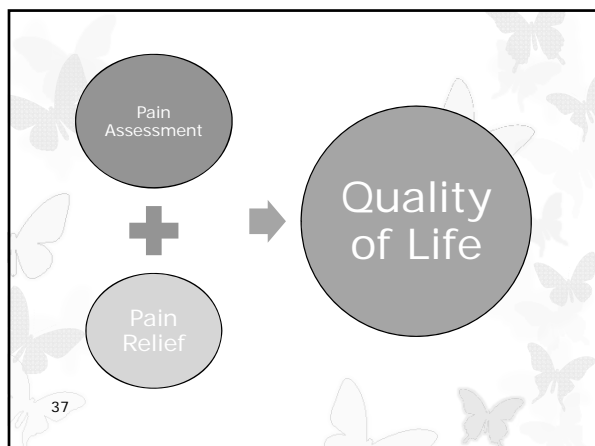
- It's never too early
- It's never too late

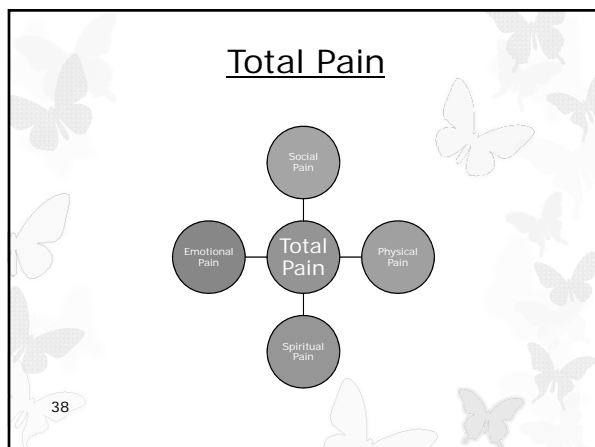
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Important Points

- In the province of Ontario a person can express his/ her wishes verbally, in writing or by any alternative means that you choose to communicate such as through a picture board or computer.
- A substitute decision maker (SDM) and Power of Attorney (POA) are only used when the person is INCAPABLE of making decisions about his/ her care and treatment

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Pain Assessment

- Self-report is the "Gold Standard" in pain assessment
- Communication barriers can make self-report difficult or impossible in persons with I/DD
- Pain and distress often go undiagnosed or misdiagnosed and under-treated, resulting in unnecessary suffering
- Effective pain assessment in non-verbal people relies on the interpretations of those with meaningful relationships
- Main indicators of pain among people with cognitive impairments: increase in aggression, restlessness, changes in speech (e.g. whining, moaning, groaning)

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A Few Tools...

- Abbey Scale
 - Measures non-verbal expressions
- CPS-NAID (Chronic Pain Scale- Nonverbal Adults w/ID)
- NCAPC (Non-Communicating Adults Pain Checklist)
- DisDat (Disability Distress Assessment Tool)
 - Developed by Palliative Care team supporting people with I/DD
- Wong-Baker Faces® Pain Rating Scale



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Comfort Measures

- Pain Management
 - Medication ports
 - Pumps
 - Breakthrough
 - Ongoing assessment
- Comfort drawn from many Domains
 - Spirituality
 - Environment/Surroundings
 - Personal belongings
 - Friends and family

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*UK study: people with I/DD received less opioid analgesia than those without (1)

Needs for People with Developmental Disabilities

- Information about what is happening – plain language
- Practical Comfort measures
- Physical signs of caring
- Familiar items and environment
- Assurance they will not be abandoned
- Assurance they will be remembered
- Respect for individuality and dignity
- Share feeling and anxieties

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Grief



"To weep is to make less the depth of grief."
~ William Shakespeare

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What is Grief

- **Grief** is a multifaceted response to loss, particularly to the loss of someone or something that has died, to which a bond or affection was formed.
- Psychological, behavioural, social and physical reactions
- Causes deep mental anguish

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What we now understand

- People with developmental disabilities respond to bereavement and loss in essentially the same way as anyone else.
- The effects of bereavement may be prolonged with people with developmental disabilities experiencing more anxiety, depression, irritability, and other signs of distress
- For those who are non-verbal, grief will require some active form of creative expression such as painting, dance, or creating a photo album (2)
- No evidence that people with developmental disabilities have less need for information about illness, death, and dying (3)

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Disenfranchised Grief

- Common misconceptions about grief
 - People with developmental disabilities don't understand or can't comprehend death
 - Fear of causing harm or provoking uncontrollable emotional response
- Danger of 'Conspiracy of Silence'
 - Such behaviour is likely to add to the person's confusion and distress.

