

What is dementia?

Dementia is an overall term for a set of symptoms that are caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language, severe enough to reduce a person's ability to perform everyday activities. A person with dementia may also experience changes in mood or behaviour.

Dementia is progressive, which means the symptoms will gradually get worse as more brain cells become damaged and eventually die.

Dementia is not a specific disease. Many diseases can cause dementia, including Alzheimer's disease, vascular dementia, Lewy Body disease, fronto-temporal dementia, and Creutzfeldt-Jakob disease. These conditions can have similar and overlapping symptoms. There is no cure for these dementias nor can their progression be reversed. Treatment options and lifestyle choices, however, can often slow the progression of the disease.

What is a person-centred approach to meal time?

The person-centred philosophy focuses on the person rather than on the condition. It recognizes that people have unique values, culture, personal history and personality. Each person has a right to dignity and respect and to participate fully in their environment.

Person-centred care is interactive. People with dementia can participate in their own care at the beginning stages of the disease. As the dementia progresses, family members play a vital role in ensuring the health and well-being of their relative.

A successful person-centred approach to meal time is based on:

- Learning about dementia, its progression, and how changes in the brain may affect the person's ability to perform everyday tasks
- Believing that communication is possible throughout the course of the disease
- Focusing on the person's abilities and skills rather than on those that have been lost
- Giving the person choices and putting their preferences first, wherever possible
- Promoting the person's independence and self-sufficiency
- Being as attentive and flexible as possible
- Making sure that the environment meets the needs of the person with dementia
- Maintaining safety.

How does dementia affect the ability to eat?

The brain is made up of several distinct parts, each with its own function. While these parts are separate, they must work together to complete the simplest task. As dementia affects each area of the brain, certain functions or abilities can be lost. One link in the chain of events may be missing and the person will need help to complete the task. For example, as dementia progresses, the brain might not be receiving triggers from the stomach to encourage eating or drinking.

A person with dementia will need help with eating and drinking as the disease progresses because of difficulties that may arise with:

- Remembering how to use cutlery
- Not knowing what to do with food that is placed in front of them
- Putting too much food in their mouth at once
- Eating too quickly
- Trying to swallow without chewing
- Trying to eat inedible items.

Maintaining a healthy, balanced diet is important for all of us. This may become difficult for a person with dementia because, due to changes in the brain resulting from dementia, they may:

- Lose interest in eating and drinking
- Have a poor appetite
- Forget to eat or drink
- Forget they have already eaten
- Have difficulties swallowing
- Overeat
- Crave certain foods more than usual.

The good news is the person with dementia can continue to enjoy food and take pleasure in spending time with others over a meal. Keeping them involved in meal times is key. By caring, prompting, and adapting some meal time rituals, the person with dementia can be encouraged to eat independently.

**“Do not get frustrated or upset as the person will sense this.
Keep it light and add humour if possible.” - Caregiver**

Changing abilities and meal time challenges: Tips and strategies

At the early stage of the disease, the person with dementia will retain many of their abilities and be fairly independent. Focus on what the person can do well when it comes to eating and drinking. As the disease progresses, however, the person will need more help with meal time.

These tips and strategies are things that can help the person with dementia adapt to the changes in their eating and drinking abilities:

Try and have a conversation with the person about their changing abilities and how you can help them make adjustments so that they can eat as independently as possible.

- If the person is having difficulty carrying out the steps required to eat or drink, offer visual and verbal cues.
- Try avoiding stepping in to feed the person, as this may diminish the person's independence.
- Keep the person involved by adapting meal activities to make the most of the person's remaining abilities. For example, simplify tasks, provide detailed instructions (one at a time), provide help when needed, and choose tasks that match their abilities.
- Focus on what the person can still do. Encourage them to help prepare the food, set the table and put dishes away.
- Ask the person with dementia about their food and dining preferences. Don't be surprised if one day you serve them their favourite meal or dessert and they tell you that they don't like it and never have.
- If the person is no longer able to prepare a meal for themselves consider using services such as Meals on Wheels, contact a local community support agency that offers help with meal preparation, buy homemade food at farmers' markets, community events, and bakeries in your neighbourhood.
- Use meal time to learn about the person's wishes for the future. Learning about their care preferences will help you honour their wishes as the disease progresses.
- Be aware of potential safety issues, such as the person with dementia getting lost in the grocery store or forgetting to turn off the stove after cooking.
- Consider arranging for an occupational therapist to assess the kitchen and other household safety matters. To find an occupational therapist near you visit www.find-an-ot.ca
- Consider ordering food in, dining out, or making several meals on the weekend and freezing them.

