

Later ^{in the} Dementia Journey

A time to
think about
some
important
questions.



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Later in the
Dementia
Journey

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This is a Canadian resource about dementia. The following email address is ONLY for comments about this booklet. It is not for patient specific questions. You will not receive a response from a healthcare professional.

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Dedicated to all the people
we have met whose lives
have been touched by dementia.
It has been our privilege to learn with you.



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Introduction

“When life sends you down a path you don’t expect, it’s okay to stop and ask for directions.”

Dementia is a name for brain diseases that get worse over time making it difficult to function without help from others.

This booklet was written for people helping someone with “late stage” or “end of life” dementia. There are many sources of general information about dementia. Please consider reading the other two booklets in our dementia series:

- An Introduction to Dementia
- The Dementia Compass

What to expect in the later stages of dementia

Late stage dementia

The Alzheimer Society of Canada defines late stage dementia as “the time at which the person eventually becomes unable to communicate verbally or look after themselves. Care is required 24 hours a day”.

People with late stage dementia will need hands on help with some or all of the following:

- Getting food from the plate to their mouths.
- Putting clothes on and taking them off.
- Changing pads or incontinence briefs if bowel and bladder are difficult to control.
- Thoroughly cleaning after using the toilet.

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- Getting clean in the tub, shower or with a sponge bath.
- Moving from the bed to a chair or standing up from a chair.

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PART 1:
**Where people
with late stage
dementia live**

It is very common for a person with dementia to need more help than can be provided by family members at home. Some of the challenges when caring for someone with late stage dementia can include:

- Loss of bowel and bladder control.
- Lack of balance and falling.
- Difficulty climbing stairs, walking and standing up.
- Not cooperating with bathing and dressing.
- Anger outbursts, suspiciousness and sleep disruption at night.

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- Health issues that require a trained nurse.
- Poor caregiver health or death of the caregiver.

People with late stage dementia usually live in one of two environments: home with “24 hour care” or in a nursing home. The goal of both of these options is to help the person with dementia be as comfortable as possible and avoid prolonged stays in hospital.

Moving to a nursing home

Although we often feel “there’s no place like home”, the person with dementia is sometimes healthier and more comfortable living in a nursing home. Three of the things that nursing homes can often provide include:

- **A regular routine:** Hopefully this routine will be tailored to the person with dementia. A regular routine is often calming for people with dementia.

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- **Twenty-four hour staffing:** Because there are paid staff members around the clock there may be more activities throughout the day and more supervision, especially overnight.
- **Prevention of caregiver burn-out:** There is research that shows that being a 24-hour caregiver can be hard on the caregivers’ physical and emotional health. Staff at the nursing home work in shifts to decrease this kind of stress. A move to a nursing home can often avoid a crisis such as the caregiver being admitted to hospital.

Even though there may be advantages to nursing homes, many people helping someone with dementia are slow to investigate nursing home options. Here is a list of some of the reasons people worry about moving a person with dementia to a nursing home.

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***A promise, in the past,
“never to move to a nursing home”***

- Many families talk about plans for the future and this is generally a good thing but often we don't know what the future will bring. At the time promises were made it may have been impossible to imagine the person with dementia needing help 24 hours a day to stay safe.
- Likely the person with dementia would not hold you to a promise if they knew that it might put both of you at risk.

The feeling that other family members or friends want the person to stay “at home”.

- Sometimes an open discussion among family members may reveal that everyone agrees it is time to consider a nursing home.
- Perhaps the people who feel that a nursing home is not necessary do not know exactly

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what is happening at home. Although it may be hard, it is important that everyone knows what is “happening behind closed doors”.

- Maybe there is a lack of understanding about the diagnosis of dementia or how dementia changes over time. If this is the case it may be helpful for them to read about dementia or contact the local Alzheimer Society.

Reluctance to be the one who makes the decision.

- Often the person with dementia asked someone to make tough decisions on their behalf. This is likely because the person with dementia valued the decision-maker's opinion.
- It is often helpful to think about decisions the person with dementia would have made for themselves if they knew what life with dementia would be like. The person with dementia may have assumed they would grow old and die suddenly in their sleep.

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- If possible, it is very important that the person making the decision be supported as this is often a very stressful time.

