

ADVANCED CARE and END-OF-LIFE PLANNING



Haldimand & Norfolk Seniors Partnership

**A training presentation for those
who would care for the aging person
with an intellectual disability**

Table of Contents

Introduction

Orientation

Introduction to Advanced Planning

Resources in Ontario and Canada

Palliative and End-of-Life Care

- People Involved in Palliative Care

A “Good” Death

Communication

- Skills
- Strategies

Pain and the Quality of Life

Physical Symptoms

- Pain
- Dyspnea
- Delirium
- Dry Mouth and Skin

Feeding and Hydrating

A Natural Process

Understanding Persons with Disabilities
and their Experience of Grief

Personal Reflections

Understanding Grief

Understanding Persons with Disabilities

Key Strategies for Care

Background

The Haldimand & Norfolk Seniors Partnership (HNSP) is a network of support agencies from across Haldimand and Norfolk Counties that works to build region-wide capacity on aspects of aging and intellectual disability. In 2013, this partnership was awarded an Ontario Trillium Foundation (OTF) grant to support a project that would facilitate an increased education and awareness about the changes someone, with an intellectual disability, may experience as he or she ages.

These materials cover the changes that may be experienced by a person following a “Biopsychosocial Model.” Because of medical advancements, people in our society are (on the whole) living longer. With aging, unfortunately, comes the increased risk factor that those with an intellectual disability, especially someone with Down Syndrome, may develop a dementia, more commonly, Alzheimer’s Disease.

The workshop was established to provide health care professionals who will be supporting these individuals with the effective knowledge and tools based on current best practices. This curriculum on aging, dementia and intellectual disabilities can be taken back to your respective agency or long-term care home to ensure best practices will be utilized. The goal of this project is to improve awareness and education with the hope that attitudinal barriers and reluctance in supporting these individuals will be reduced.



Organizations of the Haldimand & Norfolk Seniors Partnership

The Haldimand & Norfolk Seniors Partnership (HNSP) consists of these nine agencies.

- Alzheimer Society (Haldimand-Norfolk)



CAMHS
Community Addiction and Mental Health
Services of Haldimand & Norfolk

- Community Addiction and Mental Health Services of Haldimand & Norfolk

- Community Care Access Centre (Hamilton, Niagara, Haldimand, Brant)



Hamilton Niagara Haldimand Brant
CCAC CASC
Community Care Access Centre
Centre d'accès aux soins communautaires



- Community Living (Haldimand)

continued . . .



... continued

- Community Living Access Support Services (Norfolk & Haldimand)



Haldimand-Norfolk
REACH

- Haldimand-Norfolk REACH

- Norfolk Association for Community Living



revera[®]
Long Term Care

- Revera Long Term Care

- Southern Network of Specialized Care



Acknowledging support for this project that comes from the . . .

Ontario Trillium Foundation



Fondation Trillium de l'Ontario

An agency of the Government of Ontario.
Un organisme du gouvernement de l'Ontario.

Adapting this resource to group work

This PowerPoint presentation has been adapted from a classroom training program that offered opportunities for small group discussion.

You may be viewing it on a computer workstation for an individual learning experience.

The graphic at the lower right-hand corner indicates where you can to include other people in discussion of the materials. It will appear on those slides where small group discussion had been planned for the original training.



Why do we need this presentation?

- People with disabilities are living longer and aging.
- Life expectancy of an individual with developmental disabilities is within 5 years of a person without a disability.
- We recognize that people with developmental disabilities 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 lives?



ADVANCED CARE PLANNING

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



The Quote

“The greatest human freedom is to live and die according to one’s own desires and beliefs.”

This is a great quote that gives a more positive outlook on these topics.

We will consider how this outlook can influence Advanced Care Planning and Palliative End-of-Life Care.

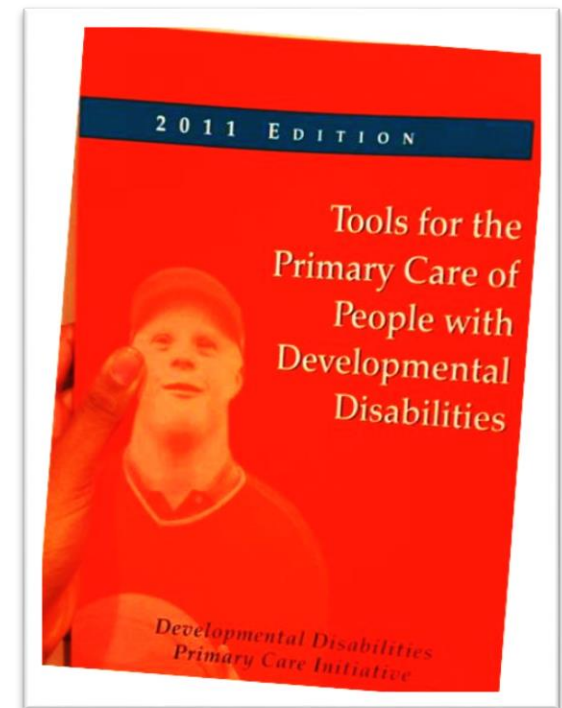


Advanced Care Planning

“Advanced Care Planning can often make a positive difference to the outcome of difficult life transitions and crises, and for end of life care.”

(Canadian Consensus Guidelines on the Primary Care of Adults with Developmental Disabilities, Canadian Consensus Guidelines)

Knowing this makes it the caregivers' responsibility to take positive action towards an important planning process.



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 Caregiver
- Documentation of your plan
- Revisit plan annually or when health changes occur



Who needs an Advanced Care Plan?

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 Advanced Care Plan
 - **MUST** for capable adults with advanced stage illness
 - **SHOULD** for capable adults with chronic illness
 - **IDEAL** to discuss with healthy capable adult



When?

NOW!

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



Important Points

- In the province of Ontario a person can express his/her wishes verbally, in writing or by any alternative means that he/she chooses 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



Substitute Decision Maker (SDM)

- Guardian of the person: usually court appointed
- Attorney named in Power of Attorney for Personal Care
- Representative appointed by the Ontario Consent and Capacity Board
- Spouse or partner: includes same sex in Ontario
- Child or custodial parent or Children's Aid Society
- A parent who has only right of access (non-custodial)
- Brother or sister
- Any other relative
- Public Guardian and Trustee (as a last resort)



Advanced Care Planning Resources

- Thinking Ahead Workbook
http://www.dds.ca.gov/ConsumerCorner/docs/ThinkingAhead_English.pdf
- Speak Up
<http://www.advancecareplanning.ca/health-care-professionals.aspx>
- Power of Attorney Kit
<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp>



PALLIATIVE and END-OF-LIFE CARE



The Final Passage

“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



Self-Reflection Activity

Draw your own death



Self-Reflection Activity

As a self-reflection exercise, take a piece of paper and draw an image of your own death.

Interpreted those instructions however you choose.

After you have taken enough time (and you may choose to do it later or over a few days) ask yourself: “What did it feel like to draw my own death?”

Further, how do you think this kind of self-awareness can help you in your role to support someone who is facing the end of his or her life?

Obviously, there are no right or wrong answers. The exercise is offered so that you can explore your own inner thoughts on death and dying.



