# Dementia and End-of-Life Care

Alzheimer Society

## Part II: What do I need to know about caring for the person?

## About this resource

The needs of people with dementia at the **end of life*** are unique and require special considerations. This resource is for you – a **family** member supporting a person with dementia – to help prepare for end of life, make some of the difficult decisions you may face, and cope with the grief and loss you might experience.

This resource is part of a four-piece series on dementia and end of life care. A description of the other resources in this series is available at the end of this booklet.

It can be hard to read a lot of information about end of life all at once; think about the issues you are most concerned about and read that section first. There is no "correct order" to reading this information. However, if you are at a turning point and need to make some decisions quickly, reading the most appropriate section may help.

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**Other Resources in this Series and Glossary of Terms found on pages 8-10.**

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*All **bolded** words are found in the Glossary of Terms located at the back of this document.

## Physical changes at end of life

People in the final months of dementia will experience increased mental and physical deterioration and will need care for 24 hours per day. It is always best if care can be provided with a **palliative care** approach in the person's home or long-term care home as **transfers to a hospital** may cause great distress for the person.

The progressive nature of dementia means symptoms will ultimately worsen over time. How quickly this occurs varies from person to person. In the final weeks before death, the person goes through changes as the body gradually shuts down. As they lose their capacity for recognizable speech, nonverbal communication through the senses of touch, smell, vision and hearing will become increasingly important.

Some of the physical changes which often occur in the later stages of dementia include:

- Profound memory loss and loss of ability to communicate with words
- Loss of mobility, inability to sit up
- Difficulty swallowing foods and liquids
- Decreased interest in taking food and liquids, weight loss
- Poor blood circulation (colder hands and feet)
- Impaired bladder and bowel function
- Prone to infection
- Loss of facial expression
- Decreased senses
- Increased sleepiness or agitation/restlessness
- Increased phlegm and mucus/secretions
- Irregular breathing
- Irregular pulse
- Skin problems
- Hiccups
- Pain

Please note that some of the above changes may occur months/weeks prior to the end of life stage.

### Effects of dehydration

Dehydration of the body as the person is dying is generally not painful in itself and with these changes the person generally does not feel pain as intensely. A lower volume of fluids in the body also decreases cough, congestion, nausea or bloating.

### Mouth and eye care

At the **end of life stage**, breathing through the mouth can cause the mouth and tongue to become dry and create discomfort. You can learn the steps from a home care person or staff at the long-term care home to keep the lips moist and to provide mouth care including cleaning the teeth, tongue and inside of the mouth.

For relief of dry eyes, you may need to use artificial tears in the person's eyes a few times throughout the day.

### ADDITIONAL RESOURCES

- For practical suggestions and tips to help you respond to these care issues, please read **Late stage** and **End of life** in the Alzheimer Society "Progression" series found at alzheimer.ca/stages

## Caring at home

Providing care will become more challenging as the disease progresses and the person you are caring for becomes more dependent on you. If you are caring for the person at home, you will need to work more closely with a physician, visiting nurse, social worker, occupational therapist and home support services to create and carry out a plan for the best care possible through this stage of the disease.

As the person's disease progresses and both of your needs change, you may need services such as home care, respite care, community programs like Meals on Wheels, and long-term care homes.

Talk to your local Alzheimer Society to learn about the services that are available in your community.

This can be a difficult time when you need more support for yourself. Try to carve out some time to take care of your own physical and emotional health too.

> **"Because my parents took care of me for at least the first 18 years of my life, it felt right to me to take care of them in the final years of their lives. Being their caregiver was tremendously rewarding. But I couldn't have done it all on my own. I was lucky to find some great volunteers to help out."**
>
> *– Barbara Dylla, a former caregiver in Montreal*

## Care in a long-term care home or hospital

If the person lives in a long-term care home or is in the hospital, keep current with the staff about the person's changing condition, care and treatment. Ask to have regular care planning meetings with staff to discuss how best to meet the person's needs at the later stages of the disease.