Media reports of neglect or poor care in nursing homes.

- Just as medical care has changed over the years, so have nursing homes. There are strict regulations that nursing homes must follow.
- It is important to take tours and ask questions about nursing homes in your area.
- By continuing to visit the person with dementia you can be reassured that the person is getting the best possible care.

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Stories about a person with dementia getting worse after moving into a nursing home.

- The move to a nursing home is a major life change. This is one of the reasons that it is better if the move does not occur during a crisis.
- Because the move is a time of change it can lead to some additional confusion or agitation. Usually it takes someone with dementia three months to settle into a new environment.
- One thing to keep in mind is that when someone with dementia needs the help available at a nursing home they are usually in a phase of dementia that progresses more quickly. As the dementia continues to get worse walking, talking and eating will become more challenging. This is not because the nursing home was a bad choice. Instead, it is because the person has a disease which continues to gets worse over time.

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Some practical things to consider about a move to a nursing home include:

- **Pets living with the person with dementia:** Often the pets cannot move with the person. It may reassure the person with dementia if there is a safe and happy plan for the pets.
- **Some nursing homes cannot let people smoke:** It may be important to talk to the family physician about “stop-smoking options” including the nicotine patch or inhalers that look and feel like cigarettes. If the person with dementia can stop smoking before moving, this may make their transition more comfortable.
- **Some decision-makers state they will not move the person with dementia to a nursing home until they are unable to recognize family.** This may even have been an instruction left by the person with dementia earlier in life. It is, unfortunately, not always

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possible to wait until the person is not aware of their surroundings. Dementia affects everyone differently. Sometimes the risk of falls or sleep disruption occurs earlier than problems with recognition.

- Another thing to consider is that the transition to a new environment (a nursing home) may actually be better if it occurs while the person can still learn to recognize some of the staff and routines.

“24 hour care” at home

It is sometimes possible for a person with late stage dementia to remain at home or move in with another person (perhaps a family member) until death. Often this is only possible if the person with dementia is relatively calm and does not require a lot of physical assistance.

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Some of the things to consider when planning to have someone with late stage dementia live at home include:

- Help will be required 24-hours a day, 7 days a week. This will be essential to keep the person with dementia safe and healthy.
- Most families cannot provide all the help that is needed to keep the person with dementia clean and healthy. Paid employees (homecare workers) will often be needed to help clean the person after a bowel or bladder movement and help the person move around safely.
- Every province is different but there is often a significant cost involved in keeping a person with dementia at home. In addition to hiring people to help, special equipment is often required. Hospital beds and equipment for the stairs may need to be purchased or rented as the government often will not provide these.

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- Depending where you live, it is often hard to find homecare workers who are willing to work overnight. It is important to remember that the homecare workers will occasionally call in sick or get stuck in traffic. You will have to make arrangements to ensure the person with dementia gets the help needed.

Avoiding crisis: The risks of admission to the hospital

In many provinces there are long waiting lists for getting assessed for help at home and for moving to a nursing home. If there is not enough help at home or if the people providing that help “burns out” the only option may be a trip to the local hospital.

Visits to the hospital are particularly hard on people with dementia. Of course sometimes trips to the hospital can not be avoided. Some of the challenges to providing care to people with dementia in the hospital include:

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- Changes in their day-to-day routine
- Rigid times for bathing, eating and taking medications
- Loud rooms with multiple strangers
- Less access to water which can lead to dehydration
- Being given sleeping pills or being tied down so that they don't walk around the unit

Some of these problems with the hospital environment can contribute to a major change in a person's thinking. This is called **delirium**. Some of the symptoms of delirium include:

- disorientation
- difficulty concentrating
- being drowsy
- seeing things that aren't there.

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Delirium often results in longer stays in hospital and can even increase the risk of death. The Canadian Coalition for Seniors' Mental Health has written a booklet called **"Delirium in Older Adults: A guide for seniors and their families"**. This is available on their website: www.ccsmh.ca/en/default.cfm#. The section called "What can I do to help my family member?" has some specific suggestions that are very helpful if a hospitalization does occur.