Definition of Hospice Palliative Care

- Hospice Palliative Care (HPC) 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

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



Palliative Care Team (fluid)

- individual
- family / caregivers
- friends / housemates
- palliative care coordinator
- nurse practitioner
- bereavement coordinator
- nursing staff (i.e., home care or other)
- palliative care physician
- chaplain / spiritual care
- hospice / volunteers



- family physician
- dietitian
- occupational therapist
- physiotherapist
- social worker
- pharmacist
- music therapist
- massage therapist
- respiratory therapist

This is a list of people who could possibly be on a Palliative Care Team.
The Palliative Care Team includes anyone who can have a positive impact on the person who is dying.



Patient and Family Characteristics

The following chart represents the **Domains of Issues** associated with a person who is experiencing illness and bereavement.

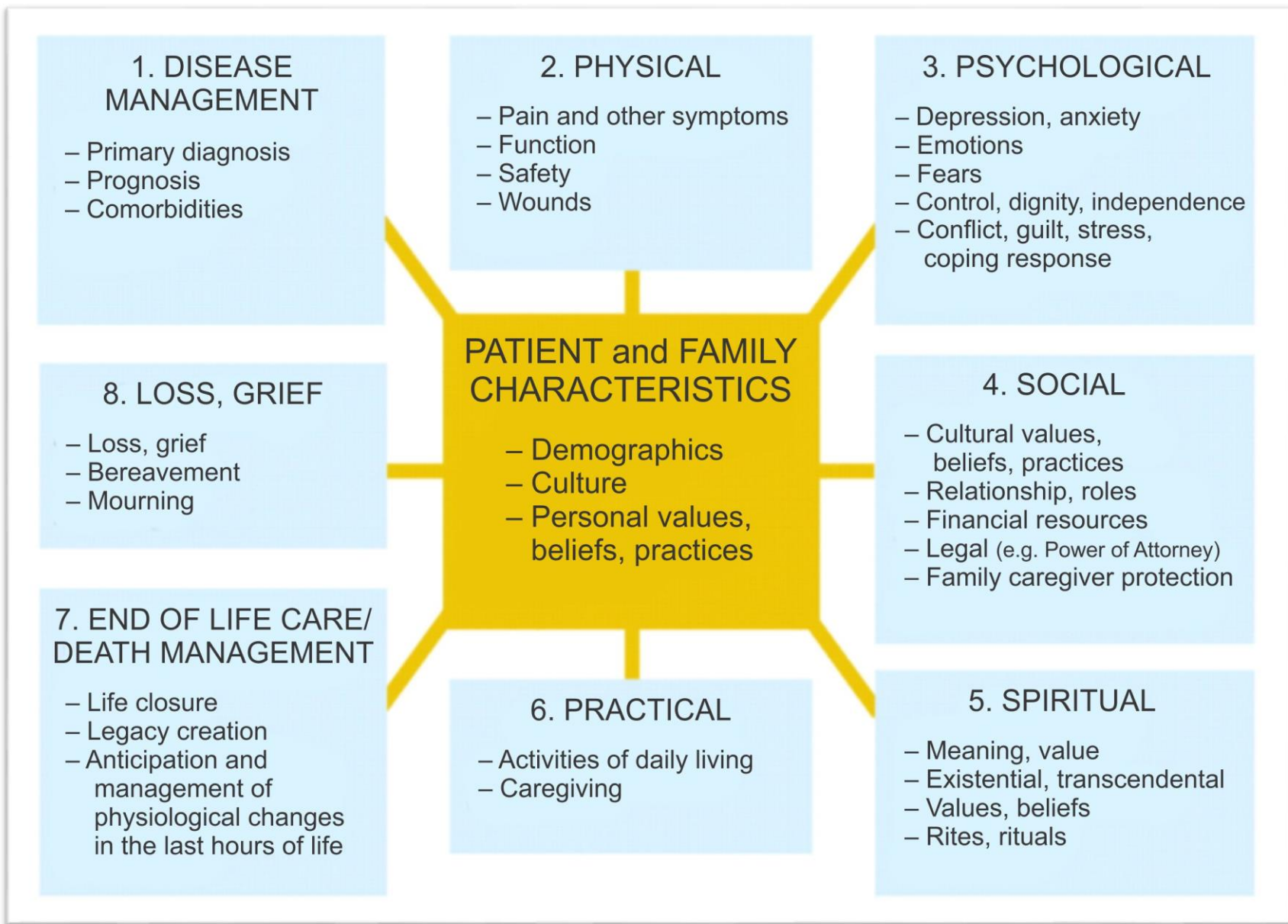
Clearly there are multiple issues that cause suffering.

These issues can be grouped into eight domains.

1. Disease Management
2. Physical (such as pain)
3. Psychological (including emotions and fears)
4. Social (such as relationships and roles)
5. Spiritual (meaning values and beliefs)
6. Practical (such daily living activities)
7. End-of-life Care (or life closure and legacy creation)
8. Loss and Grief

This chart helps by seeing the person from all angles in order to achieve the best possible palliative care.





What is a “Good” Death?





What is a “good death”?

What do you think are the elements of a “good” death?

Can you describe what that would look like?



A Comfortable Death

- Care must be person-specific
- Family focused
- Shift of hope from “Hope for Life” to “Hope for Peaceful Death”
- Family is “family” first, “caregivers” only if comfortable
- Respect for cultural, spiritual and religious needs and beliefs



A Comfortable Death

To ensure a person has a comfortable death—in other words a death that is dignified and peaceful—a mindset shift needs to occur.

First and foremost it must be person-specific. Everyone's journey is different and everyone's needs will be based on their life experiences, beliefs and values.

The recipients of palliative care go beyond the person who is dying and envelops the whole family. Therefore strategies need to be aimed at everyone in this group that you would see involved with the person facing death.

Attitudinally, we need to make the shift from hope for a cure and for life to a hope for a peaceful death. We need to aim our strategies directly at that overall goal.

Keep in mind that the family needs to maintain its role as a family above all. Family members should only be caregivers if they are comfortable with and desire that role in the person's life.

Always be respectful and seek to be as knowledgeable as possible about cultural, spiritual and religious beliefs so that you can embed those aspects into the plan of care.



Communication Skills

Communication can pose a major barrier

- Expressing pain or distress effectively
- Expressing emotional feelings
- Understanding complicated concepts (e.g., treatment planning)
- Understanding abstract concepts (e.g., grief, death)



Communication Skills

Communication plays an important role in all care provision. But with Palliative Care, for people who have a developmental disability, it is an area that requires added consideration, planning and troubleshooting.

The inability to effectively communicate pain or distress is a major barrier for people with intellectual disabilities in receiving adequate care. Emotional feelings and other notions such as grief and death are abstract concepts that can be very difficult for the person to understand and express.

In addition to their possible lack of ability to communicate effectively, death, the dying experience and the illness itself are quite complex concepts that will require different approaches and methods of communication to assist in comprehension.



Communication Strategies

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



Communication Strategies

To support someone who has these difficulties you must first carefully consider the person's ability to understand. Don't make assumptions that the person can understand something simply because he/she has agreed to it. Also don't assume you can just provide the minimal amount of information. You will need to work with all the tools available to get the information across in clear and easy to understand ways.

