

Caregiving for Patients with Advanced Dementia



DOVER PARK HOSPICE
Every Moment Matters



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Introduction

Caregiving for someone with advanced dementia is an intense, emotional, and often exhausting journey. As the condition progresses, the caregiving role becomes more comprehensive, covering physical, emotional, and sometimes even spiritual aspects of care.

This guide is intended for Dover Park patients at home. It is intended to empower you, as a caregiver, to make informed choices and respond to likely care needs, even as you receive support from our Home Care Team.

This guide is to be used as a reference for information and is not a substitute for training. Unless explicitly advised to do so by the clinical team, do not attempt any intervention on your own. Where in doubt, approach the Home Care Team for clarification or training.

What to Expect

As the disease advances, the needs of the person living with dementia will change and increase.

A person with late-stage dementia usually:

- Has difficulty eating and swallowing
- Needs assistance walking and eventually is unable to walk
- Needs full-time help with personal care
- Is vulnerable to infections, especially pneumonia
- Loses the ability to communicate with words

Your Role as the Caregiver

During the late stages, your role as a caregiver focuses on preserving quality of life and dignity. Although a person in the late stage of dementia typically loses the ability to talk and express needs, some core of the person's self may remain. This means that you may be able to continue to connect throughout the late stage of the disease.

Consider other forms of stimulation to connect:

Smell

- Smell is very powerful
- Scents and smell can create a link and bring back reassuring memories of times gone by such as rubbing lotion with a favorite scent into the skin

Touch

- Holding hands, stroking a person's face or arms, or brushing their hair can be soothing and help make a connection

Vision

- A family photograph or a picture of a favourite view can produce a reaction

Music

- Playing or humming favourite tunes can bring back happy memories

Singing

- People with dementia who stopped speaking a long time ago can sing along to a familiar tune, remembering the words

Dancing and movement

- Depending on their mobility, the person with dementia may connect through dancing
- They may get up, move around or put their arms in a familiar dance
- Move their fingers or feet to the rhythm

Art

- Connections can be made through art by the simple sensory act of holding a brush or pencil and scribbling, painting or drawing on paper
- Depending on their mobility, your loved one may copy your mark-making or strokes; or engage by 'following' your line.

Care Dimensions

In this section, we explore the following dimensions:

- Communication
- Food and fluids
- Bowel and bladder function
- Skin and body health
- Infections and pneumonia
- Pain and illness

Such understanding would cultivate empathy, patience and strengthen bonds. It also empowers you to personalise your loved ones' care in a way honours their preferences.

Communication

In the late stages of dementia, communication is significantly impacted. Both speech and language can change. The person with advanced dementia is not aware of their communication deficits.

They may not be able to think beyond their own needs to notice the perception challenges of the family caregiver with whom they are communicating.

The person with dementia will experience:

- increasing problems understanding what is being said to them and what is going on around them
- find it difficult to communicate with other people
- express worry or concern through repeated questions or a repeated focus on certain words / topics

- disorganized thinking, resulting in conversation that jumps around frequently and words or ideas may be expressed that are entirely unrelated
- words become easily entangled, sentences are mixed up, and correct grammar may be lost
- gradually lose their speech, may have trouble pronouncing words, forget to pronounce certain syllables, or begin to stutter

Food and Fluids

One of the most important daily caregiving tasks during late-stage dementia is monitoring eating.

As a person becomes less active, he or she will require less food. But, a person with dementia may also forget to eat or lose his or her appetite.

Adding sugar to food and serving favorite foods may encourage eating; the doctor may even suggest supplements between meals to add calories if weight loss is a problem.

To help the person with dementia stay nourished, allow plenty of time for eating and try these tips:

- Make sure the person is in a comfortable, upright position.
 - To aid digestion, keep the person upright for 30 minutes after eating.

- Adapt foods if swallowing is a problem.
 - Choose soft foods that can be chewed and swallowed easily. Make liquids thicker by adding food thickener to water, juice, milk, broth or soup.
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- Assist the person with feeding.
 - Alternate small bites with fluids. You may need to remind the person to chew or swallow. Make sure all food and fluid is swallowed before continuing on with the next bite.
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- Encourage fluids.
 - The person may not realize that he or she is thirsty because the sense of thirst diminishes in the late stages of dementia. Encourage the person to drink liquids or eat foods with high liquid content, such as watermelon, peaches, pears or sherbet.

- Monitor weight.
 - Although weight loss during the end of life is to be expected, it also may be a sign of inadequate nutrition, another illness or medication side effects.

Bowel and Bladder Function

Many people lose control of their bladder in the later stages of dementia. Some also lose control of their bowels. This may happen all or most of the time, or may just be a case of occasional leakage.

To maintain bowel and bladder function:

- Set a toileting schedule.
 - Keep a written record of when the person goes to the bathroom, and when and how much the person eats and drinks. This will help you track the person's natural routine, and then you can plan a schedule. If the person is not able to get to the toilet, use a bedside commode.
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- Limit liquids before bedtime.
 - Limit liquids at least two hours before bedtime, but be sure to provide adequate fluids throughout the day.

