

Promoting Quality at End of Life for those Living with Dementia

Learning Objectives

- * To identify and utilize the principles of a palliative approach to pain and symptom management for end of life care

“People are not palliative – our approach to their care is palliative”

What does this mean?

- * When cure is no longer possible - ***QUALITY of life is paramount!***
- * The focus is on the whole person and their family and helping them cope with their illness rather than focusing on the illness and its influence on the disease process.



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- * To address considerations when engaging people and their families in Advance Care Planning Goals of Care conversations.

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- * To recognize the importance of a thorough assessment of the person's pain and other symptoms to develop an end of life plan for care



- * To understand the importance of a person centered approach to palliative care

We must take the basic principles of palliative care, assess each person and then develop a plan of care based on that person's needs.....

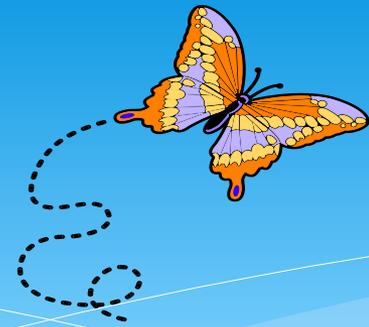


“Life is pleasant, death is peaceful. It is the transition that is troublesome”

- Isaac Asimov

The Principles of Palliative Care

- * Focuses on quality of life and the quality of dying
- * Is for all persons with a progressive, life threatening, incurable illness
- * Applies to people of all ages
- * **Is not just for the terminal phases of life or the last few weeks or days**



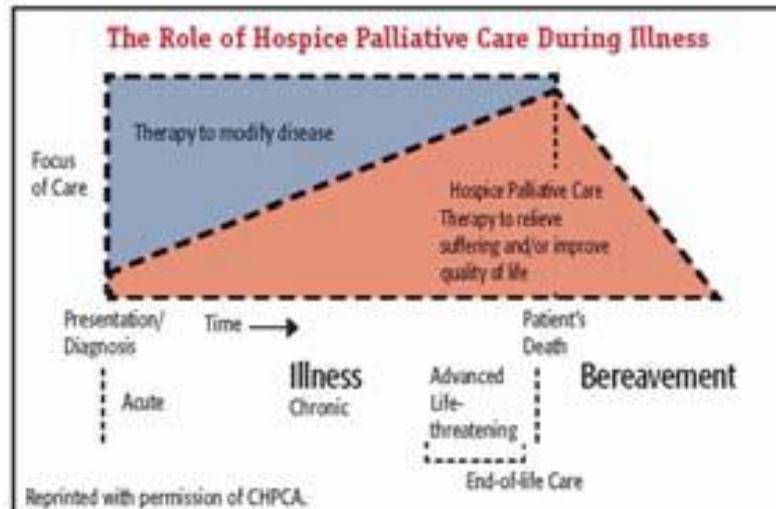
- * Is active care – including aggressive management of symptoms
- * Requires a set of knowledge, attitudes and skill-based competencies
- * Acknowledges the interdependence of various causes of suffering
- * Recognizes the whole person: physically, psychosocially, emotionally, culturally and spiritually
- * Acknowledges the illness experience of the person and family



- * Is most effectively delivered by interdisciplinary collaboration
- * Is both an approach (an integral component of primary care) and a specialty
- * Grief and bereavement is integral to palliative care.



Role of hospice palliative care during illness



The ABCDs of Dignity Conserving Care

Dignity is multidimensional construct:

- * Attitudes
- * Behaviour
- * Compassion
- * Dialogue

Chochinov H. Dignity and the essence of medicine: ABCD of dignity conserving care.
BMJ 2007;335:184-187

* Attitudes

- How would I be feeling in this person's shoes?
- Am I aware how my attitudes toward the person may be affecting him or her?

