

RIVERVIEW HEALTH CENTRE

**PROMOTING
QUALITY OF LIFE IN
PLANNING CARE

DURING THE END
STAGE OF DEMENTIA**



PROMOTING QUALITY OF LIFE DURING END STAGE OF DEMENTIA

DECISION MAKING

Being a caregiver or substitute decision maker for a person with dementia can come with a tremendous sense of responsibility and evoke many emotional reactions. Some of the most challenging decisions arise as a loved one reaches the end stage of their illness. The following information provides you with results of some of the current research surrounding the end or late stage of dementia. We hope that this will help you to make informed decisions regarding your loved one's care as they progress through the final stage of their illness. As you read this information, feel free to discuss any questions or concerns with the Health Care Team.



Common Signs & Symptoms of Decline in End Stage Dementia

Although the experience may differ for each person, there are some common signs and symptoms seen during the end stage of this terminal illness. As the disease progresses, the death of brain cells causes eventual loss of the body's physical and mental functioning including:

1. Decreased Mobility

Due to a loss of motor skills, individuals with dementia may:

- ◆ Be unsafe to walk independently and be more prone to falls
- ◆ Lose the ability to walk and require the use of a wheelchair
- ◆ Eventually become bedridden

Common Signs and Symptoms of Decline in End Stage Dementia continued...

2. Incontinence

- ◆ Loss of bowel and/or bladder control

3. Eating or Swallowing Difficulties

The loss of the ability to eat or swallow is a very common sign of end stage dementia. Eating or swallowing difficulties are perhaps some of the most distressing symptoms experienced by family caregivers due to the strong social meaning that is attached to food.

Common changes include:

- ◆ Forgetting how to use utensils, the loss of recognition of food items or chewing difficulties
- ◆ Feeling full earlier in the meal
- ◆ Decreased desire to eat or drink
- ◆ Refusal of foods or fluids



- ◆ Loss of the ability to swallow, or “forgetting how” to swallow may occur. The muscles in the throat may no longer have the strength or coordination to move the food and/or liquid along the pathway to the stomach. This is assessed by a Speech-Language-Pathologist (SLP)

4. Other Gastrointestinal Problems

As eating function is lost, the following symptoms may also be experienced:

- ◆ Nausea and vomiting
- ◆ Constipation or diarrhea

5. Weight Loss

May result from a loss of appetite or the inability to consume food and drink safely due to decreased swallowing abilities or increased sleepiness as the illness progresses.



As the digestive system and other body processes shut down, the body has trouble tolerating food.

6. Susceptibility to Infections

Immune system responses have been found to be reduced in advanced dementia. This increases the risk for infections. Infections of the urinary tract, bowels, lungs, skin and eyes are most common.

- * The risk for urinary tract infections is increased due to urinary incontinence and immobility.
- * Impaired swallowing increases the risk for aspiration pneumonia, caused when food or liquids enter the lungs.

7. Pressure Sores

- * Open areas in the skin known as pressure sores or ulcers, may develop due to poor



blood circulation fragile skin, immobility, poor nutrition and weak immune systems.

8. Dry Mouth

- * Membranes of the mouth may become dry due to less fluid intake, various medical conditions or as a side effect of some medications.

9. Sleepiness

- * As dementia progresses, individuals may become less alert and more withdrawn
- * Sleeping for large parts of the day may be noted. The person may not be able to stay awake or be alert enough to eat or drink safely.

10. Reductions in Medications

- * When the person cannot swallow, or medications are no longer needed due to a change in condition, fewer pills will be given.

Advance Care Planning and Goals of Care

Involves discussions and information sharing between families and the Health Care Team so that informed decisions regarding health care choices can be made. We want to establish a “Goal of Care” that will provide information about the most appropriate health care interventions for your family member.

As a substitute decision maker, your decisions should be based on your loved one’s wishes. Your loved one may have specified their wishes in an Advanced Health Care Directive or Living Will. If no such legal document exists, then we rely on you to help us with decision making. As we decide on the goal of care, it is important to reflect upon previous discussions you may have had with your loved one regarding their wishes at end of life and what would be considered to be in their “best interest”. To do this, it is important to weigh the benefits and burdens of interventions, in discussion with the Health Care Team. A key question to consider is whether or not the intervention will add to or take away from the person’s overall comfort and well-being, or promote quality of life.



The WRHA has provided three different ‘Goals of Care’ **C-Comfort, M-Medical and R-Resuscitation**. Current research findings regarding benefits and burdens of some of the available comfort measures and medical interventions are presented here:

C = Comfort

In comfort care, the goal is to provide maximum comfort, control of symptoms and maintain quality of life.

Comfort measures can be provided right here at Riverview Health Centre so that the individual with dementia can remain in their own familiar environment. Comfort measures will always be provided no matter what goal of care is chosen.

- ⇒ **Medications** to control symptoms and promote comfort can be provided in a number of ways. These methods include swallowed (by mouth), sublingual (small amounts of liquid or quick dissolving tablets placed under the tongue), subcutaneous (through a needle placed below the skin into underlying tissues), with a transdermal patch (controlled amounts of medication are absorbed through a patch applied to the skin), or rectally (by suppository).
- ⇒ **Spiritual Care** is important for care of the whole person (body, mind and spirit). Spirituality involves a connectedness to a person's deeper self, to an Ultimate Reality that goes beyond the material world, and to others such as family and friends. Fostering these connections for persons with dementia becomes increasingly important to help decrease feelings of isolation. Spiritual care may involve practices and rituals particular to certain faith groups or individual beliefs. These can include prayer, Sacrament of the Sick, communion, chanting, reading of sacred texts, smudging and sacred music; or



may simply involve ‘being with’ the person in support and companionship.