### Work with staff to provide person-centred care

**Person-centred** care involves a relationship between staff, the person with dementia and the **family** to provide care that is shaped by the person's unique interests, likes and dislikes. Both person-centred care and end of life care have a common goal of improving the quality of living and dying for the person with dementia.

Communicating appropriate information about the person's history, previous occupation and daily routines can greatly help staff in providing more person-centred care. The Alzheimer Society's *All about me* booklet [alzheimer.ca/allaboutme] may be useful in recording this information.

Visit our page on person-centred care on our website at www.alzheimer.ca

## Importance of palliative care

The overall goals of **palliative** and end of life care are to improve the quality of living and dying for people with dementia and their **family**. A **palliative approach** to care is not only beneficial at the **end of life** but often for months in advance. **Palliative care** can start much earlier and be provided at the same time as potentially curative treatments. A person may continue to receive any necessary medications. These include medications to manage chronic conditions such as diabetes or high blood pressure, as well as those that prevent pain and discomfort. The Canadian Virtual Hospice defines palliative care as "an approach to care that focuses on comfort and quality of life for those affected by progressive, life threatening illness. The goal of palliative care is to control pain and other symptoms, support emotional, spiritual and cultural needs and maximize functioning."

In the past, a palliative care approach was most commonly offered to individuals in the final stages of dying from cancer. But there is now a consensus among experts that a palliative approach to care for people in advanced dementia is considered the best practice and that the care should be individualized to meet the needs, values and preferences of the person and their family.

> **"It's important for staff to be informed about the 'little things' that will help keep the person comfortable."**
>
> *– Barbara Dylla, a former caregiver in Montreal*

Effective **comfort care** requires that staff have the skills to assess facial expressions, movements, reactions and changes in the individual so they can effectively diagnose and treat any discomfort. A **person-centred approach** to palliative and end of life care involves not only good physical care, but also compassionate communication and support to minimize the person's emotional and spiritual distress, and maximize their comfort and well-being. The staff are there for you and other family members to confide in and to provide support.

Planning for end of life care should begin as soon as possible after a diagnosis of dementia. As part of this planning, people with dementia and their families may want to consider long-term care homes that adopt a palliative approach to end of life care and give staff the specialized training needed to provide personalized palliative care. Also, it may be helpful to check if the long-term care home provides a private space for the person and the family to spend final days or hours together.

### ADDITIONAL RESOURCES

- Palliative approach to care for people with advanced dementia: a best practice information sheet for health professionals by the Joanna Briggs Institute.
- One chance to get it right, by the Leadership Alliance for the Care of Dying People, provides information on how individualized palliative care plans that reflect the needs and preferences of the dying person can be developed and carried out. Found at www.gov.uk
- Comfort care at the end of life for persons with Alzheimer's disease or other degenerative diseases of the brain: a guide for caregivers, by the Health and Social Services Centre — University Institute of Geriatrics of Sherbrooke
- Webinar: Dementia and End of life Care, by the Alzheimer Society of Canada and brainXchange found at www.brainxchange.ca

# Understanding pain management

It is important to remember that people with dementia feel pain, just like everyone else. Major causes of pain often stem from immobility, arthritis, infections or a combination of conditions, referred to as **comorbidities**. A person who has constant pain needs regular pain medication to control it and be comfortable.

## Challenges of recognizing pain

As a person with dementia progresses through the disease, they will become less and less able to express themselves verbally, thus making it increasingly difficult to tell others when they are in pain. As a result, pain often goes undetected and untreated, causing the person with dementia to communicate their distress through their behaviour, such as becoming agitated, withdrawn or combative. You may be able to find out if the person is in pain by asking direct simple questions such as "Are you in pain?", "Is it sore? or "Does it hurt?" but often the person with advanced dementia will not be able to answer your question verbally.

## Non-verbal signs of pain

In order to ensure that the person with dementia is not experiencing untreated or inadequately managed pain, it is important to look for non-verbal signs of pain such as grimacing, moaning, uncharacteristic behaviours or physical changes such as sweating or elevated heart rate. A change in the person's behaviour, which may indicate pain, is often noticed first by family and friends.