* Behaviour

- Paying attention to the tone of contact & voice
- Looking at person
- Going the extra mile





* Compassion

- Getting in touch with one's own feelings before entering room and in presence of the person
- Spoken or unspoken communication that acknowledges the person beyond their illness
- An understanding look
- A gentle touch on the shoulder, arm or hand



* Dialogue

- "What do I need to know about you as a person to give you the best care possible?"
- "At this time in your life, what are the things that are most important to you, or that concern you most?"
- "What are most proud of in our life?"
- "Are you concerned about how your illness is affecting other people close to you?" (burden)

The Art of Being Present

“When a nurse is with us, in the sense of being present, we feel the security of her protective gaze, we feel valued as a person, the focus of her attention...We sense the nurse is close enough to feel with us, sharing the loss that accompanies the disease we are experiencing in a sensitive, intimate way...She understands. When a nurse is truly present, seeing and feeling all these things, we sense a kind of hopefulness...For a moment we are not alone.”

Bottorff, 1991

Guidelines for being there..



- * Place yourself at the same level as the person.
- * Say the person's name.
- * Offer opportunity for privacy and uninterrupted time for unhurried discussion.
- * Be yourself, be ordinary.
- * Observe and match mood and behaviour.
- * Be guided by the person about how much contact is comfortable.
- * Find common ground as you share time together.

Guidelines for being there...



- * Heaviness, sadness, anger, and frustration may need to be acknowledged before any further issues are raised.
- * Be specific about how you can help and what is going to happen.
- * Set boundaries.
- * Respond to opportunities to talk about death.
- * Be respectful.

Effective communicators are good at:

- * Active listening:
 - * Eye contact
 - * Attentive body language:
 - * Relaxed posture
 - * Slightly leaning forward
 - * Animated tone of voice
 - * Appropriate closeness
 - * Interested facial expression
 - * Head nodding
 - * Verbal following



The Families of Dying Persons



What is a family? Who makes up a family?

- * Family is who the person says it is.
- * May include the biological family, the family of acquisition (related by marriage or contract), or people of choice and friends.



Family reactions to a dying person....



- * A life threatening illness affects all members of a family.
- * Family can be as deeply disturbed by the illness as the person who is dying.
- * The most difficult thing for the family can be dealing with their own emotions.
- * Some family members can cope while others feel completely overwhelmed.



COMMUNICATING
**WITH
FAMILIES**



How to support the family in Crisis...

- * Be a good listener
- * Respond in a non-judgmental way
- * Provide honest reassurance
- * Consult with the family and keep them informed

Ethics: What is it?

- * We have all developed certain values in life
- * Some values we share with others
- * Some of our values differ
- * Ethics is about finding a way forward when values are not alike
- * Sometimes it is not clear what the right or best way forward might be

Ethical principles

- * Autonomy – self governing, independence
- * Beneficence – do good
- * Non-maleficence – do no harm
- * Justice – fairness, what is legal

Autonomy

- * What are the goals of care?
- * What would the person want?

Clinical applications:

- * When the decision to use a comfort focused approach to care is reflected by the consensus – based process of Advance Care Planning

Non-maleficence

- * Means to “do no harm.” Physicians must refrain from providing ineffective treatments or acting with malice toward persons.
- * This principle, however, offers little useful guidance to physicians since many beneficial therapies also have serious risks.
- * The pertinent ethical issue is whether the benefits outweigh the burdens.

Clinical Applications

- * Physicians should not provide ineffective treatments to a person as these offer risk with no possibility of benefit and thus have a chance of harming them.
- * In addition, physicians must not do anything that would purposely harm a person without the action being balanced by proportional benefit.

Balancing Beneficence and Non-maleficence

- * One of the most common ethical dilemmas arises in the balancing of beneficence and non-maleficence. This balance is the one between the benefits and risks of treatment and plays a role in nearly every medical decision such as whether to order a particular test, medication, procedure, operation or treatment.

Advance Care Planning

- * The ongoing process of dialogue, knowledge sharing, and informed decision-making that needs to occur at any time when future or potential end-of-life treatment options and goal of care are being considered or revisited.
- * It is the conversations, the process not just the document.

Foundations for the conversation

- * What can *realistically be offered*
- * What options support quality care?

“Don’t tell him...”

- * Sometimes families may feel it best not to share information with the person, even when the person has some ability to understand.
- * This becomes even more complicated when the person suffers from dementia.
- * If the person is able to understand not sharing takes away any opportunity for the person to participate in making choices about their care as well as completing any projects or conversations

* In situations where death will be an inescapable outcome, family may nonetheless feel that the choices about care are life and death decisions (treating infections, hydrating, tube feedings, etc.)