Meal time can be stressful for caregivers. Make sure you are taking care of yourself and ask for help from friends and family.

To promote independence try:

- Calling the person with dementia to remind them to eat
- Preparing nutritious finger foods
- Using bowls, spoons, and no-spill glasses on a non-skid surface
- Writing down simple step-by-step instructions about how to prepare a particular meal
- Using labels or pictures on cupboards and drawers to make it easier to find kitchen tools and food items
- Organizing the kitchen so that items needed to make a meal are in clear sight
- Storing food, utensils, pots, and pans on lower shelves (storing them on higher ones could pose a falling hazard due to balance problems).

If you are having meals delivered to the person, don't assume they are always eaten. They may be forgotten in the refrigerator. Cue the person when it is time to take the meal out of the fridge and warm it up.

²See the Alzheimer Society's booklet *All about me* for help with this.

³For more information, read the Alzheimer Society's "Heads Up for Healthier Brains" brochure.

Meal time is an opportunity

Meal time is more than just about eating food. It physically brings people together and gives everyone a chance to relate socially and emotionally as they talk about their day, reminisce about the past and learn from each other. Dining with others can give the person with dementia something to look forward to in their day and reduce the potential for isolation.

If the person with dementia cannot communicate verbally, they can still listen to conversation, which is another way of being involved. You can also communicate through laughter. Laughter is social and infectious, and it joins people together. It also helps people respond to difficult or embarrassing situations.

Gatherings with extended family and friends, holiday dinners, and birthdays allow family members and caregivers to stay connected to the person with dementia because they might be participating in fewer activities together. Where possible, however, keep dining groups small, so the person with dementia does not become overwhelmed by the noise and intensity. Although these are happy occasions, they can be extremely stressful for the person with dementia.

“It is not what is important to you and what you believe the person should be eating or doing, it is about keeping the person with the disease content and happy.” - Caregiver

Shifting roles

You may be unprepared to take on meal preparation, perhaps because you have not done it in the past. The person with dementia, meanwhile, may be unwilling to give up the food preparation role because they fear a loss of identity or because they don't realize they are having difficulty with it.

To honour the identity of the person with dementia and allow them to stay connected, give yourselves time to transition into your new roles. This may mean that the person with dementia will move from doing most of the food preparation to doing less, while you do progressively more.

Nutrition

There is no special diet required for people with dementia, but a healthy lifestyle is as important to brain health as it is to the rest of your body. Diabetes, hypertension, high cholesterol and obesity are all risk factors for dementia. Many healthy food choices will improve your brain health. Eat a varied diet rich in dark-coloured fruits and vegetables, including foods rich in anti-oxidants such as blueberries and spinach, and omega 3 oils found in fish and canola oils. If you need help planning, discuss with a registered dietitian or your physician.

“Don't become too distressed if not every meal is nutritionally balanced. You can only do so much, so try not to be perfectionistic.” - Caregiver

What should I expect?

Early stage

In the early stages of dementia, the person's eating habits usually don't change. Here are some issues for people with dementia that may occur, and tips and strategies that could help:

Challenges you may experience	Helpful strategies to try
<p>Memory loss Skipping meals, forgetting to eat or forgetting that they have eaten.</p>	<ul style="list-style-type: none"> • If you support someone living with dementia, you might call the person to remind them to eat, or cue them when it is time to take a pre-cooked meal out of the fridge and warm it up. • If you live alone with dementia, try posting reminders for meal time or setting an alarm.
<p>Decreased judgement Unknowingly leaving the stove (or other kitchen appliances) on.</p>	<ul style="list-style-type: none"> • If you support someone living with dementia, remind them to set the timer when using the stove or oven. • If you live alone with dementia: <ul style="list-style-type: none"> o Leave written reminders to turn off the stove and make sure they are placed where they can be seen often. o If you set a timer for something, use a sticky note to remind yourself what the timer is for. o Purchase appliances with automatic shut-off switches (such as electric kettles). o Have an occupational therapist come in to assess your kitchen for safety concerns. o Consider ordering meals and fresh fruit and vegetables from your local community support agency, such as Meals on Wheels.