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Key strategies

- Provide accurate and honest information
 - Be aware of ability to comprehend
- Provide support to process it – plain language
- Provide opportunities for expression of grief and condolences
- Provide reassurance
 - that there is no blame
 - on the ways things will be different

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Key Strategies (cont.)

- Promote conversations about the loved one
 - to honour the lost life
 - to remember the love they shared
 - to think about what the person who has died might want for the individual
- Provide opportunities for the person to make connections to the past, present and future:
 - Look at pictures and share memories
 - Make a book or a memory box about the person who died
 - Give them something that belonged to the person
 - Light a candle in honour of the person
 - Visit places they used to go together

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Case Study #2: Brent

Brent moved into the institution when he was just a toddler.

- Brent was diagnosed with Cerebral Palsy and Profound Developmental Disability
- Reflux, Epilepsy and Chronic Respiratory Infections
- No language skills
- No independent mobility ("total" personal care)
- G-tube for nutritional support
- Many hospital admissions for pneumonia that could not be effectively treated in his home.

At age 27, Brent moved into a community group home (2003)

- Family began to visit
- Lived with 3 housemates for 8 years
- Loved Elvis music and TV game shows
- Loved animals of all kinds

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Case Study #2: Brent

Brent was experiencing respiratory difficulties.

- Staff began usual treatments
- Brent wasn't improving as he normally does
- Took him to the local hospital for further assessment
- He stayed in the hospital for two weeks
- Was not responding to the IV medications
- He was having difficulty sleeping in the hospital setting
- Most of his specialized equipment was not available
- None of his personal comforts of home
- Brent was deemed "palliative" and sent home to be in his own environment.

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Case Study #2: Brent

Questions:

1. When does Palliative Care begin for Brent?
2. Who is grieving?
3. What are some ways to help those who are grieving?
4. What needs to be considered in providing good end-of-life care for Brent?

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"You matter because you are you,
and you matter to the end of your
life. We will do all we can not only
to help you die peacefully, but also
to live until you die."

~ Dame Cicely Saunders

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References

1. Bekkema N, de Veer AJE, Wagemans AMA, Hertogh CMPM, Francke AL. Decision making about medical interventions in the end-of-life care of people with intellectual disabilities: a national survey of the considerations and beliefs of GPs, ID physicians and care staff. *Patient Education and Counseling*, 2014; 96: 204-209.
2. Kirkendall AM, Waldrop D, Moore RP. Caring for people with intellectual disabilities and life-limiting illness: merging person-centred planning and patient-centered, family-focused care. *Journal of Social Work in End-of-Life and Palliative Care*, 2012; 8(2): 135-150.
3. Ryan K, Guerin S, Dodd P, McEvoy J. Communication contexts about illness, death and dying for people with intellectual disabilities and life-limiting illness. *Palliative and Supportive Care*, 2011; 9: 201-208.
4. http://kc.vanderbilt.edu/kennedy_files/CopingWithLossandIntellectualDisabilitiesJune2011.pdf Guide to Advance Care Planning. 2006 edition.

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Resources/ Tools

Advance Care Planning Resources

Power of Attorney Kit

<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp>

California Department of Developmental Services - Thinking Ahead Workbook

http://www.dds.ca.gov/ConsumerCorner/docs/ThinkingAhead_English.pdf

Make your plan

<http://www.advancecareplanning.ca/making-your-plan.aspx>

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Resources/ Tools

Pain Resources

Wong-Baker Faces® Pain Rating Scale
<http://wongbakerfaces.org/resources/>

Non-Communicating Adults Pain Checklist (NCAPC)
<http://bit.ly/1Ffs8C8>

Abbey Pain Scale
http://www.apsoc.org.au/PDF/Publications/4_Abbey_Pain_Scale.pdf

Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)
<http://pediatric-pain.ca/wp-content/uploads/2013/04/CPSNAID.pdf>

Disability Distress Assessment Tool (DisDAT)
http://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf

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Resources/ Tools

Grief Resources

Helping People With Intellectual Disabilities Cope With Loss
http://kc.vanderbilt.edu/kennedy_files/CopingWithLossandIntellectualDisabilitiesJune2011.pdf

Managing Grief Better: People With Intellectual Disabilities, Professor Sheila Hollins
<http://www.intellectualdisability.info/mental-health/managing-grief-better-people-with-intellectual-disabilities/>

A Caregiver's Guide
http://www.stlazarus.ca/english/news_pages/caregiversguide.html

Celebration of Life Checklist
http://www.aging-and-disability.org/documents/celebration_of_life_checklist.pdf

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Questions?

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