“I know you’re being asked to make some very difficult choices about care, and it must feel that you’re having to make life and death decisions”

‘You do remember that this is not a survivable condition, and none of the choices you make can change that outcome.’

It's all about communication....

“As you know, things are changing quickly. We can make sure he's comfortable, but I don't believe that he has much time. His systems are shutting down, and this will reach a point where his heart can no longer keep beating. While you may have heard of times where people will try to restart the heart beating with CPR, that can't work in this type of situation, as it's not possible to fix the problems that caused the heart to stop....”



This is similar to explaining why hoped for surgery cannot be done, or a specific chemotherapy will not be given in a circumstance where it can't work or will be too toxic. In these situations the intervention would not be offered.

Considerations

- * “Comfort Care”
- * “Medical Care”
- * “Resuscitation”



Understanding
the dying person

Assessing the person

- * **Accurate and consistent assessment** of pain and other symptoms at end of life is imperative. Poor pain and symptom assessment is one of the barriers to effective symptom management. Assessment is vital to obtain optimal symptom management
- * Clinical information is always **PERSON SPECIFIC**
- * When in doubt: **LOOK AT THE PERSON**
- * Plan ahead for predictable situations

Physical changes

- Fluid retention
- Muscle wasting
- Pallor or jaundice
- Skin problems
- Amputation/mastectomy common
- Body odour
- Lack of appetite
- Difficulty breathing
- Decreased mobility
- Memory Loss
- Decreased ability for self care



Pain Assessment

- * Pain is a symptom that elderly and cognitively impaired do experience.
- * Pain sensitivity or perception remains with age and cognitive impairment.
- * The cognitively impaired may not verbally express that they are experiencing pain.

COMPASS Tool

Room # _____

Today's Date: _____

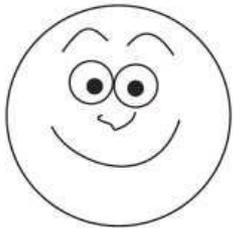
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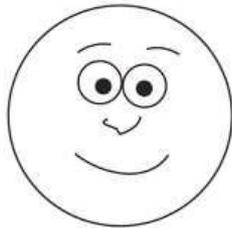
Place patient label here
(Must include CR)

1. Edmonton Symptom Assessment System Revised (ESAS-R) Please circle the number that best describes how you feel NOW :		3. Medications Have there been any changes since your last visit? <input type="checkbox"/> Yes (If yes, please list): <input type="checkbox"/> No change in medication	
1. No Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Pain	4. Other Have you smoked in the past six weeks? <input type="checkbox"/> Yes <input type="checkbox"/> No Are you interested in quitting smoking? <input type="checkbox"/> Yes <input type="checkbox"/> No
2. No Tiredness <i>(Tiredness = lack of energy)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Tiredness	
3. No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Drowsiness	
4. No Nausea	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Nausea	
5. No Lack of Appetite	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Lack of Appetite	
6. No Shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Shortness of Breath	
7. No Depression <i>(Depression = feeling sad)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Depression	
8. No Anxiety <i>(Anxiety = feeling nervous)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Anxiety	
9. Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Wellbeing	
10. No _____	0 1 2 3 4 5 6 7 8 9 10	Worst Possible _____	
Other problem (for example: night sweats, wound issues)			
2. Canadian Problem Checklist Please check all of the following items that have been a concern or problem for you in the PAST WEEK INCLUDING TODAY :			
Physical: <input type="checkbox"/> Concentration/Memory <input type="checkbox"/> Sleep <input type="checkbox"/> Weight <input type="checkbox"/> Constipation <input type="checkbox"/> Diarrhea <input type="checkbox"/> Swallowing <input type="checkbox"/> Mouth sores <input type="checkbox"/> Falling/Loss of balance <input type="checkbox"/> Vision or hearing changes <input type="checkbox"/> Heartburn/Indigestion <input type="checkbox"/> Numbness/Tingling <input type="checkbox"/> Changes to skin/nails <input type="checkbox"/> Bleeding/Brusing <input type="checkbox"/> Bladder problems	Practical: <input type="checkbox"/> Work / School <input type="checkbox"/> Finances <input type="checkbox"/> Accommodation <input type="checkbox"/> Getting to and from appointments <input type="checkbox"/> Child/Family/Elder care <input type="checkbox"/> Trouble with my daily activities	Emotional: <input type="checkbox"/> Fears / Worries <input type="checkbox"/> Sadness <input type="checkbox"/> Frustration/Anger <input type="checkbox"/> Changes in appearance <input type="checkbox"/> Intimacy / Sexuality <input type="checkbox"/> Fertility <input type="checkbox"/> Coping <input type="checkbox"/> Loss of interest in everyday things <input type="checkbox"/> Loss/grief	Dignity: <input type="checkbox"/> Loss of control <input type="checkbox"/> Embarrassment/shame <input type="checkbox"/> Not feeling respected/understood <input type="checkbox"/> Not feeling worthwhile/valued <input type="checkbox"/> Feeling like I am no longer the person I once was
Spiritual: <input type="checkbox"/> Meaning/Purpose of life <input type="checkbox"/> Faith	Informational: <input type="checkbox"/> Understanding my illness and/or treatment <input type="checkbox"/> Talking with the health care team <input type="checkbox"/> Making treatment decisions <input type="checkbox"/> Knowing about available resource		Social/Family: <input type="checkbox"/> Feeling a burden to others <input type="checkbox"/> Worry about family/ friends <input type="checkbox"/> Feeling alone <input type="checkbox"/> Relationship difficulties