- Use incontinence products.
 - Adult diapers and bed pads at night can serve as a backup to the daytime toileting schedule.
- Monitor bowel movements.
 - It is not necessary for the person to have a bowel movement every day
 - But, if there had been 3 consecutive days without a bowel movement, he or she may be constipated. In such instances, it may help to add natural laxatives to the diet, such as prunes or fiber-rich foods (bran or whole-grain bread).

Skin and Body Health

A person with late-stage dementia can become bedridden or chair-bound. This inability to move around can cause skin breakdown, pressure sores and “freezing” of joints.

To keep skin and body healthy:

- Relieve body pressure and improve circulation.
 - Change the person’s position at least every two hours to help keep him or her mobile.
 - Gently massage hands and feet with lotion.
- Learn how to lift the person.
 - A care provider, such as a nurse or physiotherapist, can provide instructions on how to properly lift the person without causing injury. **Do not** lift by pulling on the person’s arms or shoulders.

Keep skin clean and dry.

- Since skin can tear or bruise easily, use gentle motions and avoid friction when cleaning. Wash with mild soap and blot dry. Check daily for rashes, sores or breakdowns.

Reduce the risk of bedsores.

- Use pillows or pads to protect bony areas such as elbows, heels and hips.

Maintain range of motion in the joints.

- “Freezing” of the joints (limb contractures) can occur when a person is confined to a chair or bed. Ask the doctor if range of motion exercises might be beneficial and, if so, how they should be performed.

Infections and Pneumonia

The inability to move around during late-stage dementia can cause a person to be more vulnerable to infections.

To help prevent infections:

- Keep the teeth and mouth clean.
 - Good oral hygiene reduces the risk of bacteria in the mouth that can lead to pneumonia. Brush the person's teeth after each meal. If the person wears dentures, remove them and clean them every night. Also, use a soft toothbrush or sponge swab to clean the gums, tongue and other soft mouth tissues.
 - Use of oral lubricating gel to moisten the mouth. Use of sodium bicarbonate or baking soda with water as cleansing solution.

- Treat cuts and scrapes immediately.
 - Clean cuts with warm soapy water and apply an antibiotic ointment. If the cut is deep, seek professional medical help.
- Protect against flu and pneumonia.
 - The flu (influenza) can lead to pneumonia (infection in the lungs). It's vital for the person with dementia as well as his or her caregivers to get flu vaccines every year to help reduce the risk. A vaccine to guard against pneumococcal pneumonia is also available. (Usually only one dose is needed, but in certain circumstances, a second dose may be given five or more years after the first dose.)

Pain and Illness

Communicating pain becomes difficult in the late stages. If you suspect the person has pain or illness, bring him or her to see a doctor to find the cause. In some cases, pain medication may be prescribed.

To recognize pain and illness:

- Look for physical signs.
 - Signs of pain and illness include pale skin tone; flushed skin tone; dry, pale gums; mouth sores; vomiting; feverish skin; or swelling of any part of the body.
- Pay attention to nonverbal signs.
 - Gestures, moaning, groaning and facial expressions (for example, wincing) may signal pain or discomfort.
- Watch for changes in behavior.
 - Anxiety, agitation, shouting and sleeping problems can all be signs of pain.

Other Changes

<p>Breathing may sound congested; may change in rate, depth and rhythm; may be periods of not breathing for 5 – 30 seconds</p>	<p>No intervention is usually necessary</p>
<p>Senses start to change:</p> <ul style="list-style-type: none">• Vision may become blurred or appear to be distant• Sensitivity to noise, lights etc; may react positively to familiar voices, such as singing or someone reading aloud	<ul style="list-style-type: none">• Keep connected through touch• Continue to talk quietly, tell stories, reminisce about past events, play music that the person likes, read• Do not talk about the person as if they are not there. Leave the room if you need to discuss something• Observe the person for signs of stress; keep lights low and noise to a minimum; consider visiting in smaller numbers

<p>Irregular pulse; agitation and restlessness</p>	<ul style="list-style-type: none">• Reassure the person• If this persists, look for causes of the behavior such as pain or thirst
<p>Emotions are still experienced and sensed by the person</p>	<p>Speak soothingly, reassuringly; remind the person that they are safe and cared for</p>
<p>Spiritual connections may remain important. The person may seem to choose their time of death</p>	<ul style="list-style-type: none">• Play/sing/recite favourite songs, scripture prayers, readings• Arrange for a faith leader to visit, if appropriate• Some individuals need permission to die. As well, some family members need permission to let go.

Late-stage Care Options

Since care needs are extensive during the late stage, they may exceed what you can provide at home, even with additional assistance.

Deciding on late-stage care can be one of the most difficult decisions families face. Families that have been through the process tell us that it is best to gather information and move forward, rather than second guessing every decisions.

There are many good ways to provide quality care. Remember, regardless of where the care takes place, the decision is about making sure the person receives the care needed.

Considering Inpatient Care

At the end of life, another option is inpatient hospice. The underlying philosophy of hospice focuses on quality and dignity by providing comfort, care and support services for people with terminal illness and their families.

For Dover Park Inpatient Hospice Services, please discuss this with your primary care nurse.