Allow plenty of time for the person to process the information.

Utilize picture cues and books.

Provide honest and simple answers.

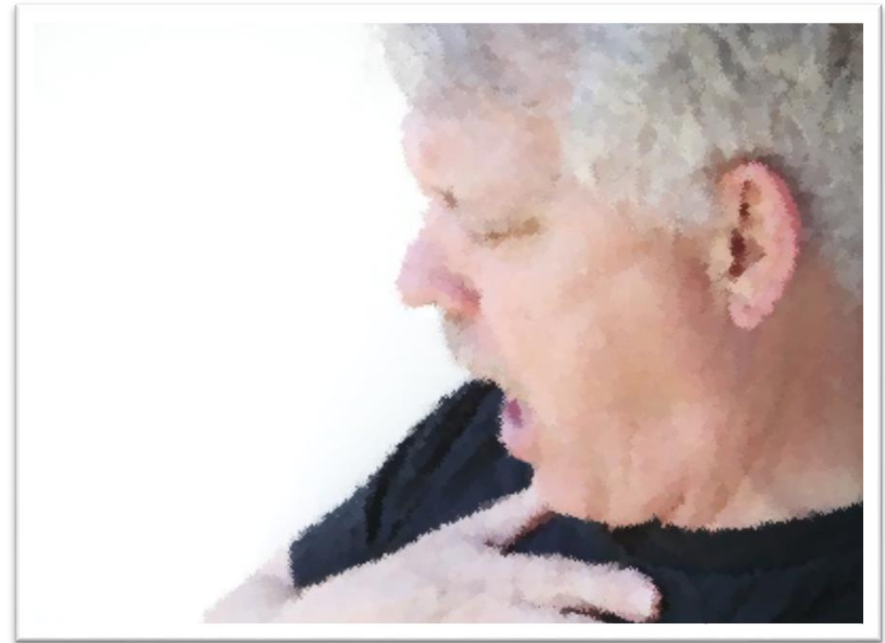
Included is a link to "Books Beyond Words" in the Resource list that can be helpful in providing plain language materials on some difficult topics such as "Getting on with Cancer."



Physical Symptoms

Symptoms of concern at end of life

- Pain
- Dyspnea (difficulty breathing)
- Secretions
- Delirium
- Dry Mouth and Skin



Physical Symptoms

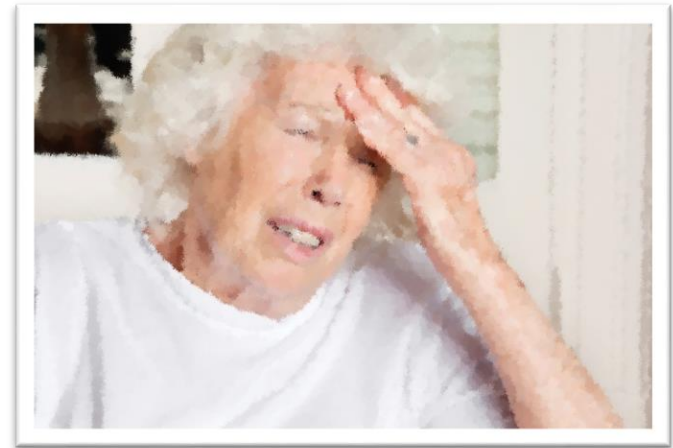
Pain, Dyspnea, Secretions, Delirium and Dry Mouth and Dry Skin are some of the most common and most troublesome symptoms that occur at the end of life.

It is important to recognize them and to be more comfortable with them.



Definition of Pain

- Pain is subjective (occurring where and when the person indicates it does), multidimensional and a highly variable experience for everyone, regardless of age or special needs. (RNAO, 2002)
- Whatever the experiencing person says it is, and existing whenever the person says it does. (McCaffery & Pasero, 1999)



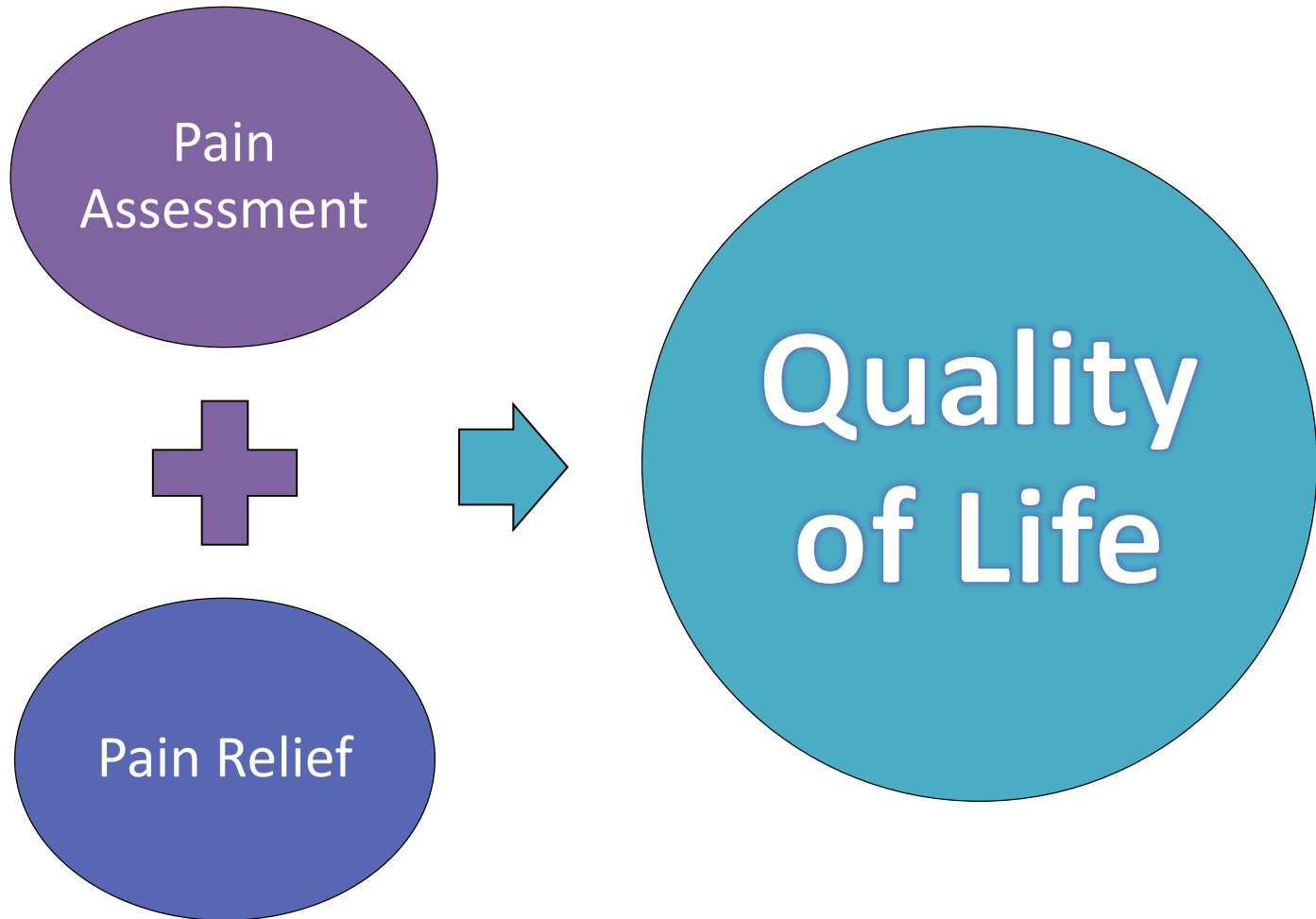
Definition of Pain

The bottom line in assessing pain or in defining pain is that it is entirely subjective. Pain is very personal and it is exactly what the person who is experiencing it says it is.