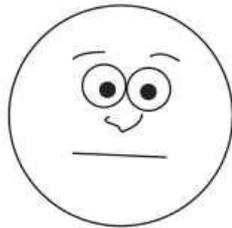
Faces Pain Scale



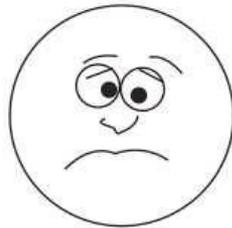
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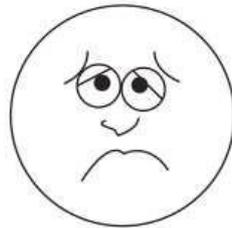
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4



6



8



10

PAINAD – Pain Assessment in Advanced Dementia

Behaviour	0	1	2	Score
Breathing Independent of vocalization	<ul style="list-style-type: none"> Normal 	<ul style="list-style-type: none"> Occasional labored breathing Short period of hyperventilation 	<ul style="list-style-type: none"> Noisy labored breathing Long period of hyperventilation Cheyne-Stokes respiration 	
Negative vocalization	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> Occasional moan or groan Low-level speech with a negative or disapproving quality 	<ul style="list-style-type: none"> Repeated troubled calling out 	
Facial expression	<ul style="list-style-type: none"> Smiling or inexpressive 	<ul style="list-style-type: none"> Sad Frightened Frown 	<ul style="list-style-type: none"> Facial grimacing 	
Body Language	<ul style="list-style-type: none"> Relaxed 	<ul style="list-style-type: none"> Tense Distressed pacing Fidgeting 	<ul style="list-style-type: none"> Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out 	
Consolability	<ul style="list-style-type: none"> No need to console 	<ul style="list-style-type: none"> Distracted or reassured by voice or touch 	<ul style="list-style-type: none"> Unable to console, distract or reassure 	
Total Score				

Pain and Symptom Management at End of Life

- * Medications should begin at **conservative starting doses**. Medications may need to be rapidly escalated which would require an individualized medication order
- * Need to review all medications, including those related to end of life care.
- * Need to understand the changes in the person's ability to metabolize the medications.

Pain and Symptom Management at End of Life

- * The dose of medication will need to be individualized and may need to be increased or decreased
- * Intervals between doses may need to be lengthened or shortened.
- * The frequency of assessment and evaluation should be increased
- * The responses cannot be predicted or generalized.

Pain

- * Accurate and consistent assessment of pain is imperative. Poor pain assessment is one of the barriers to effective pain management.
- * Assessment of pain is ongoing.
- * Use the oral route for medication administration whenever possible
- * Opioids are appropriate and safe for treatment of pain.
- * Regular scheduling of pain medications is required to reach an optimum level of analgesia.