Middle stage

The ability to follow the many steps required in both preparing and eating meals may diminish during the middle stage. Here are some issues related to eating and drinking for people with dementia that may occur, and tips and strategies that could help:

Challenges you may experience	Helpful strategies to try
<p>Constipation Constipation is a common complication of some neurological disorders that affect the nerves involved in digestion. Constipation is also caused by not drinking enough fluids or low fibre intake. A person with dementia might choose not to drink because they have difficulty getting to the washroom in time or because of incontinence issues. Constipation can be a side effect of medication.</p>	<ul style="list-style-type: none"> • Remind the person with dementia to drink liquids throughout the day to avoid dehydration and thus constipation. • If the person tends to be restless and less likely to sit down and eat, offer juice boxes, water bottles and portable snacks such as a fruits so they can stay hydrated and nourished while they are walking. • Try to position the person's bed so that they can clearly see the toilet. • To ensure they can find the bathroom quickly, consider putting signs in the home to direct them or putting a picture of a toilet on the bathroom door. • Consider a bedside urinal or bedpan, or renting a commode and placing it near the bed.

Challenges you may experience	Helpful strategies to try
<p>Dehydration</p> <p>The person may forget to drink or may not get enough fluids because they may not realize they are thirsty.</p>	<ul style="list-style-type: none"> • Be sure to offer regular drinks of water, juice or other fluids to avoid dehydration. • During the day, liquids should not be limited.
<p>Decreased appetite/Weight loss</p> <p>Medications or other conditions (such as heart condition, diabetes, constipation or depression) may lead to loss of appetite.</p> <p>Oral health issues such as cavities or gum diseases (gingivitis) can cause pain and affect the person's appetite. This can lead to unintentional weight loss or responsive behaviour.</p> <p>Dentures not fitting properly or dry mouth can also contribute to decreased appetite.</p> <p>Pacing and wandering sometimes occur in the middle stages of Alzheimer's disease. If the person is walking regularly, they will need more calories to maintain their weight.</p>	<ul style="list-style-type: none"> • Prepare appetizing meals and try to eat together. • Prepare the person's favourite meals to encourage eating. Consider talking to your doctor about using vitamin and meal supplements. • While extra carbohydrates and fats are not necessarily healthy, they do help maintain a person's weight. • Small, frequent meals or nutritious snacks may be more tempting and easier to eat than three main meals a day, particularly if the person's appetite is small. • Daily oral health and regular dental appointments are essential to keep the mouth and teeth healthy. • Schedule regular dental checkups and make sure the dentist has experience working with people with dementia. If your dentist is challenged to provide care to the person with dementia, suggest the additional resources listed at the end of this information sheet. • Consider using information from the person's life history to incorporate previous social roles to encourage eating (e.g. having tea with friends, eating snacks with a movie, religious observances involving food, baking).
<p>Overeating</p> <p>A person with dementia may overeat if they forget they have already eaten, have a craving for certain foods or be hoarding their food to eat later.</p> <p>Frontotemporal dementia, which affects the areas of the brain generally associated with personality, behaviour, emotions, language, speech, abstract thinking and movement may also lead to overeating because it may cause people to compulsively put things in their mouth, even inedible items.</p>	<ul style="list-style-type: none"> • Monitor the person with dementia to discourage overstuffing. To prevent choking, cut food into small portions. Also remind them to chew, swallow, and slow down. • Overeating could be due to boredom or depression, so make sure the person is occupied with meaningful activities throughout the day. • Overeating may be due to a preference for specific foods. If the person is diabetic, do blood sugar checks prior to meals. Make healthy snacks easily available, such as pieces of fruit, yogurt, and applesauce. • Stagger food items so that only one is visible to be eaten at a time (i.e. present one food item, take that away, present another food item, take that away). • Limit food intake to avoid becoming overweight, and if you can't, provide as much healthy food as possible (fruits, yogurt).

