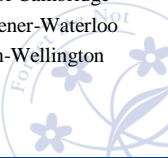




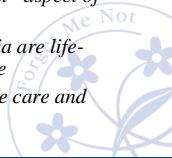
Palliative Care for Persons with Dementia

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The times they are a changing....

- *We die at older ages now and often of chronic terminal illnesses*
- *Initiation of the concept of providing palliative care to people with a diagnosis other than cancer (McIlfrack)*
- *Diseases causing dementia were not considered terminal, because dementia was thought to be a "normal" aspect of aging*
- *Now recognized that diseases causing dementia are life-threatening illnesses with no possibility of cure*
- *Need to make the distinction between palliative care and hospice care*



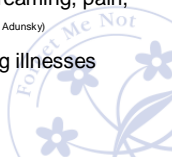
Agenda

- Why look at palliative care for persons with dementia differently ?
- Needs of people with dementia
- Communication in dementia care
- Specialized dementia care and tools



Palliative care for dementia is largely absent now

- prevalence of untreated pain for NH residents estimated at 45-80 % (Miller, Brown and Von Roenn)
- one study 90% of those with dementia died with high or intermediate levels of suffering (not calm, screaming, pain, decubitus ulcers, invasive actions etc.) (Aminoff & Adunsky)
- behavioural symptoms caused by coexisting illnesses may be ascribed to dementia (Burgess)





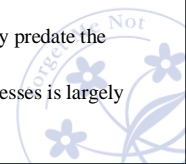
Palliative care should be present from the beginning

- using a palliative approach from the beginning addresses emotional needs from the beginning (Burgess)
- helpful features of a palliative program are
 - continual follow-up and evaluation
 - attention to all symptoms causing distress
 - avoidance of hospitalization (crisis prevention) (Kristjanson)



Why is palliative care for those with dementia different ?

- Long, slow and unpredictable journey
- Communication is drastically impaired
- Actions and behaviours of people with dementia are often not rooted in 'reality' as we see it
- Complex picture – other chronic illnesses may predate the development of dementia
- Identification and diagnosis of coexisting illnesses is largely based on behavioural indicators (Burgess)



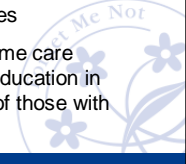
Why is palliative care for those with dementia different?

- previously, home care was seen as temporary (Loengard)
- there is a disconnect between traditional home care and the needs of a person with dementia
- caregiving is not short-term, but lasts for many years, and can be dangerous – 63% higher mortality risk (Santina)



Focus - the need for palliative care from the beginning

- until this point, only family doctors and (perhaps) the Alzheimer Society chapters are involved from beginning to end and beyond
- there is a need for all health care workers to understand the basic pattern of the of dementing illnesses
- there is a need for all people working in home care agencies or acute care services to receive education in order to understand and respect the needs of those with dementia





When could / should /does palliative care for people with dementia begin?

- Variety of answers due to:
 - “Clinicians’ reluctance and/or inability to define palliative status and predict time to death for this group.” (McInturick, 2006)
 - Palliative care still seen primarily as meaning ‘terminal care’, restricting the service and care provided during the ‘dying stage’
 - Perceptions across disciplines and professions differ on the point of when does a person become palliative with palliative care needs



Palliative care needs throughout the illness trajectory

- Early – education, driving adjustment, adjusting to work loss / disability income needs if under 65, need for help with passing time due to decreased executive function, establishing Powers of Attorney, adjusting roles, bereavement and depression (continues for all stages)
- Middle – adjusting to home care, use of day programs, caregiver respite, increased family involvement in care
- Late – adjusting to placement, advocacy during placement, support for continued involvement, terminal care



Palliative care vs hospice / terminal care?

- palliative care should begin at the beginning of the illness
- terminal, hospice care generally accepted as the last six months of life
- need an assessment tool for dementia clients based on research showing which indicators converge six months prior to death (Mitchell and Kiely)
- following terminal care directives must be consistent amongst care providers



We are responding.....

- to the need for palliative care throughout the course of the terminal illness of diseases causing dementia
- First Link Program – will strengthen access to the services of the Alzheimer Society chapters and ancillary community services from the time of diagnosis
- Ongoing care will avoid crises (hospitalization, premature placement, caregiver burnout)
- Education, especially with the PIECES and U-First format will increase understanding of the public and health care service personnel



Focus on Alzheimer's disease.