Always believe a person with a life-limiting illness when he says he's in pain and respond according to the expression or feedback.



Quality of Life



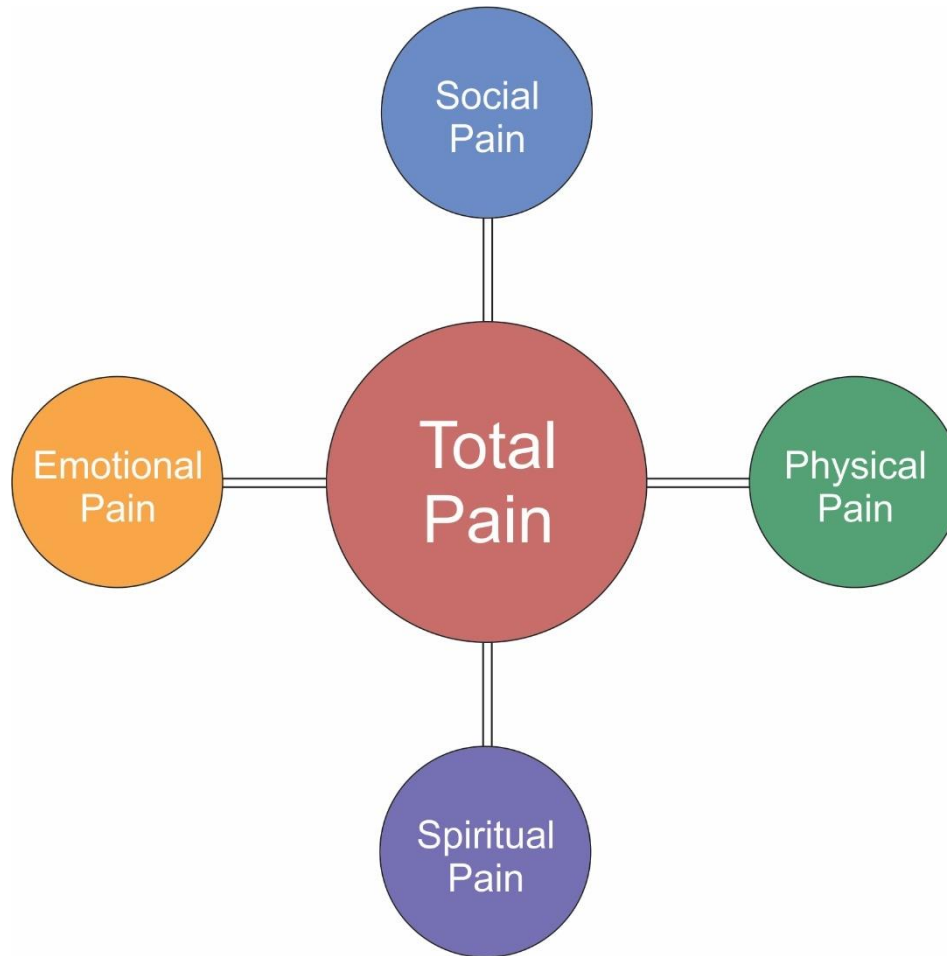
Quality of Life

Good quality of life for a person suffering at the end of life hinges on adequate pain relief. This puts the caregiver in a very important position of continuous assessment of the pain that he is experiencing and providing the relief immediately.

If what is made available to you appears to be insufficient to maintain good pain control, this is your opportunity to advocate and work with the physician to ensure that the best pain management control is in place for this person. This is where communication will be very important between family, caregivers and the palliative care team.



Total Pain



Total Pain

An important factor in effectively managing pain and providing optimal comfort and minimal suffering is to examine pain from all sources and provide relief on all levels.

People experience suffering from each of these domains as their lives are ending and they require support to manage each of them. Only when you've considered "Total Pain" have you really done all you can in order to minimize suffering in the dying person's experience.

As a caregiver, it's important to examine the different domains for the person to understand what has been important to him/her and how to support the person through losses of identity or connection. Think back to the Domain of Issues diagram shown earlier.

An example of this in action would be to think of a person who has worked in the kitchen at the day program for the last 8 years. The illness has progressed to the point where the person is no longer able to work. She has spent 8 years identifying herself as a contributing member of the kitchen team and defining a great deal of her value as a person in that role in her life. This is a loss that will cause this person emotional pain from the loss of her role in society and social pain from the disconnection from co-workers, friends and customers engaged with on a daily basis.

The need is to come up with some strategies to offset these losses and allow for closure.



Pain Assessment

- Self-report is the “Gold Standard” in pain assessment
- Communication barriers can make self-report difficult or impossible in persons with ID/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)



Pain Assessment

While clearly most caregivers and healthcare providers rely on a person's self-report for assessing pain, often this method is not available when working with people with Intellectual Disabilities.

Often, even those individuals who have good communication skills can have difficulty effectively expressing or describing their symptoms. This can result in under-treatment and unnecessary suffering for the individual.

Knowing this makes it very important to rely on those who have meaningful relationships with the person to get the most accurate assessment of subtle communications or behavioural changes that might indicate pain.

However, be cautious to be objective and avoid applying your personal feelings and or beliefs to the assessment. Using concrete tools will assist with objectivity. Some of these tools are shared on the next page.



A Few Tools...

- CPS-NAID (Chronic Pain Scale–Nonverbal Adults w/ID)
- NCAPC (Non-Communicating Adults Pain Checklist)
- Abbey Scale
- DisDat (Disability Distress Assessment Tool)
 - Developed by a palliative care team supporting people with ID/DD
- Wong–Baker Faces® Pain Rating Scale



Some Tools for Pain Assessment

These are a few tools that can be helpful when working with people with Intellectual Disabilities. While this is certainly not an exhaustive list, these tools are either specifically designed for people with Intellectual Disabilities or for those with cognitive or communication impairment.

You will need to find some tools that specifically meet the needs of your situation.