Challenges you may experience	Helpful strategies to try
<p>Decreased judgement</p> <p>A person with dementia may not recognize the cutlery on the table or the food items on the plate. They may use a knife to pick up food instead of a fork, or put food on their fork and not know what to do with it. They may try to drink from a plate rather than a cup.</p>	<ul style="list-style-type: none"> • Cue the person with words or actions. The person might be able to mimic your motions for eating, such as putting food on a fork and bringing it to their mouth. • Use simple, easy-to-understand instructions. For example, “Pick up your fork. Put some food on it. Raise it to your mouth.” • If necessary, place the spoon in the person’s hand, put your hand over theirs and guide the food to the mouth. They may be able to continue eating independently after a few assists. • If they are obviously struggling with a task, be respectful and ask if they would like assistance, rather than making this assumption.
<p>Lack of concentration</p> <p>Eating involves carrying out a series of complex skills, such as cutting up food, moving it to the fork, placing it in the mouth, chewing, and swallowing. This requires a level of concentration someone with dementia may not be able to maintain. Having distractions around may also cause the person to lose their concentration.</p>	<ul style="list-style-type: none"> • Limit distractions: Serve meals in a quiet place so that the person can focus on eating. Turn off the television, radio and telephone ringer. • Simplify the table and the setting. Consider removing flowers, centerpieces and condiments. Use only the utensils needed for the meal. • Serve the meal one course at a time with only the necessary cutlery. This provides a clear objective and prevents the person from getting overwhelmed. • Try to keep the atmosphere as calm and relaxing as possible. • Try to be flexible. If the person with dementia does not want to be with other people while eating, don’t force them to eat at the table. If they want to stay in the living room where they are comfortable, allow this. It may be difficult for them to change routines. You can always use TV trays in the living room.
<p>Refusing food/Spitting food out</p> <p>A person with dementia may refuse or spit out food if they:</p> <ul style="list-style-type: none"> • Have forgotten how to eat, chew, or swallow • Need help to eat • Dislike the taste or texture • Don’t know it’s time to eat. • Is trying to express something, such as the food is too hot or cold. <p>Conversely, they might keep food in their mouth because they don’t know what to do with it after it is chewed. They might also not be feeling well.</p>	<ul style="list-style-type: none"> • Check the temperature of the food to ensure it is neither too hot nor too cold. • Offer the person’s favourite foods. • Remind the person to swallow if they don’t know what to do with the food after it is chewed. • Check with a doctor or speech language pathologist if there are concerns with their ability to swallow. • Maintain regular dental and physical check-ups. To ensure the maximum sensory experience, schedule visual and hearing check-ups as well.

Challenges you may experience	Helpful strategies to try
<p>Declining visual and motor abilities</p> <p>A person's vision and ability to understand where objects are in relation to each other change as the disease progresses. This may make it difficult to distinguish items on the table. It can also affect movement and co-ordination.</p>	<ul style="list-style-type: none"> • Provide a sharp colour contrast between the table or placemat and the plate. • Avoid patterned dishes, tablecloths and placemats because they might confuse or distract the person. • Provide food that is colourful and easily distinguishable on the plate. • Avoid using Styrofoam cups and paper napkins, which might be eaten by mistake. • Choose cutlery and dishes that are easy to hold. • Serve food in large bowls instead of plates or use plates with rims or protective edges that are easy to hold onto. • Cups and mugs with larger handles may be easier to use than standard cups with small handles; ones with lids can prevent spilling. • Offer the person only one utensil. Spoons are the easiest to use. Use ones with large handles or ones with a different texture or colour to make it easier to identify and handle. • Ensure plates are stable; use mats or even a wet cloth underneath to prevent slipping. • Since independence is encouraged for as long as possible, meal time can get messy. Consider using a large table napkin so that the mess can be caught and the napkin can be taken away without too much distress for the person with dementia. You might also consider using a clothing protector. • Avoid using sharp knives or fragile china. • Cut food carefully into bite-size pieces (about the size of a quarter). Remove all bones, garnishes, and non-edible items from the plate. • Provide finger foods, i.e. everyday foods that are prepared in a way that makes them easy to pick up and be eaten with the hands. These foods help maintain independence if the person is unable to use utensils because they don't have to rely on help from someone else to eat. Some finger food ideas are: cheese cubes, small sandwiches, small pieces of chicken, fresh, sliced fruits and vegetables, potato wedges, chicken strips, and fish sticks. Fruit can be peeled if preferred, but the peel may make it easier for the person to grip the fruit, especially if it's slippery.