- A disease of the brain & most common type of dementia
- Is not a normal part of aging
- Progressive, degenerative and irreversible
- No known cause or cure
- Incidence increases with age
- Can last from 2 to 20 years
- Incidence of AD will increase in the future
- **Waterloo Wellington 2006 total population 678,546**
- **>65 = 81,670; 1/13 have ADRD = 6,282**
- **>85 = 9,885; 1/3 have ADRD = 3,295 (half)**
- **~ 310 under 65 have ADRD (5%)**



Communication is the Key

- Communication has both verbal and non-verbal components
- Communication involves:
 - The messenger
 - The receiver
 - The message



Needs of people with dementia

- **WHAT WE ALL NEED**
- Respect
- Emotional closeness
- Autonomy
- To be valued
- Dignity
- Holistic care

Also need:

- Adapted environment, tasks and communication techniques,
educated caregivers



Enhancing Communication

- Listen to **how** the person is speaking in addition to the words used
- Pay attention to their **body language, facial expression and tone of voice**
- See **behaviour as an attempt to communicate needs**
- Look for the **feelings** behind their words
- Offer your **undivided attention**





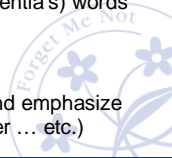
Communication Tips –

- Listen with your eyes, ears and heart
- Establish eye contact
- Find a quiet place to talk
- If the words are hard to understand, respond to the feelings
- Touch is very powerful and can say more than words
- Give lots of time for response
- Reassure with facial expressions and smiles



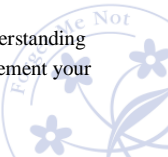
Communication Tips -

- Although the person may be very dependent, it is important to treat them like an adult
- Important not to rush them
- Learn to embrace silence and honour presence
- be aware that the PWD's (Person with Dementia's) words may have different meanings (eg. "Fire")
- Utilize reassuring phrases
- Verbalize the significant value of their life and emphasize with repetition (ie. You are a wonderful mother ... etc.)



Communication Tips –

- KISSS – **K**ep **I**t **S**oft **S**imple **S**low
- Offer one instruction, thought, or idea at a time
- Use familiar words
- Help fill in words as appropriate
- Use closed-ended questions
- Clarify what the person is saying to ensure understanding
- Use props, gestures and written words to supplement your verbal



Holistic Care

- Looks at all the persons needs
- Gives you the bigger picture -
 - Helps you avoid “can’t see the forest for the trees”
- Can help you understand when dementia changes verbal communication to communication by behaviour
- Helps us individualize care
- Aids us in reviewing complex situations





Gathering the P.I.E.C.E.S.

- A practical tool for understanding behaviour
- Looks at the whole person – Physical, Intellectual, Emotional, Capabilities, Environment, and Social



Act on the Physical

- Promote physical comfort
- Attend to basic needs
- Compensate for limitations
- Share information with team members
- Ensure consistency of care



Think about it: Physical

- Pain and other physical conditions can cause changes in behaviour
- Are basic needs being met?
- Does the person have physical discomfort?
- What changes in physical condition can I see?



Think about it: Intellectual

- Dementia affects the person's memory, thinking, language, problem-solving and self-awareness.
 - Changes in memory
 - Difficulty recognizing familiar objects or people
 - Impulsive behaviour
 - Forgetting how to do things
 - Problems finding words and understanding
 - Misinterpreting context and situations





Act on the Intellectual

- Keep in mind the effect of *what* and *how* I communicate
- Avoid challenging or arguing; validate feelings
- Remember this person sees the world differently
- Share with the team what approaches work or do not work



Act on the Emotional

- Be sensitive to the person's unique needs
 - *Understand the person's unique triggers and indicators of agitation, anxiety and fear*
 - Provide comfort and reassurance when needed
 - Get information from family or team that could help you understand the person's feelings
 - Share information to help others be supportive
- "Dignity is helping the person feel valued" (Kristjanson)*



Think about it: Emotional

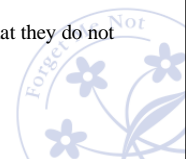
A person may experience problems adjusting to changes