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PART 2: Making comfort the priority

Regardless of where a person with dementia is living, everyone’s goal is usually the happiness and comfort of the individual with dementia. As the person enters the late stage of dementia (being dependent on others for eating, toileting and bathing) it may be time to reassess the ways in which we tackle factors that impact health and happiness. Some of these factors include:

- medications
- food and nutrition
- pain control
- skin irritation.
- constipation
- shortness of breath
- spiritual health

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Medications

Most people with late stage dementia are on many medications. These medications and vitamins were likely started years ago to help treat or prevent specific diseases and prolong life. These medications may no longer be needed and may be causing side effects. Common symptoms, such as decreased appetite and generally feeling unwell, are often thought to be part of getting older but may be caused by pills.

It can be complicated to sort out which medications are causing side effects. Decisions about changes in medications should always be discussed with your health-care team. In people with late stage dementia it is reasonable for most of the medications to be stopped. Interestingly, the person may actually feel better after

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pills have been stopped. Medications that improve comfort, including those for pain, shortness of breath, constipation and anxiety should likely be continued.

Food and nutrition

Eating challenges are very common in late stage dementia. People with late stage dementia will often:

- lose their appetites
- be unable to feed themselves
- choke on food.

Difficulty swallowing and choking on food usually signals that the person has entered the final phase of their disease. There are a number of things that can be done when eating becomes difficult.

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- **Medication adjustments:** It is common for medications to cause swallowing problems or poor appetite. In the late stage of the dementia, it is sometimes helpful to give only medications that are needed for comfort. You can request a review of medications by your health-care team.
- **Continuing to eat:** Most people with late stage dementia get pleasure from eating and drinking. Your involvement can be very helpful.
 - You can identify favorite foods (ice cream for example). These may include foods that have been avoided in the past. Perhaps it is no longer necessary to be on a rigid diet because of high cholesterol, blood pressure or diabetes.
 - Patients with late stage dementia usually need to be fed by someone else. Sometimes if you plan a visit at meal time you can offer to help the staff.

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- Snacks can be provided between meals and drinks should be offered regularly through the day.
- Sometimes a decision is made to minimize the chance of choking by changing the texture of the food. For example, the food may be minced and fluids might be thickened. If you notice that the person with dementia seems to strongly dislike the change in texture it might be worth discussing this with your health-care team.
- **Artificial feeding:** If food is not swallowed properly, it can get stuck in the windpipe or cause pneumonia. In this type of situation, caregivers sometimes ask about “feeding tubes”. These are tubes inserted through the nose or through the skin into the stomach. In patients with late stage dementia, studies show that feeding tubes do not prolong life, improve comfort or prevent pneumonia.

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Feeding tubes are usually not recommended as they have not been shown to help and can cause harm. One of the most serious consequences of feeding tubes is the need to tie down the person to prevent the tube from being pulled out.

Pain control

Pain is not always well managed in the older adult. There is a greater chance that pain may go untreated for older adults with dementia. Often this is because the person with dementia cannot tell you they are in pain. Signs of pain can include:

- rubbing the painful body part
- an increase in restlessness or agitation
- inability to sleep
- decrease or loss of appetite
- staying in bed or not wanting to walk

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- decreased ability to do things independently
- facial grimacing
- crying, groaning or screaming.

Some of the times during which pain is more common include:

- first thing in the morning
- during the morning routine of bathing, grooming and dressing
- after sitting for long periods of time
- during a walk.

If you suspect the person with dementia is experiencing pain it is important to contact your health-care team. It is generally safe to try a hot or cold pack if supervised (remember, the person with dementia may not tell you the temperature is too extreme). There can be risks associated with some over the counter pain medications. Generally

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acetaminophen (Tylenol™) is safer than anti-inflammatory medications like ibuprofen (Advil™) or ASA (acetylsalicylic acid or Aspirin™) but again, you should discuss use of these medications with your health-care team.

Skin Irritation

For many reasons, aging skin is more fragile than skin on younger people. Skin rashes, bruising, tears and sores can all be very uncomfortable. There are several things you can do to protect the skin:

- Use alcohol-free lotions for dry and flakey skin.
- Ensure that boney parts of the body do not rub against hard surfaces.
- Promptly change wet or soiled incontinence products.