- * PRN pain medications are used to control breakthrough pain and assist in the titration of client needs. When a PRN medication is given it is important to continue to give the regular scheduled dose at the regular scheduled time.
- * Incident pain is defined as a pain that results from an activity, unlike breakthrough pain it is often predictable and short lived for example, dressing changes, turning and positioning, extended ambulation. Medication should be administered 15-30 minutes before the activity.

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- * The appropriate dose of pain medications is the amount of medication required to control the person's pain with the fewest side effects; it should be titrated to analgesic effect and avoid toxicity.
 - * There is no maximum daily dose.

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- * There is often uncertainty about whether a person's restlessness and moaning is related to pain, delirium, or dyspnea. If unsure, then opioids should be considered. The addition of methotrimeprazine may also be helpful as it has analgesic properties.

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- * Hydromorphone may be preferred over morphine due to fewer active metabolites (toxicity) that may accumulate, resulting in less side effects
 - * Potential side effects from pain medications for example constipation and nausea etc., must be monitored and treated. It should be noted that these are side effects and not allergies.

- 
- * Long-acting medication preparations (sustained-release, “CONTIN” preparations, or transdermal fentanyl patches) should **not** be used to manage rapidly evolving symptoms.
 - * If death is near and the person is already on a stable dose of fentanyl patch, this medication should be continued and additional short-acting opioids added for titration of comfort.

How do we know that opioids are not compromising the person?

- * A common barrier to the effective use of opioids and sedatives in managing pain or dyspnea is the misconception that they will compromise the client's respiratory efforts and potentially hasten death. There is no evidence that opioids compromise clients when given in doses proportionate to the degree of distress; in fact, there is evidence that they may prolong survival. Often, the person dying will be breathing rapidly. In the final moments, irregularly spaced apneic episodes occur, resulting in an erratic pattern of breathing. Clusters of rapid breaths and increasingly frequent and prolonged apneic episodes commonly follow. This typically unfolds quickly; over a few seconds to several minutes following which breathing ceases.

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- * In contrast, excessive opioid doses cause a progressive slowing of breathing which tends to unfold more gradually with the respiratory pattern remaining regular. Pupils are generally pin point.
 - * This is an important distinction to recognize, as staff and family may be concerned that repeated doses of opioids may contribute to the decline. When administering medications to a client who is dying, there will invariably be a point at which the person dies **after (but not due to)** receiving a medication dose.

Shortness of Breath

- * Non-pharmacological interventions include calm reassurance, elevating head of bed, cool air with an open window or a fan.
- * Short acting formulations of opioids are the main pharmacologic palliative intervention (i.e. immediate-release morphine or hydromorphone rather than long-acting medications or transdermal fentanyl)

- * Methotrimeprazine (Nozinan) is often helpful in alleviating agitation and providing additional sedation without significantly adding to the respiratory depressant effects of opioids.
- * Benzodiazepines such as Lorazepam may also help with anxiety in the context of dyspnea, however the literature does not consistently show benefit in dyspnea itself. Benzodiazepines are more likely to increase the respiratory depressant effects of opioids than neuroleptics such as methotrimeprazine. If additional sedation is needed during rapid escalation of opioid doses, methotrimeprazine is preferred.

The Role of Supplemental Oxygen in Palliation of Dyspnea

- * The potential benefit of oxygen in relieving the experience of breathlessness at the end of life is controversial, however **comfort can be achieved without supplemental oxygen** using opioids such as morphine or hydromorphone as well as methotrimeprazine or a benzodiazepine such as Lorazepam.
- * There is no role for the monitoring of oxygen saturation in comfort-focused care at the end of life. If the person appears comfortable, oxygen levels are irrelevant and should not influence care. If the person appears uncomfortable, comfort should be pursued through the adjustment of opioid and sedative medications regardless of oxygen levels.

Fever

- * Treatment of fever is a comfort measure
- * Fever is considered a temp of 38 or higher however at the end of life we do not usually check vital signs
- * Treatment should be given when the person is warm to touch, may be red faced and/or occasionally restless.