Challenges you may experience	Helpful strategies to try
<p>Responsive behaviour, such as agitation and anger</p> <p>Behaviour that is challenging for others (such as hitting or pushing food away) can be triggered by:</p> <ul style="list-style-type: none"> • The environment the person is eating in • Frustration because of lack of skills, co-ordination and memory loss • Being rushed • Needing help to eat • Being fed • Inability to sit through an entire meal • Recognition of caregiver frustration. <p>Other reasons for responsive behaviour include side effects of medications, communication challenges, the type of dementia the person has or the stage that they are in, depression, or another diagnosis.</p>	<ul style="list-style-type: none"> • Present only one food item at a time. • Don't rush the meal. The person may start and stop eating many times. • If the person doesn't want to eat, take a break, involve them in another activity, and return to eating later. • Avoid introducing unfamiliar routines, such as serving breakfast to a person who has never routinely eaten breakfast. • Avoid nagging and criticism. • Consider having nutritious foods on hand that the person can eat "on the go," such as yogurt cups, fruits, cereal bars, etc. • Consult a health-care professional if you suspect medication or depression may be causing responsive behaviours.

"People with dementia or Alzheimer's disease progress at different rates – you will have to do what is best for your family member at each stage of the disease." - Caregiver

Late stage

In the late stage of the dementia (also referred to as “severe” or advanced Alzheimer’s disease), individuals experience increased mental and physical deterioration. Here are some issues related to eating and drinking for people with dementia that may occur, and tips and strategies that could help:

Challenges you may experience	Helpful strategies to try
<p>People in this stage will often lose their appetite, be unable to feed themselves and have difficulty swallowing, which can cause choking.</p>	<ul style="list-style-type: none">• Vegetables can be cooked so they are soft to eat. Remove any hard elements or skins.• Serve soft foods such as applesauce, pudding, yogurt, cottage cheese, gelatin, oatmeal, and scrambled eggs.• Breakfast cereals soaked in milk will soften the texture.• Fresh fruit can be peeled and mashed. Canned fruit is often softer.• In the later stages of dementia, there is more of a concern about the person’s quality of life than there is about eating a healthy, balanced diet. If someone wants three desserts, but no vegetables, you may want to accommodate this. You might consider serving fruit as desserts, which has most of the same nutrients as vegetables.• Provide nutritious foods that can be taken from a cup or a mug. The ability to hold a mug and to drink is often retained until late in the disease. Protein milkshakes or liquid food supplements can sometimes take the place of a full-course meal. You can also mix healthy foods in a blender and let the person drink their meal.• If the person seems to choke or cough when drinking thin liquids, try offering thickened fluids, smoothies and shakes (made of nutritious foods), puddings, yogurt, or pureed fruits to maintain hydration.• Use nutritional supplements if the person is not getting enough calories. Speak to their doctor about what kinds of supplements are best.• Make sure you cut food into small pieces and make it soft enough to eat. Chop meat into thin slices, and mash canned fish.• Don’t use a straw; it may cause more swallowing problems. Instead, have the person drink small sips from a cup.• Give the person more cold drinks than hot drinks. Cold drinks are easier to swallow.

Dining out

Dining out can relieve the stress of planning, shopping, and preparing a meal. It brings family and friends together and strengthens bonds between them. It also offers a welcome change of scenery for both the person with dementia and their caregiver, who can feel socially isolated being at home every day. Going out to eat allows the person with dementia to dress up and continue to be part of their community.