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- Help the person with dementia shift position regularly if they are unable to move themselves.
- Elevate the heels off the bed by rolling a soft blanket under the feet.
- Bring any new skin redness or sores to the attention of your health-care team.

In some cases an occupational therapist may be asked to assess the situation. There are many different skin protection products available including special cushions, chairs and mattresses.

Constipation

Constipation is common. People with dementia may be very uncomfortable from constipation. In severe cases constipation can lead to pain, vomiting, delirium and sometimes blockage! Factors that can lead to constipation include:

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- inadequate fiber in the diet
- not drinking enough water
- decreased daily activity
- commonly used medications.

People with dementia may not recognize the need to have a bowel movement. There are a number of things you can try to help a person with dementia have regular bowel movements.

- Take the person to the bathroom and help them get ready for the toilet first thing in the morning and right after each meal.
- Watch for signs that the person may need to go to the toilet.
- Give the person a glass of water or other non-caffeinated beverage with every meal and between meals.

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- Increase the fruit, vegetables and whole grains in the diet if the person with dementia will eat them.
- If possible, try going for a walk together to encourage the bowels to get moving.
- If bowel movements are less than every other day you should likely talk to your health-care team about laxative options.

Shortness of breath

- People with shortness of breath work harder to breathe and often breathe faster. There can also be some coughing or an increase in phlegm. There are many causes of shortness of breath. Sometimes there is a treatable cause. Often if the shortness of breath keeps coming back or is not getting better with treatment this can be a sign that the person is nearing the end of life. It is important to talk to your health care team about shortness of breath.

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Things that may help comfort someone with shortness of breath include:

- directing a cool fan towards their face
- opening a window
- changing their position in bed regularly
- propping their head up on pillows
- considering the use of a hospital bed which can be adjusted to raise the person’s head.

Often when people see someone with shortness of breath they think they need oxygen. Unless there is a specific lung or heart problem, oxygen is generally not helpful. Even when the body’s oxygen level is low, many people with dementia will not keep the oxygen mask on.

If the shortness of breath is very distressing the palliative care team may be asked to give some advice. Palliative care is a special area

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of medicine that focuses on helping seriously ill people be more comfortable.

Comfort from spiritual care

Spiritual care often includes faith or religion. People with dementia have a spiritual side to them that often reflects previous experiences. Spiritual health can often be supported by:

- singing or hearing hymns
- attending religious services
- hearing and saying familiar prayers
- having family or friends visit
- being in a quiet space
- holding or viewing spiritual objects (for example prayer beads)
- experiencing nature.

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What to expect as late stage dementia progresses: End of life with dementia

Currently there is no cure for dementia. Dementia is a terminal disease which means that it will eventually lead to death.

There are many reasons why it is difficult to predict how long someone will live after being diagnosed with dementia. Some of the factors that predict how long someone will live include:

- **Duration of dementia symptoms and stage of dementia at the time of diagnosis:** People who need help eating, bathing and dressing will likely not live as long after diagnosis as people with milder symptoms at the time of diagnosis.
- **Type of dementia:** Some kinds of dementia gradually get worse in a relatively smooth

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decline. This rate of decline differs among kinds of dementia. Other kinds of dementia can stay the same for a period of time then get worse relatively suddenly. For further information about specific types of dementia talk to your health care team.

- **Other medical problems:** People with dementia may have other diseases including heart and lung diseases that lead to an earlier death.

Some of the signs that a person with dementia is not expected to live much longer include:

- not being able to get out of bed
- choking when swallowing or eating very little
- repeated high fevers or infections including pneumonia or urinary tract infections
- being drowsy more of the day and being harder to wake up.

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PART 3: **Decision-making**

Who makes the decisions?

People with late stage dementia are no longer able to make decisions about their health care. Although the specifics may vary slightly depending on where you live, there are some common things that apply to decision-making for people with dementia:

- The medical team will ask the appointed decision-maker to make important decisions on behalf of the person with dementia. This will likely include medical decisions as well as decisions about where the person with dementia should live.