⇒ **Recreational Therapies** are available to promote quality of life through stimulating memories, appealing to the senses and promoting social connections. These could include sensory stimulation, music and memory books.

Other ways you as a family member may participate in keeping your loved one comfortable:

- * Gentle massage or touch
- * Applications of scented lotions or putting scented oils in the room
- * Providing a warm or fuzzy blanket or stuffed toy
- * Arranging for visits from other family and

friends as well as pets

- * If deemed safe to do so by the nurse or speech language pathologist, food and fluids should continue to be offered by hand for 'comfort' as long as the resident is still interested. For those family members who want to help feed their loved one, a Silver Spoons Dysphagia Management Program learning package is available to help ensure safe feeding
- * Oral care as tolerated by the resident (staff will provide guidance to family members who wish to participate)
- * Moisture spray or gels, lip balm, as well as ice chips and fluids as tolerated (as directed by SLP and nursing staff)

M = Medical Interventions

“When the Goal of Care is to provide medical care and interventions, the focus is on care and control of the patient/resident condition. The consensus is that the patient/

Resident/client may benefit from, and is accepting of, any appropriate investigations/interventions that can be offered excluding attempted resuscitation”.

⇒ **Artificial Feeding (Tube Feeding)**

- ◆ When individuals with dementia stop eating, families sometimes wonder about tube feeding (sometimes termed ‘artificial nutrition’) where a tube is placed into the stomach either through the nose or directly through a small surgical opening through the abdominal wall. Special liquid food (formula) is put through the tube.

Burdens or Complications of Tube Feeding

- ◆ Tube obstruction (blockage of the tube)
- ◆ Tube migration (tube moves from where it was originally inserted)
- ◆ Tube leakage (it can leak directly into the lungs or other body cavities)
- ◆ Wound infection (at the site in the abdomen where the tube is inserted)
- ◆ Aspiration (formula leaks into the airway)

and aspiration pneumonia (chest infection resulting from aspiration)

- ◆ Gastrointestinal bleeding
- ◆ Individuals with dementia may attempt to pull out their feeding tube requiring the use of restraints
- ◆ Tube insertion and maintenance would require transfer to an acute care facility or a chronic care unit as this is not a treatment available in the Personal Care Home

Effects of Tube Feeding at the End Stage of Life

There is no documented benefits of tube feeding in the end stage of life. Research evidence indicates that:

- ◆ Weight gain will not be achieved
- ◆ The risk of aspiration pneumonia is not decreased (and tube feeding may in fact increase this risk)
- ◆ The risk of malnutrition or pressure ulcers is not decreased
- ◆ Functional status and individual comfort are not improved



⇒ **Artificial Hydration**

When individuals with end-stage dementia stop drinking, dehydration naturally sets in. This may lead to questions about artificial methods of hydration, such as fluid being delivered through a needle directly into a vein (IV) or via a needle into the tissue under the skin (Hypodermoclysis or HDC)

Burdens or Complications of Artificial Hydration

- ◆ Discomfort with needle insertion
- ◆ Individual with dementia may attempt to pull out the IV or HDC needle requiring the use of restraints
- ◆ Dislodgement or movement of the needle out of the vein

- ◆ Potential for discomfort or infection at the needle insertion site
- ◆ Excess fluid may accumulate in body tissues or result in increased secretions in the lungs or a full bladder
- ◆ IV therapy will require transfer to an acute care facility

There is no evidence to show that individuals are more comfortable receiving IV fluids at the end of life. There are, however, documented benefits of dehydration at end of life.

Benefits of Dehydration at End of Life

- ◆ Helps to decrease fluid in the lungs (individuals are less congested which eases breathing)
- ◆ Less nausea, vomiting, upset stomach and bloating
- ◆ Increases endorphins, the brains natural chemicals that provide for a feeling of well-being, decreasing pain and discomfort
- ◆ Decreased urine production which leads to less incontinence and retention



⇒ **Antibiotic Therapy**

The risks and benefits of antibiotic therapy to treat infections during end stage dementia need to be considered on an individual basis and should be discussed with the physician. However, the research shows that antibiotic therapy does not increase the survival rates of individuals with severe dementia and is not necessary for symptom control

General Risks to Antibiotic Therapy

- ◆ Serious side effects, including allergic reactions, may occur. Other examples include diarrhea or upset stomach, depending upon the antibiotic used

⇒ **Transfer to an Acute Care Setting**

If the decision is made to have medical treatment/interventions that cannot be provided in the Personal Care Home (e.g. IV fluids or IV medications, and tube feeds) transfer to an acute care facility will be necessary



Burdens to Transferring from the PCH to Acute Care Settings

- ◆ Research shows that individuals with dementia exhibit further decline in physical and mental functioning after transfer to an acute care facility. This decline often does not improve at discharge from the acute care centre
- ◆ Increased confusion, incontinence, falls and anorexia (poor food intake) are common
- ◆ The unfamiliar environment and staff found in an acute care setting may cause increased anxiety, fear and agitation in an individual with advanced dementia

We hope that this information will be helpful in assisting you to make informed decisions surrounding the care of your loved one with end stage dementia. All members of the Interdisciplinary Team (Spiritual Care Advisor, Nurses, Social Worker, Physician, Pharmacist, Dietician, Physiotherapist, Occupational Therapist, Speech Language Pathology and Recreational Therapist) are available to provide you with further information and support as needed.

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For More Information:

Alzheimer Society of Manitoba

www.alzheimer.mb.ca

Canadian Virtual Hospice

www.virtualhospice.ca

Nurturing Life..One Person..One Family..One Moment at a Time



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