> **"My siblings and I learned to recognize the subtle signs – wincing, frowning or increasing agitation – that indicated our father was in pain or discomfort. Having an end-of-life comfort care plan in place meant we could request an extra or increased dose of morphine to alleviate his suffering."**
>
> *– Barbara Dylla, a former caregiver in Montreal*

This intimate knowledge of the person with dementia is valuable and should be shared with care providers. However, showing such signs does not always indicate pain and the person may instead be scared or frustrated. All sounds and changes should be considered for what the person is trying to communicate.

> **"You have to take yourself out of the situation and think of the person who is dying. It's not about you; it's about your loved one. It was about making my mom comfortable and going through the transition from life to death with her."**
>
> *– Debbie George, a caregiver in Nova Scotia*

### Pain Scale for people with dementia

Pain scales can also help staff and family caregivers assess whether a person with dementia is in pain, especially if the person can't tell you in words.

These pain scales record the signs and symptoms that are likely to indicate the presence and intensity of pain that the person is experiencing. For example, the Abbey Pain Scale can be used to help measure pain for persons with dementia who cannot express themselves verbally. This scale suggests six possible signs of pain:

- Vocalizations such as whimpering, groaning, crying
- Facial expressions such as looking tense, frowning, grimacing, looking frightened
- Changes in body language such as fidgeting, rocking, guarding a part of the body, becoming withdrawn
- Behavioural changes such as increased confusion, refusing to eat, change in usual behaviour patterns
- Physiological changes such as temperature, pulse or abnormal blood pressure, perspiring, flushing or becoming pale
- Physical changes such as skin tears, pressure areas, arthritis, contractures

### Opioids

**Opioids**, such as morphine, are often the most effective medications to relieve moderate to severe pain. Pain medication is often given regularly to control pain in the last weeks and days of illness. In addition to morphine, medications for anxiety or hallucinations are often given because they can be highly effective in providing a more comfortable **end of life**.

Since pain is easier to prevent than it is to relieve, it should be treated on a regular basis rather than on an 'as required' basis. Some caregivers have concerns about the use of opioids, fearing that the person may develop an addiction. Many experts believe that the risk of addiction for people who take opioids for pain near the end of life is very low because a brain in pain reacts differently than a brain not in pain. Discuss the benefits and risks of opioids with health-care providers to help you decide if they are the best option for managing pain, especially toward the end of life.

## Comforting the person

> **"She wanted us to hold her hand at all times. We felt we were giving her comfort. We stayed with her and stroked her hand, making her transition as easy as possible."**
>
> *– Debbie George, a caregiver in Nova Scotia*

Even though the person may not seem to be aware of you during the last stage, your presence is still a comfort. Here are some suggestions on how to offer comfort to the person:

- Connect through the senses such as holding the person's hand, smelling a perfume together or listening to music that the person has enjoyed in the past
- Continue to touch and reassure the person that you are close by
- Speak calmly and naturally
- If needed, wash the skin gently and blot dry, using as little force and friction as possible
- Raise the head of the bed if breathing is difficult or raise the person's upper body with pillows
- Gently massage hands and feet with lotion
- Tell stories, reminisce about past events, read aloud or listen to music together
- Keep lights low
- When the person no longer accepts food or drink, keep the lips moist and get direction on providing mouth care including cleaning the teeth, tongue and inside of the mouth
- Speak soothingly and reassuringly to remind the person that they are safe and cared for
- Focus on the person's physical, emotional and spiritual needs
- Use proper pain control medications to relieve any pain or discomfort
- Use slow, gentle movements to reposition the person to relieve pressure areas but do so in one part of the body at a time
- Follow the person's lead. For example, if they wince when trying to move them, stop doing it and try at a later time

It is important to check with health-care professionals before offering any food or fluids to the person. Some people may begin to experience difficulties with swallowing. You can find some strategies that may help when offering food and fluids to a person experiencing difficulties with swallowing in the Late stage brochure from the Alzheimer Society "Progression" series.