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- Ideally, the person with dementia will have had some discussions with the person making decisions on their behalf.
- Some people with dementia will have an advanced health care directive or “living will”. This will likely help guide the decision-making.
- The decision-maker is supposed to make decisions that the person with dementia would have chosen. This is not always the choice the decision-maker would make for themselves.
- Decision-making can be difficult, especially if people disagree. If this situation occurs, a family meeting with the health care team is often helpful so that everyone has the same information and understands the situation.

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What decisions will need to be made:

- **Living arrangements:** As discussed earlier, there comes a time when decisions need to be made about the most comfortable and safest living arrangements possible for the person with late and end stage dementia. People with late stage and end of life dementia are not able to make decisions for themselves. There are several different scenarios that can arise at this time:
 - Most of the time the person with dementia will be willing to co-operate with the plans that the decision-maker and the health-care team feel are most appropriate.
 - Ideally, all the family members and people interested in the person’s well-being will also agree with the plan.
 - If there is disagreement among family members or if the person with dementia

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refuses to go along with the plans but cannot make safe decisions, the official decision-maker will be asked to finalize the decision. The person designated to make these important decisions can differ depending on the province in which you live.

- Rarely, a formal assessment will need to be done to determine if the person with dementia is safe to make decisions.
- Unfortunately, sometimes, when the person with dementia has not signed official documents earlier in life, it may be necessary to go to court to decide who should be making the decisions.
- **Cardiopulmonary resuscitation (CPR):**
When a person is admitted to a hospital or nursing home, the decision-maker is usually asked to decide about CPR. If the heart stops or the person stops breathing, the team will start CPR unless the decision has been made

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beforehand to let natural death occur. CPR involves use of injection drugs, electric shocks and a breathing machine to attempt to restart the heart. Despite heroic efforts most people with late stage dementia cannot be revived or may never be able to come off the breathing machine in the intensive care unit.

If the decision is made not to perform CPR when the heart stops beating, this does not mean all medical treatment will be denied for other medical situations. For example, if the person has an infection, they will still be offered antibiotics even though they do not want CPR. There are many phrases used in the medical system to describe the situation where CPR is not desired including:

- allow natural death (AND)
- do not resuscitate (DNR)
- no code.

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The decision to forego CPR can also be chosen for people living in a private home. A doctor can sign a note, which is often put on the refrigerator door, to state the person does not want CPR. If “911” is called, the ambulance attendants will need to know that CPR is not desired as soon as possible.

- **Goals of treatment:** Most people with dementia, admitted to a nursing home or living at home supported at a nursing home level of care, are in the final stages of their lives. At this stage it is expected that the person may naturally die in the next 6 to 18 months. At the time of admission and periodically during a nursing home stay you may be asked to decide on the “level of care” desired for a few specific situations including:
 - artificial nutrition and hydration
(See Artificial feeding page 31)

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- transfer to hospital if a new medical condition develops
- antibiotics for infections.

Regardless of where the person with dementia is living, you may want to consider if the person with late or end stage dementia would have wanted the focus to be “comfort care” or more aggressive medical treatment at this stage of the illness. The health-care team should be able to provide you with an opinion about whether additional medical tests and treatments are likely to promote comfort or prolong life. In some situations, the palliative care team may be able to help discuss care decisions.

- **Autopsy:** An autopsy is the process of looking at the inside of a person after they die. This is done by specially trained doctors called pathologists. Sometimes people with

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dementia will have an autopsy of the brain and the pathologist will not need to look at the rest of the body. Some of the reasons why an autopsy may be done include:

- Request by the person with dementia earlier in life or a request from the family.
- If there is some doubt about the type of brain disease that caused the dementia and there is interest from the family to clarify the diagnosis.
- Participation in a research study either before death or an interest in donating the brain to a collection of brains (called a “brain bank”) for the use of researchers working to better understand dementia.
- Sometimes if death is unexpected or if death occurs within 24 hours of transfer to hospital, the family may be asked to allow an autopsy to be done (this varies among provinces).

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If you or the person with dementia is interested in an autopsy of the brain it is often necessary to make these arrangements ahead of time. Often signatures will be necessary on consent forms to allow the autopsy to be done. Every province and community is different. There may be a fee associated with the autopsy. Not all communities have access to brain banks for the use of researchers. If you have further questions about brain autopsies, talk to your health care team. The Alzheimer Society also has some information about autopsy on its website: www.alzheimer.ca.