The following are available on the PDF version of this presentation

- CPS-NAID (Chronic Pain Scale–Nonverbal Adults with ID)
- Abbey Scale
- DisDat (Disability Distress Assessment Tool)
- Wong–Baker Faces® Pain Rating Scale

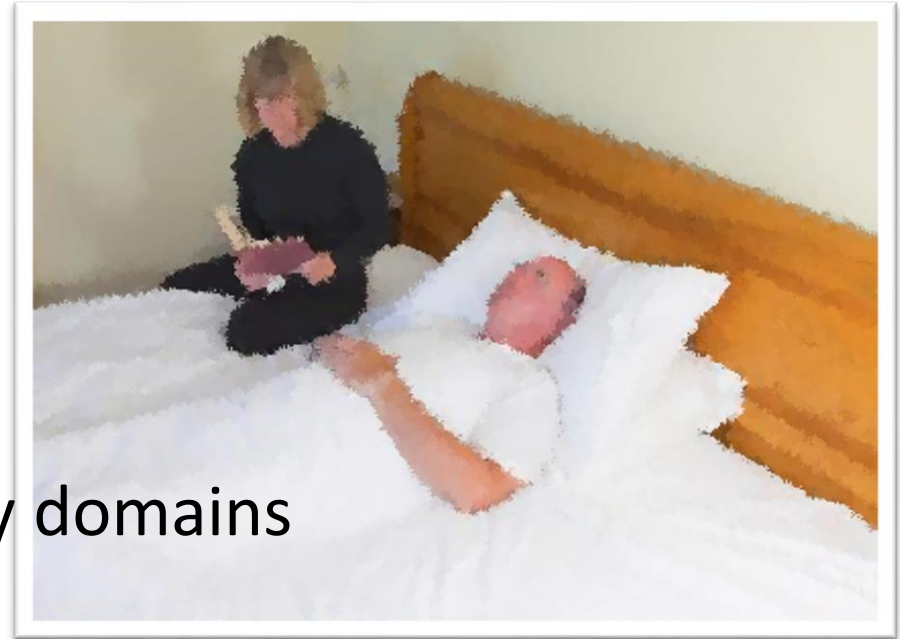
Ensure that you take the time to carefully and thoroughly assess for pain. Use multiple tools. Assess repeatedly.

Give plenty of time for communication to occur when possible.



Comfort Measures

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



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

Comfort Measures

Pain management for a terminal illness should never be only “prn.” Ongoing assessment of the pain experience should guide treatment and dosing changes to minimize the need for “breakthrough” pain relief.

Pain = Suffering, so job #1 in Palliative Care is to minimize suffering.

Do not be hesitant with pain management. It is one of the greatest contributors to a peaceful death.

In community settings, maintain a close relationship with palliative care professionals and utilize their services fully.

Incorporate all aspects of the person’s comfort into their end-of-life care by considering all of the domains mentioned previously:

Spirituality, Environment, Personal Belongings, Family and Friends.



Dyspnea (Shortness of Breath)

- Body cannot get enough air
- Lungs cannot deliver enough oxygen
- Causes – anxiety, illness
- Signs
 - Skin around mouth and nail beds may be blue tinged
 - Respirations may be gurgling
 - Breathing may be difficult when walking, talking or even at rest



Dyspnea (Shortness of Breath)

There are several other physical symptoms that occur at the end of life.

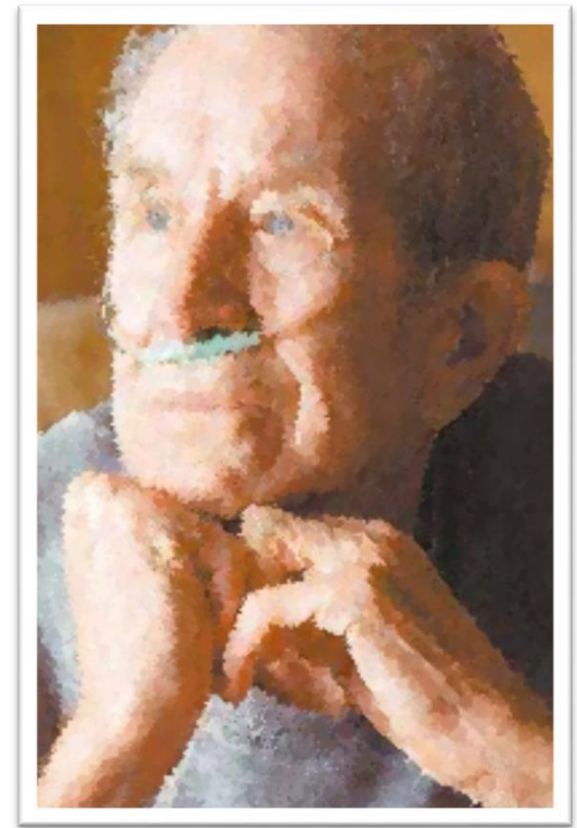
Dyspnea, commonly referred to as shortness of breath, occurs when the body cannot get enough oxygen. It can be very anxiety producing both for the person experiencing it and for the carers.

In dyspnea, you will notice a blueish tinge to the skin around the mouth and the nail beds. The person may be making gurgling sounds when he/she breathes.



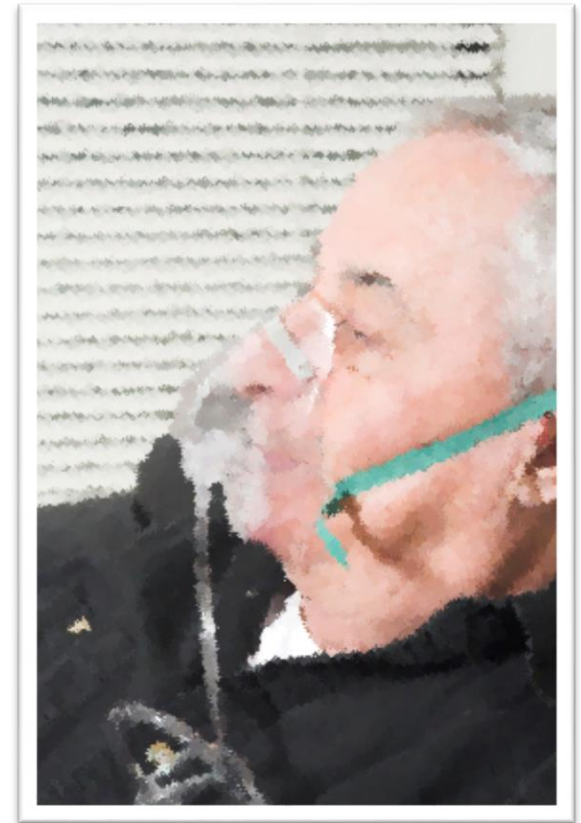
Supportive Care Strategies for Dyspnea

- Positioning – raising head of bed
- Fan to keep air moving
- Window/door open
- Limit people in environment
- Cool, moist towel
- Conserve energy when doing ADLs
- Oxygen mask or cannula
- Prevent skin irritation from elastic/tube
- Document observations
- Communicate with team



Terminal Respiratory Congestion

- Rattling, gurgling respirations caused by accumulation of secretions that the person cannot clear
- Distressing for family and carers
- Treatment geared toward comfort of family and carers



Terminal Respiratory Congestion

Someone who is suffering from an illness that affects their respiratory system can experience something called Air Hunger. This is quite a distressing symptom for the client. Air hunger can be treated with medication such as Versed that will stop the brain from feeling deprived of air and reduce the associated anxiety.