- * Maximum of Acetaminophen 3000 – 4000 mg. within 24 hours from all sources

Causes of Fever

- * Infection - dependent in goals of care there may be some indication to treat the infection – however there would need to be a very in depth conversation before antibiotics would be considered at end of life.
- * May be tumor related
- * May be a side effect of medication

Nausea and vomiting

- * Needs to be treated if the person is experiencing either symptom.
- * If the nausea or vomiting is occasional then medications may be given on an as needed basis but if the person is experiencing either nausea or vomiting on a regular basis the medication should be regularly scheduled.
- * Metoclopramide 10 to 20 mg orally/subcutaneously qid and up to 3 additional breakthrough doses in 24 hours
- * Haloperidol 0.5 to 2 mg bid orally/subcutaneously q4h and up to 3 additional breakthrough doses in 24 hours

Feeding and Hydration

- * Discussion with family will be very important
- * An understandable and very common concern is that food and fluid intake is compromised at the end of life.
- * We also know that:
 - Not feeling hungry and not eating very much is a normal response for people who are at the end of life.
 - Most people at end of life complain of dry mouth rather than thirst

Considerations for hydration

- * If hydration is decided upon, it should be initiated as a trial for a specific period of time and reviewed with client and/or family regularly. In this situation it is often easier to discontinue hydration if no benefit is found.
- * Fluids can be administered subcutaneously (Normal Saline via hypodermoclysis) if no risks identified – but should be initiated as suggested for a specific time period and reassess regularly for adverse effects – pooling in ankles, abdomen or chest...
- * Opioid Toxicity needs to be treated.

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- * In the terminal phase of progressive illness there is virtually always a profound loss of appetite (and therefore an absence of hunger). The literature is clear that the body cannot use calories to become stronger or to gain weight. Instead, it breaks down its own energy stores (muscle/fat/carbohydrates) regardless of caloric intake.
 - * Efforts to improve caloric intake by enteral or parenteral means have no role in addressing comfort, functional status, or survival in such end of life scenarios.

Considerations for Artificial Nutrition

- * If a tube feeding is requested, such intervention should be made with specific goals in mind and the benefits and burdens of therapy **MUST** be reassessed regularly
- * This should never be an emergency discussion/decision
- * Needs to be team involvement in discussion with family with risks and benefits clearly defined - Decisions must be informed
- * Decisions are individualized and aligned with goals of care – quality of life
- * Based on ethical principles: Do good; do no harm; autonomy – right to choice; justice – what is legally accepted

Respiratory Congestion/Secretions

- * This refers to deep pulmonary secretions which accumulate due to weak cough and terminal lower respiratory infection; sometimes referred to as the “death rattle”. Prevalence is as high as 92% at end of life.
- * Terms such as drowning, suffocation, and the death rattle have negative connotations for family and should be avoided in conversation.
- * Respiratory secretions do not mean the person is short of breath, the person will not suffocate.
- * Although an unconscious person would not be aware of secretions, they are disturbing to those at the bedside.

Respiratory Congestion/Secretions

Medications:

- * Glycopyrrolate 0.2 to 0.4mg subcutaneously q2h prn
- * Atropine 1% eye drops 1 to 2 drops sublingually or buccally q1h prn
- * Scopolamine 0.4 mg subcutaneously and Intranasally via nasal Atomizer q2h prn
- * Scopolamine Transderm Patch 1.5 mg q72 hrs

Psychosocial issues

Dr. Kubler-Ross Stages of Dying:

1. Denial
2. Anger
3. Fear
4. Sadness
5. Acceptance



Feelings of Anxiousness

- * Intermittent times of anxiousness
- * Lorazepam 0.5 to 1 mg q4h orally or sublingually or subcutaneously prn

Agitation/Restlessness

- * End of life agitation when someone is tossing in bed, sitting up, lying down etc... need to consider emotional angst as well as increased pain
- * With the goal of care being that the person remains restful until death occurs, **it may not be possible to fine-tune sedation to a balance of being calm yet interactive**, and pursuit of this unrealistic goal will only ensure unacceptable restlessness.
- * Haloperidol 0.5 to 2 mg bid orally/subcutaneously and up to 3 additional breakthrough doses in 24 hours
- * Methotrimeprazine 6.25 to 15 mg orally/ subcutaneously q4-6h prn