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Part 4: How life changes for the caregiver

What is your role when someone else is doing the day-to-day caregiving?

- **“Person-centered care”** - Formal (or paid) caregivers are often very knowledgeable about helping people with dementia. That being said, they will not have the background knowledge you have about the person with dementia. Here are some suggestions about how you can pass on important information to the care team:
 - Create a life history poster – If you have time, use a piece of poster board to organize some pictures and factual information about the person’s life history. The poster can be

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Photo courtesy of Jean Mahon



placed on the wall at home or can move with the person into a nursing home. This can give the formal caregivers information to improve conversation and “person-centered care”.

- Outline a brief Life Story – On pages 69-72 we have provided questions that can be completed. The purpose of this information

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is to help people providing care to see the a person as a whole - not as a “dementia patient”.

- Complete a Sensory History – On pages 73-77 we have provided questions about personal preferences. We all know the things we like and the things that really irritate us. Some people love the smell of cinnamon; it makes them think of big family holidays. Other people smell cinnamon and think it smells like aunt Thelma’s cat. By knowing this information ahead of time, formal caregivers can make choices which are more likely to be enjoyed by the person with dementia.

- **Advocacy** – Most of the time caregivers paid to come to the home or working in a nursing home are trying their best to provide good care. Often they will ask for your opinion about how the person with dementia can be made

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more comfortable. It is important to remember that you continue to have a voice. Some venues for expressing your opinions include:

- scheduled family conferences
 - resident and family councils
 - informal discussions with staff.
- **Education** – You will likely have learned a lot about dementia through your experiences over the last few years. If you feel able, you may find it rewarding to share some of your knowledge and experience with other people trying to help someone with dementia. There are a number of ways in which you may share this important information including:
 - People who know about your journey may ask you questions. In addition to any personal suggestions you may have, it is often helpful to suggest they contact the local Alzheimer Society office or go to the website at www.alzheimer.ca.

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- If you feel comfortable sharing your experiences with others, you could consider contacting your local Alzheimer Society office to see if they have volunteer opportunities. People with real-life experience ,are especially helpful in the Alzheimer Society support groups. (Remember, the Alzheimer Society helps people with all kinds of dementia!)

The emotional roller-coaster of the later stages of dementia

No one can predict how they will feel as the person with dementia moves through the later stages of dementia. This is almost always a time of dramatic changes for everyone involved. These changes may have seemed gradual or may have happened more rapidly than expected. No matter how much you attempted to prepare for the future by reading or attending education sessions,

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there are bound to be things you didn't expect. This can cause quite a variety of mixed emotions including:

- **Anger** - It is not uncommon to have periods during which you may be angry. This anger may be focused on a specific target, such as a negative incident, or may be more general. Often it is important to consciously think about what is making you angry so that it doesn't take over your life.
- **Relief** - There may be times, during the later stages of dementia, when you experience a sense of relief. This is not inappropriate or unusual. Both you and the person with dementia have been through a long, hard journey. Others may not understand or have the same reaction. That does not make your feelings "wrong".
- **Boredom** - If your life has been very "tied up" with activities to keep the person with

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dementia comfortable and safe, you may now have some time in your schedule that you have not had, perhaps for years. If this is the case you may want to consider activities available in your community. Exercising the mind and body can help you adapt to changes in your life.

- **Loneliness** – Over the years, your social network may have changed dramatically. Sometimes friends and family have "pulled away" because they were uncomfortable being around the person with dementia or "did not want to bother you". You may have become very involved with support groups and your contact with these groups may be winding down. You may lose your close relationships with home care workers or with nursing home staff. You will be the best judge of how much time you want to spend with others but this may be a time for you to reach out to friends and say you are interested in getting together.

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- **Grief** - Many people feel a sense of grief, even while the person with dementia is still alive. This can start at any stage of dementia because grief is the way we experience what we have lost.
- **Sadness** – It is perfectly normal to have periods of time during which you are sad and it is not unusual to cry during these times. Unfortunately, it’s not always possible to schedule these times of sadness to occur in the privacy of your own home. Don’t be alarmed. The people around you are likely to be very understanding if they know about the dramatic changes that have been occurring in your life.
- **Depression** - There is a time when grief and sadness take over and this is a time when it is important to talk to your own health-care team about the emotions you are experiencing. Some of the symptoms of depression include:

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- loss of appetite
- dramatic changes in sleep (too much or too little)
- loss of interest and enjoyment
- wishing you could die.