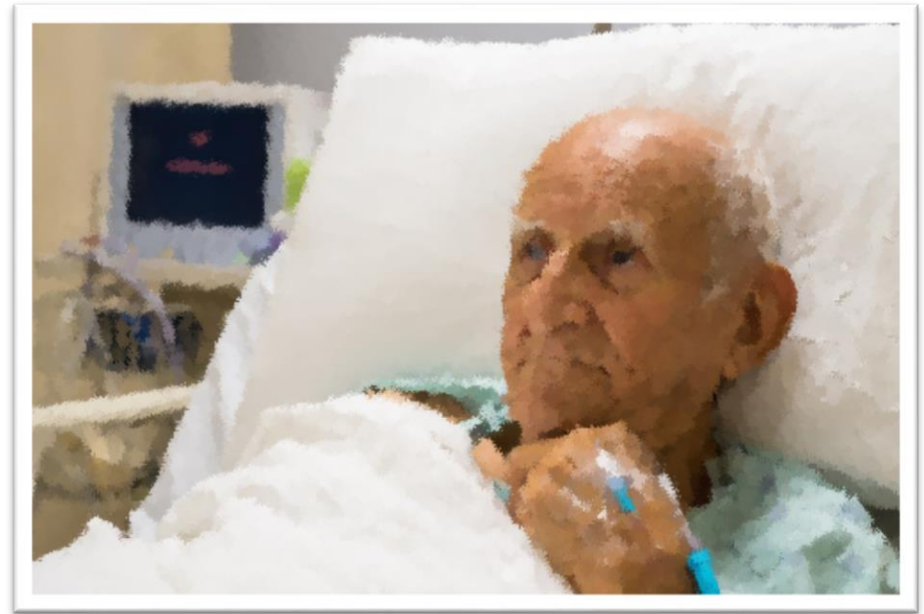
A build up of oral secretions and moisture is a very common experience in the final stages of a person's life. It can be managed with medication to eliminate or minimize the gurgling sound that might be upsetting to family or caregivers.

Either of these symptoms can be a natural part of the progression towards death but they can be very distressing to both the person and the caregivers. So, this treatment is not intended to prolong life but, instead, is geared toward increasing the comfort of the family and caregivers.



Supportive Care Strategies

- Provide reassurance to family
- Position for comfort (on their side or with head of bed raised)
- Provide good oral and nasal care
- Document observations
- Communicate with team



Delirium (Confusion)

- Difficulty thinking and acting appropriately
- Disturbing thoughts

Signs

- Restlessness, anxiety
- Reduced attention
- Disturbed sleep-wake cycle
- Hallucinations
- Disorganized thinking
- Incoherent speech
- Disorientation to person, place and time
- Memory impairment



Delirium (Confusion)

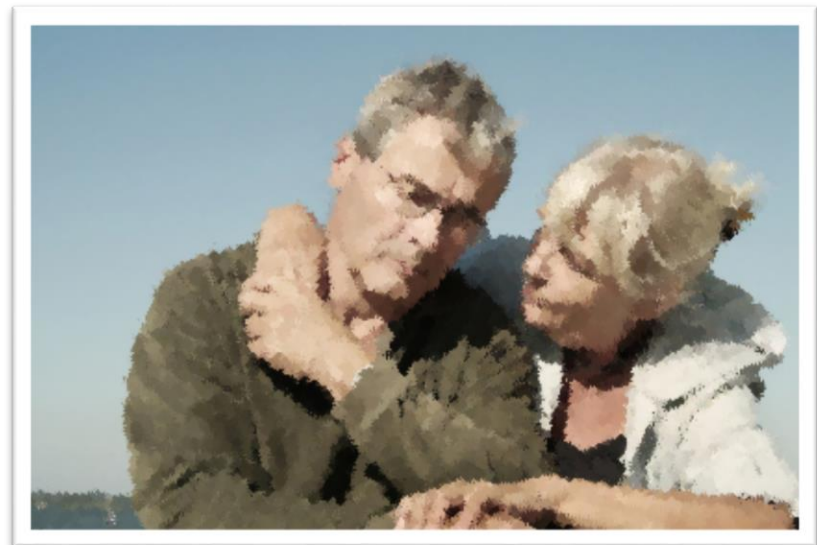
Delirium is another symptom that occurs frequently at the end of life. It involves changes to the person's cognitive function and prevents him/her from thinking or behaving in an appropriate manner. Communication of this symptom to the health care provider is very important to ensure that it is not being caused by an acute problem that should be addressed.

Delirium can present itself as restlessness or anxiety, disturbed sleep cycles, hallucinations and thought disturbances, a lack of orientation and lapses in memory.



Supportive Care Strategies

- Provide calm, quiet environment
- Speak in calm, soothing manner
- Provide familiar objects
- Encourage contact with friends and family
- Gently correct misperceptions
- Document observations
- Communicate with team



Dry Mouth and Skin

- Mouth breathing common
 - will cause dryness in oral membranes and increase suffering
- Use toothettes dipped in cool water
 - avoid mouthwash (may contain alcohol that increases dryness)
- Humidified air in room
- Lips: use water-based lubricant (not Vaseline, especially with oxygen)



Dry Mouth and Skin

Dry mouth and dry skin are common problems in the late stages of life for various reasons (such as mouth breathing or poor hydration).

To provide comfort in this situation you can use toothettes dipped in cool water to soothe the mouth and lubricate lips to prevent chapping and splitting.



Skin Care

- Essential for comfort
- Air mattress, egg crate mattress
- Light bedding to prevent restlessness
- Keep skin moist (pay attention to heels, elbows and other places where skin contacts bedding)
- Turn slowly
- Use supportive devices (pillows, wedges)



Skin Care

Good skin care is absolutely essential for the person you are caring for to maintain their comfort.

Specialty mattress toppers and light bedding can be helpful.

Use lotion to keep skin moist, paying special attention to bony prominences and to the areas of the skin that rest against the mattress.

Reposition the person often and with great care. Use pillows or wedges to help them maintain the position.



Feeding and Hydrating

Ethical quandary . . .

Should we
feed and hydrate
the dying person?



Feeding and Hydrating

As a caregiver, it is natural to want to feed someone. We frequently associate food with caring and love and many of our celebrations are associated with food.

These notions make it very difficult to let go of the idea that someone needs nutrition and can cause feelings of guilt and helplessness on the part of the caregiver.

People often feel it is cruel to deny food and fluids and that the person will suffer and die sooner as a result of withholding this basic necessity.

There is no research to support the idea that the person will die sooner and I will help you understand what happens to the body that makes food and fluids unnecessary at this stage of the dying process in the coming slides.



Common Misconceptions

- Food = Caring & Love
- The person must be hungry or thirsty
- It is cruel to deny food and fluids
- They will suffer without food and fluids
- They will die sooner



Common Misconceptions

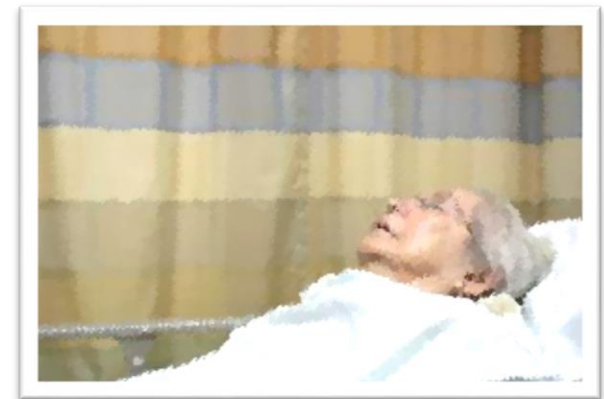
This can be a very difficult decision for carers to address—whether or not we should feed and hydrate a dying person.