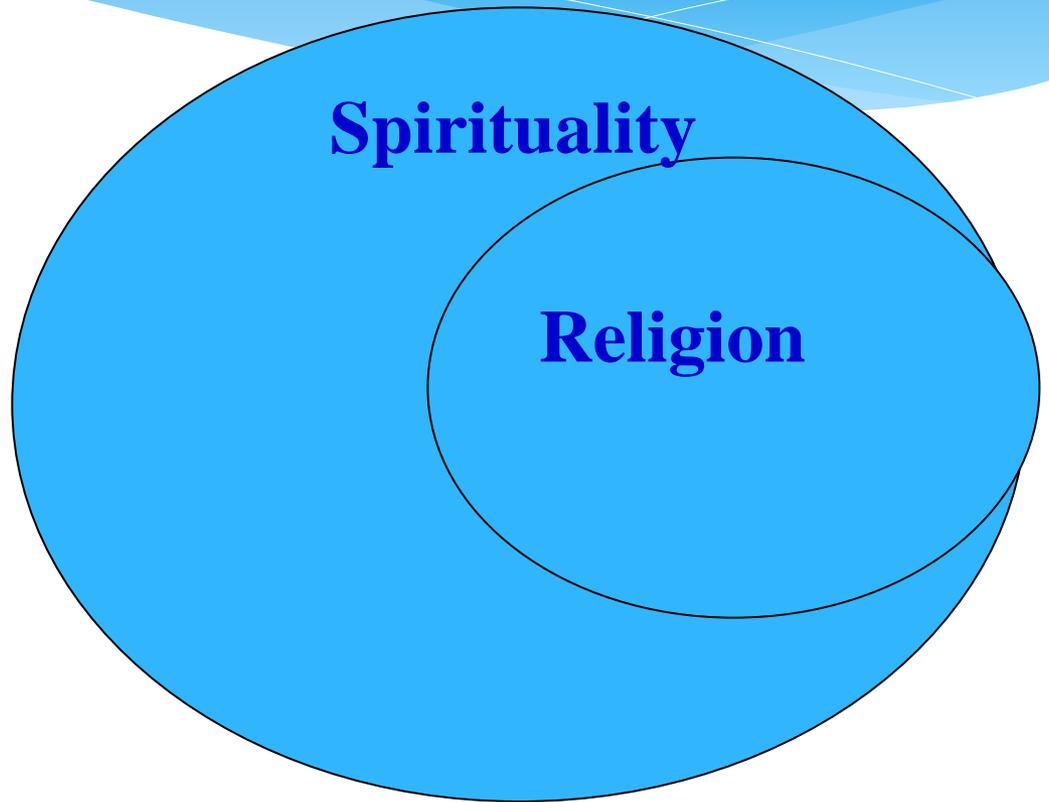
Spiritual Issues



- * Life threatening illness may encourage people to become introspective
- * A person's spiritual beliefs are based on both cultural and personal experiences
- * There are many different spiritual belief systems in existence today



Spiritual needs:
To be treated with
dignity & worth,
someone to
listen,
to stay and talk
when fears and
difficult questions
arise.



Religious needs:
For communion, anointing, prayer, and/or
other things connected to the person's
faith community

The Precipitous Decline

- * The rapid deterioration in the final days of life can be surprising for many, and upsetting for family members who may feel that they have missed the opportunity to say goodbye.
- * With progressive physical and cognitive decline, there is little physiological reserve; this is much like someone being supported by very thin ice... any added burden results in falling through very suddenly.
- * At times the very medications being given for comfort are blamed for the rapid changes being seen; it may be necessary to review the sequence of changes with family, to reaffirm the imperative of comfort, and to reframe the approach to care as “what would he/she want in these circumstances?”

How to Promote Quality at End of Life for Those Living with Dementia?

- * Consider Palliative Care Concepts
- * Referenced Pain and Symptom Assessment and Management Guidelines
- * Advance Care Planning Policy and Concepts
- * Ethics Committee and Ethical Decision Making Framework
- * Resources: Canadian Virtual Hospice
Dignity Therapy
WRHA - Advance Care Planning

We enter this world surrounded by love, comfort and care.
Don't we deserve the same when we leave?



Photo