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What support is available for caregivers?

As described above, some of the changes that occur in the later stages of dementia can dramatically change the support systems you have relied on in the past. The supports available may differ depending on where you live but there is always a combination of casual and formal support available to help you through this time of transition. Here are some suggestions:

- **Friends and family** – Regardless of their involvement up until now, friends and family may be just what you need. More often than not friends and family are happy when you call because they have been thinking of picking up the phone themselves but didn't know what to say.

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- **Alzheimer Society of Canada** – The Alzheimer Society of Canada provides face-to-face and telephone support to anyone who makes contact with them. They help with all kinds of dementia. “It’s not just for Alzheimer’s disease!” Depending on where you live, there may also be support groups organized by the local Alzheimer Society for people who know someone with the later stages of dementia. You can call your local office to find out what they offer or go online at www.alzheimer.ca.
- **Online communities** – These days one of the most popular ways to get support, in the privacy of your own home, is to join an online support group. This is often done without sharing personal details like names and addresses. You should never have to share any financial information such as credit card numbers or social security numbers to

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join. These online support groups may be particularly helpful if you live in a rural area or if you want more information about one of the rarer forms of dementia.

- **Nursing home family councils** – If the person with dementia has moved to a nursing home there may be a group that gets together to discuss various topics. These groups may be a way to get to know the people you are passing in the halls when you visit. Ask the staff at the nursing home if such a group exists.
- **Spiritual care** - Some people are connected to a spiritual or religious community. It may have been some time since you were last able to regularly attend activities with your faith community. This may be a time to reconnect with your spiritual side or perhaps this would be a new venture for you. Regardless of the degree to which you are interested in

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participating in organized activities, addressing your spiritual needs may help you adjust to the dramatic changes that have been occurring in your life.

- **Your health-care team** – There are times when friends, family and support groups can help you adjust to the changes occurring in your life. It is important to remember that you may need to involve your health-care team. If you are feeling unwell, are experiencing symptoms of depression (see page 60) or have not made time for your own “check-up,” it is important for you to schedule an appointment with your family physician or primary health-care team.

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Part 5: Additional information

There are many online sources of information. We highly recommend these:

- **The Alzheimer Society of Canada**
 - www.alzheimer.ca
- **Lewy Body Dementia Association**
 - www.lbda.org
- **National Institute on Aging:
Caring for a Person with Alzheimer Disease**
 - www.nia.nih.gov/Alzheimers/Publication
- **Comfort Care AT THE END OF LIFE FOR PERSONS WITH ALZHEIMER'S DISEASE OR OTHER Degenerative Diseases of the Brain**
 - www.expertise-sante.com/guide_arcand_caron

- **Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities**
 - www.alzheimers-illinois.org/pti/comfort_care_guide.asp
- **The Canadian Coalition for Seniors' Mental Health: "Delirium in Older Adults: A guide for seniors and their families"**.
 - www.ccsmh.ca/en/default.cfm#.

Other written resources recommended include:

- **Caring for your loved one. An education guide for caregivers of persons with dementia.** Baycrest Center for Geriatric Care. 2nd Canadian Edition.
- **The 36-Hour Day.** Nancy Mace and Peter Rabins. Warner Books, 2006.
- **A Caregiver's Guide to Lewy Body Dementia.** Whitworth and Whitworth. demosHEALTH 2010
- **Caring for a Loved One with Alzheimer's Disease. A Guide for the Home Caregiver.** Johns Hopkins Medicine, 2010.

The following were used in the preparation of this booklet:

- **Reaching Out to the Spiritual Nature of Persons With Dementia**
www.baylor.edu/content/services/document.php/60623.pdf
- **Caring for Patients with terminal Alzheimer's Disease.**
Ladislav Volicer. The Canadian Review of Alzheimer's Disease and Other Dementias.
- **PATH: A New Approach to End-of-life Care.**
Moorhouse and Mallery. The Canadian Review of Alzheimer's Disease and Other Dementias.
- **Counseling the Alzheimer's Caregiver.**
A Resource for Health Care Professional.
Mittelman et al. AMA Press, 2003.
- **New Brunswick Association for Spiritual Care.** www.nbasc.ca

Website addresses current as of March 2013.