Ultimately, this is a topic for which you would want to receive some guidance from the palliative care team.



What is Actually Happening?

- When the body is dying the organs shut down
- The heart, brain, liver and kidneys are less and less able to perform their functions
- The digestive system becomes disabled
- Food or fluids can cause choking and aspiration which can lead to aspiration pneumonia



What is Actually Happening?

For persons in the final phase of illness, the withholding of food and fluids is not painful. To the contrary, the administration of food and fluids to dying persons can extend their general discomfort and frustrate their desire to let go and allow nature to take its course. When a person is in the late stages of life and are actively dying, many changes occur in the body.

The function of the major organs begins to deteriorate and the digestive system shuts down causing the person's appetite to diminish. Providing food at this stage may cause nausea and vomiting and can also cause severe abdominal discomfort.

When the body is slowing and shutting down, fluids can go "down the wrong way" causing choking and possibly aspiration leading to aspiration pneumonia. This can often result in early and uncomfortable death.



A Natural Process

- Ceasing to eat and drink is a normal part of the dying process
- Hunger is rarely experienced
- Nature's path to a peaceful death
- Decreased secretions
- Euphoria caused by ketone formation
- Decreased anxiety



A Natural Process

As strange as this may sound, there are positive effects on the experience of the dying person in having little to no food intake as death approaches and is simply a normal part of the process.

Hunger is rarely experienced by the dying person and a decrease in some of the more troubling symptoms actually occurs. Oral secretions thicken and diminish for the person who has difficulty swallowing and they don't require suctioning as often or at all. They also experience a decrease in the lung secretions that can cause a drowning sensation.

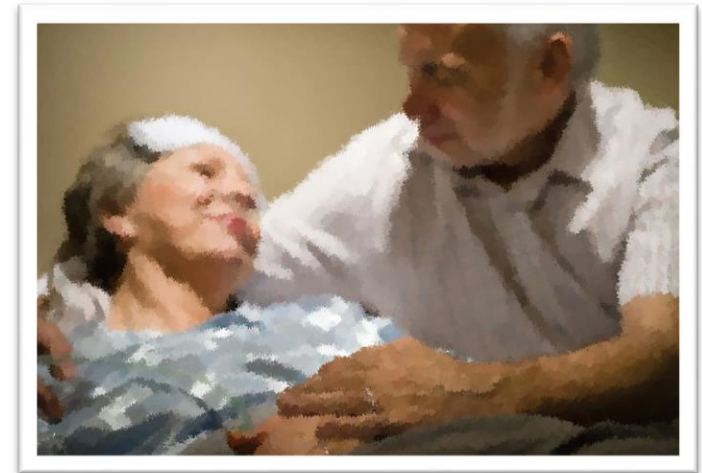
Gastric secretions are decreased reducing the incidence of nausea and vomiting.

Ketone formation occurs which provides a mild sensation of euphoria reducing anxiety and eliminating the typical physical experience of hunger and thirst.



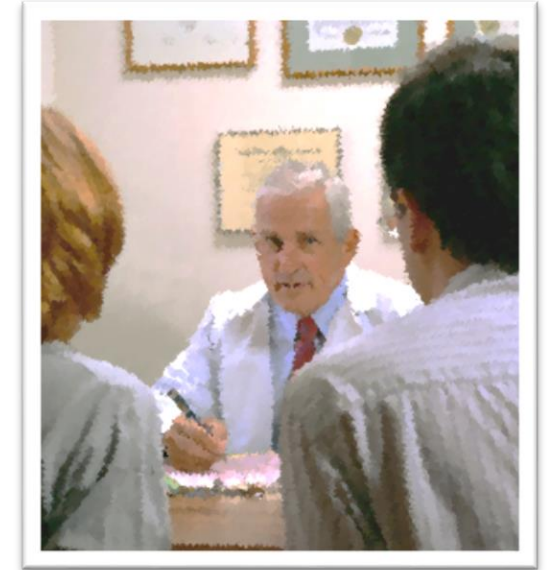
Supportive Care Strategies

- Be mindful of symptoms
- Careful assessment
- Treat all symptoms
- Moisten lips and mouth
- Provide “Comfort Care”



Making the Decision

- Prior known wishes?
- Competent SDM makes ultimate decision
- Consult with Doctor or Palliative Care team
- Consider goals of hydration and nutrition at this stage
- Weigh potential benefits and harm
- Health Care Professionals will respect wishes and ensure competence



Making the Decision

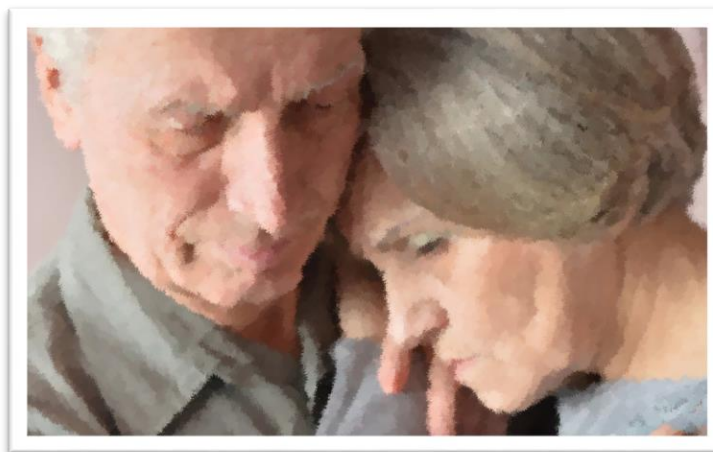
The decision whether or not to provide food and fluids to the dying person should be carefully considered. If the person has an Advanced Care Plan perhaps this has been addressed and those wishes should be followed. Barring that, a competent SDM will make these ultimate decisions. It is wise to discuss this in detail with your primary care provider or clinical members of the Palliative Care Team and always consider what goal you are trying to achieve as with any treatment decision. And carefully consider the pros and cons of the decision.

Healthcare professionals have a responsibility to provide you with information to make an informed decision and ensure that the decision is made by a person that is competent. A competent decision must be respected.



Needs to Consider for People with an ID/DD

- 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



People with ID/DD

Specifically when working with people with Intellectual Disabilities you need to take steps to minimize fear and anxiety at the end of life. As this can all be quite confusing to the person, be sure to provide adequate information in simple terms to help them understand what is happening and what they can expect.