While dining out with a person with dementia can be a positive change, it can also present challenges. Planning ahead can help. Here are some tips:

- Going out earlier in the day may be best, so the person is not too tired. Service may be faster and there may be fewer people. By going at non-peak times you also won't feel as rushed and overwhelmed.
- The person with dementia can show the staff a card saying they have memory loss or let the server know.
- Eat out in familiar places where the person with dementia already knows the menu, and where serving staff are familiar with your needs.
- If the menu is long and complex, narrow the choices for the person with dementia. Menus with pictures can help with selections.
- The person with dementia can write down a list of their favourite foods and drinks beforehand, so they remember their preferences or can show the server.
- Consider previewing the menu online and deciding what to eat before going to the restaurant so the person doesn't feel rushed or pressured to make a decision when they are there.
- Ask the wait staff for a written copy of the specials instead of having them listed verbally, because the person with dementia might not remember them all.
- Order finger foods.
- Be selective about where you sit. If a quiet corner is best, ask for a table there.
- Try to find restaurants with family washrooms so that there is enough space if the person with dementia uses a walker or wheelchair.
- Manoeuvring with a cane, walker or wheelchair can be a challenge. Consider the type of dining (e.g. buffet) or type of restaurant and seating (fixed seats such as booths) that might work best.
- Consider going to family restaurants or coffee shops; they are less formal and have more finger food items on the menu.
- Some people with dementia lose their inhibitions and judgment and may conduct themselves inappropriately at the table. If this happens, help guide their behaviour.
- Paying the bill: offer assistance if the person with dementia needs help to calculate the tip or make change, use gift certificates, or allow the restaurant to keep a tab (if possible) so you can dine there regularly without having to pay right away.



Meal time tips for caregivers

Cut this section out and put it on your fridge to have useful tips available for meal time.

- ✓ **Remember** the person's personal preferences when preparing food.
- ✓ **Reduce distractions:** Serve meals in a quiet place so that the person can focus on eating. Turn off the television, radio and telephone ringer.
- ✓ **Be patient:** Don't rush the meal. The person may start and stop eating many times. Cue or encourage them if they are having difficulties.
- ✓ **Keep it simple:** Simplify the table by removing centerpieces and condiments. Avoid patterned tablecloths, plates, and placemats. Consider offering only one food item at a time and give the person only one utensil to use.
- ✓ **Serve finger foods:** Cut food up into small pieces so it can be picked up and eaten with the hands. Finger foods allow people to feed themselves and maintain a level of independence.
- ✓ **Show and talk:** Cue the person with words or actions. They might be able to mimic your motions for eating.
- ✓ **Take time** to relax, talk, laugh and enjoy your meal together!

1-800-616-8816

www.alzheimer.ca



Dining out tips for caregivers

Cut this section out and put it in your wallet or purse so you have useful tips available for dining out.

- ✓ Go out during non-peak times so the person with dementia won't feel rushed.
- ✓ Dine at a restaurant with family washrooms if the person with dementia uses a walker or wheelchair.
- ✓ Request a table in a quiet corner to avoid noise and distractions.
- ✓ Inform the server: The person with dementia can show staff a card saying they have memory loss or let the server know.
- ✓ Ask for it in writing: Ask the server for a written copy of the specials instead of having them listed verbally.

1-800-616-8816

www.alzheimer.ca

The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities right across Canada, the Society:

- Offers information, support and education programs for people with dementia, their families and caregivers
- Funds research to find a cure and improve the care of people with dementia
- Promotes public education and awareness of Alzheimer's disease and other dementias to ensure people know where to turn for help
- Influences policy and decision-making to address the needs of people with dementia and their caregivers.

For more information, contact your local Alzheimer Society or visit our website at www.alzheimer.ca.

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Alzheimer Society

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Where can I get further information?

Please refer to the following resources or contact your local Alzheimer Society: www.alzheimer.ca.

Progression series:

Overview
Early stage
Middle stage
Late stage
End of life

Day to day series:

Communication
Personal care
Long-term care

Other dementias:

Creutzfeldt-Jakob disease
Lewy body dementia and Pick's disease
Frontotemporal dementia
Vascular dementia
Down syndrome

Tough issues:

Decision-making: Respecting individual choice
Quality of life
Living alone

Guidelines for care:

Person-centred care of people with dementia living in care homes

Additional resources

Canadian Association of Occupational Therapists

Are you looking for an occupational therapist?
Check the OT Finder Tool at www.caot.ca.
Phone: 613-523-CAOT (2268) Toll-free: 800-434-2268

Alzheimer Society



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