Appendix 1 Life Story

(Fill in the parts that are applicable.)

My name is

Most of my friends call me

I was born on in

I grew up in
and came from a family of

I met my spouse

I married on

I have children. Their names are:

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I have grandchildren and great
grandchildren. Their names are:

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People I regularly see or talk about include:

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I would like you to know I had many interests which included the following:

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.....

My favorite things to do in my childhood were:

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.....

My favorite things to do as an adult (include hobbies):

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.....

My favorite types of books and music are:

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.....

This is what I like to do to relax:

.....
.....



My favorite things are:

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.....

I worked most of my life as:

.....
.....

I belonged to various groups, committees, volunteer work, that included:

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.....

My spiritual beliefs included:

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.....

Three accomplishments/successes/ achievements that I am most proud of are (consider including education, certificates, courses etc.):

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I have had these pets over the years:

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Other things you should know about me include: (Please consider including military service. Is your military service something you like to talk about?)

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Please indicate below:

- YES, I give consent for this information to be shared with the people around me so they know more about me.
- NO, I do not give consent for this information to be shared with the people around me.

Signature of patient or substitute decision-maker:

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Date:



Appendix 2 Sensory Preferences

Favorite smells: examples include roses, pine, sea air, foods, soaps and perfumes, laundry detergent

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Disliked smells: examples include specific foods cooking, soaps and perfumes

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Favorite foods: examples include sweets, salty snacks, cold or warm (ice cream vs. oatmeal)

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Disliked foods: examples include specific flavors like curry, cinnamon, fish

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Favorite food textures: examples include crunchy, chewy, drinking through a straw, drinks with or without ice, milkshake thickness

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I like to have something in my mouth:

examples include chewing gum, peppermints, toothpick, straw of hay, cigarette

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Preferred background noise: examples include favorite types of music, nature sounds, quiet, talk radio

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What volume is preferred?

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Favorite TV/radio shows:

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Disliked background noise: examples include specific types of music, television, quiet

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Room temperature preference:

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What clothes are usually worn inside:

examples include T-shirt, vest, long-sleeve shirt with buttons or without, sweater, shoes, slippers

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Favorite fabrics: (wool, silk, cotton, polyester, rough textures, fuzzy textures)

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Disliked fabrics:

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Other:

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Level of personal contact: (please circle)

- Enjoy holding hands or a pat on shoulder? **Yes No**
- Having hair brushed? **Yes No**
- Having face or hand lotion put on? **Yes No**
- Massage? **Yes No**

Favorite resting position: examples include rocking in a chair, reclining in a LazyBoy, sitting in a firm chair, lying down in bed

Preferred level of activity: walking, dancing, rocking, being still, changing position

Something in the hands? examples include a rosary, cigarette, cell phone

Night time routine:

- Normal bedtime
- Before bed routine
- Pajamas/night dress/other
- Sheets tucked in or loose
- Weight of blankets

Morning routine:

- Time of waking
- Time of getting out of bed
- Breakfast? **Yes No**

Bathing routine:

- Shower, bath, other
- Preferred soaps or other products



Adapted from Life History and Sensory Preference Survey, Tracy McGrath BPE, Recreation therapist



If you have noticed gradual changes in memory and thinking, it may be helpful to read about dementia. As time goes by you will likely have new questions. The Dementia Trilogy is a set of three booklets about dementia.



An Introduction to Dementia lists the earliest signs of dementia. It helps answer some of the more common questions like, “What is the difference between dementia and Alzheimer’s disease?”



The Dementia Compass offers some tips to help a person with dementia with their day-to-day activities. It also describes some personality changes that can be symptoms of dementia.



Later in the Dementia Journey provides helpful yet sensitive information to help focus on comfort in the later stages of dementia.

*Feedback about The Dementia Trilogy—
“Most noteworthy is the manner in which they were written: in simple language made easy to understand... the information provided has given us the power we need to face the future together.” Marie C.*