## Glossary of Terms

**Advance care planning:** Process of planning for a person's future health-care where the person has conversations with close family and friends about their values and beliefs.

**Advance health directive:** Set of documents containing instructions that consent to, or refuse, specified medical treatments and that states the care and lifestyle preferences in anticipating possible future circumstances.

**Aggressive medical care:** Intensive medical treatment designed to preserve and prolong life.

**Ambiguous loss:** Type of loss you feel when a person with dementia is physically here, but may not be mentally or emotionally present in the same way as before.

**Antibiotics:** Medication used to treat bacterial infections.

**Artificial / Intravenous hydration:** Liquid administered to a person through a needle in a vein in the person's hand or another part of the body.

**Bereavement services:** Services provided to anyone who has experienced a loss including the process of healing from the loss.

**Cardiopulmonary resuscitation (CPR):** Treatment used in emergencies to restore function when a person's heart and/or breathing stop working (heart attack).

**Care or support of a family member:** This means that you provide psychological or emotional support; or arrange care by a third party; or directly provide or participate in the care.

**Comorbidity:** When two or more chronic conditions exist at the same time.

**Compassionate care benefits:** Benefits paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill with a significant risk of death.

**Do not resuscitate (DNR) / Do not attempt resuscitation (DNAR):** Legal order to withhold cardiopulmonary resuscitation (CPR) in respect of the person's wishes.

**Emergency hospitalization:** When a person is admitted to a hospital without warning.

**End of life:** Stage of life where a person is living with and impaired by a condition.

**Family:** Includes anyone in the supportive network of the person with dementia.

**Feeding tube:** Medical device used to provide nutrition to a person who has a difficult time eating or swallowing.

**Funeral director:** Also known as a mortician or undertaker, a funeral director is responsible for conducting funeral rites. This person often performs the embalming and burial or cremation of the dead, as well as the planning and arrangement of the actual funeral ceremony.

**Geriatrician:** A physician who specializes in the diagnosis, treatment and prevention of disease in older people and the problems specific to aging.

**Health-care team:** A team of medical professionals that often includes a physician, nurse, pharmacist, clinical nutritionist, social worker and other support staff.

**Hospice:** A comprehensive service provided to people living with and dying from a fatal condition. This may include medical care, respite care and end of life care for people who are unable to die at home.

**Living will:** Legal document detailing a person's desires regarding their medical treatment in the event that they become incapable of communicating their wishes on their own.

**Medical intervention:** Treatment undertaken to improve health or help with a particular problem.

**Opioids:** Medications that relieve pain.

**Palliative approach:** An approach to care that aims to improve the quality of life for individuals with a fatal condition and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, psychological, social, cultural and spiritual needs.

**Palliative / Comfort care:** Type of health care for patients and families facing life-threatening illness. Palliative care helps patients to achieve the best possible quality of life right up until the end of life. Palliative care is also called end-of-life, or comfort care (Canadian Virtual Hospice).

**Person-centred care:** A philosophy that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and to participate fully in their environment.

**Psychological family:** People you naturally turn to in times of crisis and celebration; the people in your life who are there for you in good times and bad.

**Substitute decision-maker:** A person who makes medical decisions and provides consent for treatment or withdrawal of treatment on behalf of another person who is incapable of communicating their wishes on their own.

**Transfers to the hospital:** Moving a person from home or the long-term care home to the hospital by ambulance.

**Ventilator:** A machine used to assist with breathing if a person cannot breathe independently.

## Other Resources in this Series:

### Part I: What decisions will I need to make?

- The importance of planning ahead
- Advance care planning
- Appointing substitute decision-maker(s)
- Medical care decisions
- Practical things to consider
- Tips for talking about end of life

### Part III: How do I care for myself and my family?

- Tips for self-care
- Getting the support you need
- Supporting children and teens
- Grief and loss
- Moving on
- Tips for coping with your grief

### Part IV: What practical information should I know?

- Compassionate care benefits
- Government benefits after death
- Important documents and questions checklist

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