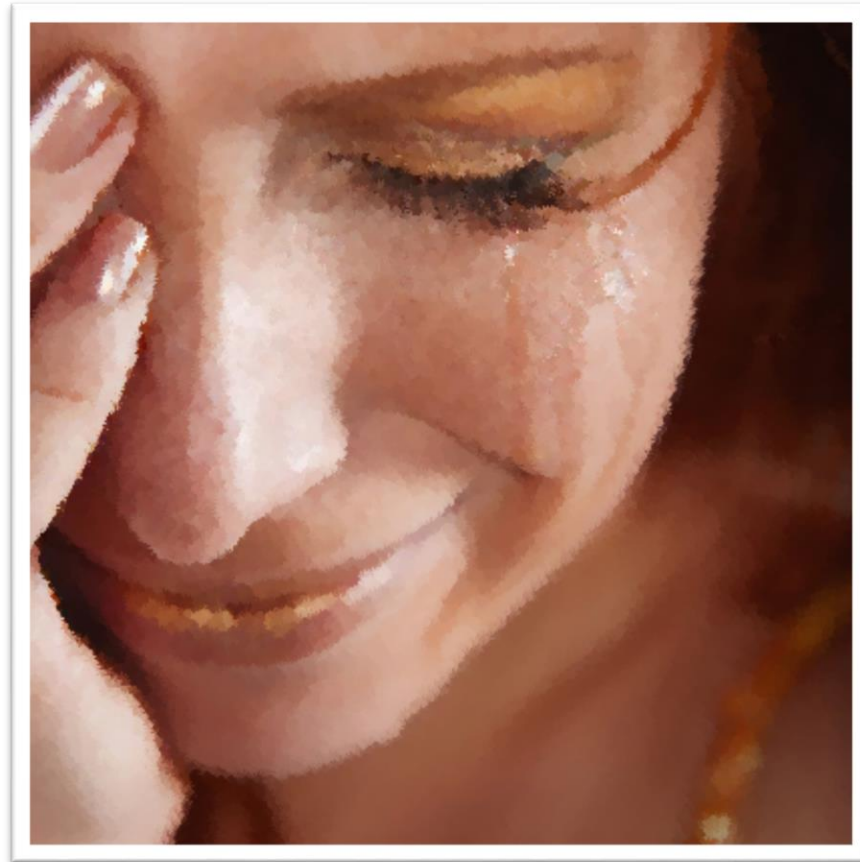
Always ensure you provide the practical comfort measures (such as pain relief) but also be certain to provide physical signs of caring such as simple, appropriate touch and surrounding them with items that are familiar and comforting.

Provide them with assurances that someone will be with them, they are not alone and that they are cared for.



Self-Reflection

Consider your own experience of grief



Self-Reflection

Take a couple minutes to consider your own first experience of a death; if not a person, then a pet.

How has that impacted you?

Pause for individual reflection.

Our personal experiences with death often impact the way in which we approach the care and support that we would provide to the dying person and the family.

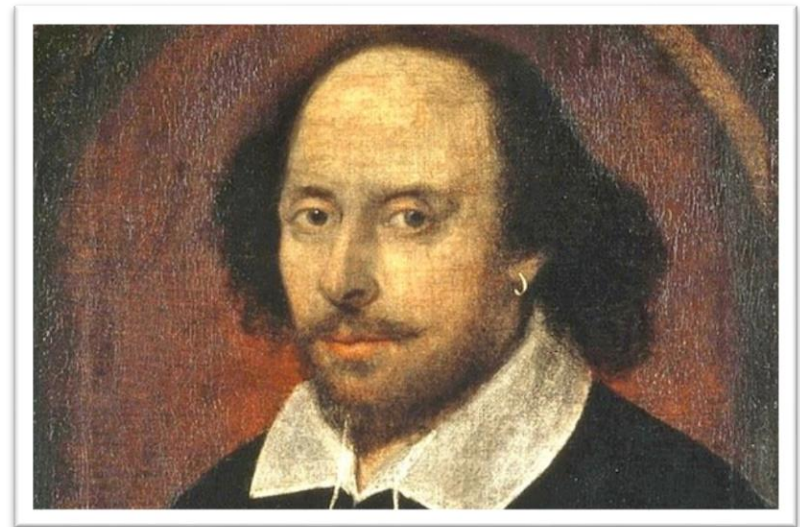
How might your own feelings and attitudes about death help or hinder your ability to support a dying person and the family?



Understanding More About Grief

“To weep is to
make less the
depth of grief.”

William Shakespeare



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



What is Disenfranchised Grief?

- Fear of causing harm by engaging in such conversations
- Concern of frightening or provoking uncontrollable emotional response
- Incorrectly assuming person with ID is not capable of participating in care planning
- Danger of “**Conspiracy of Silence**”
- Such behaviour is likely to add to the person's confusion and distress.



What is Disenfranchised Grief?

Carers are often unsure if they should talk to a person with ID/DD about their illness or that of a loved one.

Common misconceptions about grief:

- People with intellectual disabilities don't understand or can't comprehend death.
- People with intellectual disabilities don't show grief, therefore experience no grief.
- Talking about it would be too upsetting for him/her.

There is a danger of creating a “conspiracy of silence,” where professionals, family and friends all know about the illness and impending death but will not talk about it in the presence of the person. Arguments such as “He won't understand” or “The truth is too upsetting” are often used.

The unintended consequence of this action is generally an increase in anxiety through confusion about what is happening or has happened.



What we understand about people with disabilities

Individuals with intellectual disabilities:

- experience grief when they lose a loved one, just like everyone else
- effects of bereavement may be prolonged and they may experience more anxiety, depression, irritability, and other signs of distress
- no evidence that people with ID have less need for information about illness, death, and dying



What we understand about people with disabilities

What we now know about people with Intellectual Disabilities is in contrast to many previously held beliefs. People with intellectual disabilities do experience grief when they lose a loved one just as much as anyone else does.

They may respond differently than you may expect by suffering the effects over a longer period of time and by having more internalized symptoms such as anxiety, depression, irritability or outward expressions of anger.

There is no evidence in current literature that suggests that people with an Intellectual Disability need to have any less information about death and dying than the average person.



Supportive Care

To effectively support a person with an intellectual disability through the bereavement process you need to provide them with accurate and honest information in a format that is clear and easy to understand.

You will need to be creative and proactive about providing opportunities for them to express their grief. For individuals who may have limited or no verbal skills active expression opportunities are best such as painting, dancing or by creating a photo album.

They will need reassurance along the way as they process the difficult information.

They will need to know they are not to blame and they will need to be walked through what it will look like to and how things will be different without this person in their life.



Key Strategies for Care

- Provide accurate and honest information
- Provide support to process it (plain language)
- Provide opportunities for expression of grief and condolences
- For those who are non-verbal, grief will require some active form of creative expression such as painting, dance, or creating a photo album



Key Strategies for Care

- Provide reassurance
 - that there is no blame
 - on the ways things will be different
- 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



Key Strategies for Care

- Provide opportunities for the individual 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



You Matter . . .

“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



Resource List for Palliative Care

- Abbey Pain Scale
- Palliative Care Case Study
- Chronic Pain Scale—for Non-Verbal Adult
- 12 Tips for Supporting an Adult
- Domains of Issues
- Dis DAT Tool
- Celebration of Life
- Thinking Ahead (Workbook)
- Thinking Ahead video (see link; 13 minutes)

<http://coalitionccc.org/tools-resources/people-with-developmental-disabilities>



Research and Writing



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ADVANCED CARE and END-OF-LIFE PLANNING



Haldimand & Norfolk Seniors Partnership

**Thank you for following this course of study.
We would value any comments or suggestions
that you have for developing this
as an e-learning website.**