- Increased tearfulness or anxiety?
- Are they bored or lonely?
- New and unusual behaviours?
- Does the person feel out of control?
- Are the person's needs of safety, love and belonging, self-esteem, self-actualization being met? (Maslow)



Think about it: Capabilities

- Knowing what the person can and cannot do will help to build on their strengths
- There may be many reasons why the person says "no" or resists help
- Can this person do more than I realize?
- The person may be frustrated or frightened that they do not remember how to do it
- They may not know that they need help





Act on Capabilities

- Think of ways to involve the person
- Compensate only for their losses
- Offer cues to get the person started
- Go slowly, using simple instructions; one at a time
- Share the strategies that work with the team



Act on the Environment

- Look for environmental factors that could explain changes in behaviour
- Evaluate where a person thinks they are in time and place
- Consider changing lighting, making the environment more familiar, use music
- Share information about the environment and brainstorm with others



Think about it: Environment

- A supportive environment will help the person maintain their abilities
- A change in the person's behaviour may be a sign that the environment is not supportive
- Is there too much distraction?
- Is there adequate lighting?
- Is there enough stimulation?



Think about it: Social

- Each person has unique social and cultural needs
- What do you know about a person's life story, accomplishments, and interests?
- What do you know about their social network?
- What do you know about their cultural heritage?





Act on the Social

- Learn more about the person's life story
- Talk to the person, their family and other caregivers to find out about their history and interests
- Listen carefully and share with all others on the team



What is pain?

Pain is what the patient says it is

Pain is what the patient expresses in his or her behaviour

Pain is whatever the experiencing person says it is, existing wherever and whenever the person says it does



'P' = Physical = Pain?

Definition:

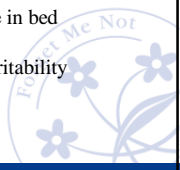
- Pain is an unpleasant subjective experience that can be communicated to others either through self-report when possible or through a set of pain-related behaviours

(McCaffery, M., & Pasero, C. 1999)



Possible non-verbal signs of pain

- Facial expression, verbalization/vocalizations- calling out heavy breathing, swearing
- body movements - rocking
- changes in interpersonal interactions-withdrawn, ↓participation in activity
- changes in activity patterns and routine-↑time in bed ↑wandering
- Mental status changes- ↑confusion, crying, irritability
- See handout





Assessment and Pain Scales

- PPSv2 (Palliative Performance Scale version 2)
- ESAS (Modified Edmonton Symptom Assessment Scale)
- RNAO Best Practice Guidelines on Pain
- All available on-line and easily googled
- Best Practice Guidelines have further materials (please see our display table)



Creating Comfort for PWD

- Use music
- Touch and massage
- Animals
- Be present
- Reminisce and reach into long term memories
- Vocalize to reassure regarding their life and its significance



A B C D E Approach to Pain

- A – Ask about pain regularly
- B – Believe the patient and family in their reports of pain and what relieves it
- C – Choose pain control options appropriate for the patient, family and setting
- D – Deliver interventions in a timely, logical and coordinated fashion
- E – Empower patients and their family members



“The best memorial of all is a healthy caregiver who is left with the strength to build a new life. This would be the wish of every person who has ever died with dementia.”

Moyra Jones





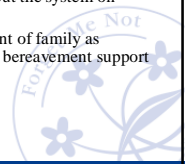
Creating Comfort for Family Care Providers

- Remember their unusual fatigue
- Role of latent grief
- Reassure them regarding the care they have given and the decisions they have needed to make
- Listen
- Help them rephrase their regrets



Summary

- Need:
- An understanding by all health care workers of the basics of dementia care
- Palliative care from the time of diagnosis
- A consistent method of assessing when terminal/hospice care should be initiated
- Consistency, communication and cooperation throughout the system on behalf of the person with dementia
- Respect and understanding of the long-term involvement of family as caregivers and decision-makers, and as people needing bereavement support throughout the illness and after death



“Life is an achievement and dying is the end of that achievement. Tell them not to be afraid of dying. It is very simple. The dying need tender loving, nothing more.”

Mother Teresa



Thank you

- Please fill in an evaluation
- Please ensure you have the handouts
- Visit our table at a break

