Day-to-Day Series

How does dementia affect the ability to eat and prepare meals?

Dementia is an overall term for a set of symptoms that are caused by diseases or conditions affecting the brain. Symptoms may include memory changes and difficulties with thinking, problem-solving, movement or language severe enough to reduce a person's ability to perform daily activities. Such activities could include eating and preparing meals.

The brain is made up of distinct parts, each with its own function. While these parts are separate, they must work together to complete any task. As dementia can affect multiple areas of the brain, it might not be able to process triggers from the stomach that encourage a person to eat or drink.

A person living with dementia may need help with eating and drinking because of:

- Forgeting how to prepare a meal
- Having challenges with how to use utensils
- 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 living with dementia as 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 that people can continue to enjoy food and take pleasure in spending time with others over a meal. Keeping them involved in meal times is important for their well-being. By caring, prompting and adapting meal times, a person living 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: strategies for caregivers

When first diagnosed, a person living with dementia will retain many of their abilities. Focus on what the person can do. As dementia progresses, however, a person may need more help. These tips and strategies can help the person living with dementia adapt to changes in eating and drinking:

- Try to 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 to avoid feeding the person, as this may reduce the person's independence.
- Adapt meal activities to make the most of the person's current 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 food, set the table and put dishes away.
- Ask the person 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 meal delivery services.
 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.
- If you are have meals delivered to the person, don't assume they are always eaten. They may be forgotten in the refrigerator. Remind the person when it is time to take the meal out of the fridge and warm it up.
- Be aware of potential safety issues, such as the person 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 <u>caot.ca/site/findot</u>.
- Consider ordering food, dining out or making several meals on the weekend and freezing them.

To promote independence try:

- Calling the person 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
- Placing items needed to make a meal in clear sight, using labels or pictures on cupboards and drawers
- Storing food, utensils, pots and pans on lower shelves (storing them on higher ones could pose a falling hazard due to balance problems)

What is a person-centred approach to meal time?

A person-centred approach 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, to make decisions about their care and to participate fully in their environment.

Person-centred care is interactive. As a person's dementia progresses, caregivers play a vital role in ensuring the health and well-being of the person they support.

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 dementia
- Focusing on the person's strengths, abilities and skills
- 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

To help you get to know the person living with dementia, use the All About Me booklet, at <u>alzheimer.ca/allaboutme</u>.

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 living with dementia something to look forward to in their day and reduce the potential for isolation.

If the person cannot communicate verbally, they might still be able to listen to conversations, which is another way of being involved. You can also communicate through laughter. Laughter joins people together. It also helps people respond to difficult or embarrassing situations.

Gatherings with extended family and friends, holiday dinners and birthdays allow people to stay connected to the person because they might be participating in fewer activities together. Where possible, however, keep dining groups small, so the person does not become overwhelmed by the noise and intensity. Although these are happy occasions, they can be extremely stressful for the person living 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 ... 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 living 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 a person's identity and help them to stay connected, give yourselves time to transition into your new roles. This may mean that the person will move from doing most of the food preparation to doing less, while you do progressively more. If the person living with dementia still enjoys being involved in food preparation, find a fun way to keep them involved. Meal time can be stressful for caregivers. Make sure you are taking care of yourself and ask for help from friends and family.

Nutrition

There is no special diet required for people living with dementia, but eating a variety of healthy foods each day 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. Discuss your diet with a registered dietitian or your doctor. See Canada's Food Guide for more information on healthy eating and recipes, at <u>food-guide.canada.ca</u>.

"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

Tips and strategies for people living with dementia and caregivers

Early stage

In the early stage of dementia, the person's eating habits usually don't change. Here are some of the changes that a person living with dementia may experience, and tips and strategies that could help:

Possible changes	Helpful strategies to try
Memory Skipping meals, forgetting to eat or forgetting that one has eaten.	 If you support someone living with dementia, you might call the person to remind them to eat, or let them know 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.

Possible changes	Helpful strategies to try
Decreased judgment Unknowingly leaving the stove (or other kitchen appliances) on.	 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: Create reminders to turn off the stove. If you set a timer for something, use a sticky note to remind yourself what the timer is for. Buy appliances with automatic shut-off switches (such as electric kettles). Have an occupational therapist come in to assess your kitchen for safety concerns. Consider ordering meals and fresh fruit and vegetables from local community support services.

Middle stage

The ability to follow the many steps required in both preparing and eating meals may be reduced during the middle stage. Here are some of the changes that a person living with dementia may experience and tips and strategies that could help:

Possible changes	Helpful strategies to try
Constipation Constipation is a common complication of some neurological disorders that affect the nerves involved in digestion.	 Remind the person to drink liquids throughout the day to avoid dehydration and 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.
Constipation is also caused by not drinking enough fluids or by low fibre intake. A person might choose not to drink because they have difficulty getting to the washroom in time or because of incontinence issues. Constipation can also be a side effect of medication.	 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, bedpan or a commode and place it near the bed.

Possible changes	Helpful strategies to try
Dehydration The person may forget to drink or may not get enough fluids because they may not realize they are thirsty.	 Be sure to offer regular drinks of water, juice or other fluids to avoid dehydration. During the day, liquids should not be limited.
Decreased appetite/weight loss Medications or other conditions (such as heart conditions, diabetes, constipation or depression) may lead to loss of appetite. Oral health issues such as cavities or gum diseases (gingivitis) can cause pain and affect a person's appetite. This can lead to unintentional weight loss or changes in a person's behaviour. Dentures not fitting properly or dry mouth can also contribute to decreased appetite. A person may also be restless and walk around more than usual. If they are walking regularly, they will need more calories to maintain their weight.	 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 a person's appetite is small. Daily oral health habits and regular dental appointments are important to keep the mouth and teeth healthy. Schedule regular dental checkups and make sure the dentist has experience working with people living with dementia. Consider using social activities to encourage eating (e.g. having tea with friends, eating snacks with a movie, religious or spiritual observances involving food, baking).
Overeating A person with dementia may overeat if they forget they have already eaten, have a craving for certain foods or be hoarding food to eat later. Frontotemporal dementia, which affects the areas of the brain associated with personality, behaviour and emotions, may cause people to compulsively put things in their mouth, even inedible items.	 When possible, eat with the person to watch for overeating. 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. 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 fruit, vegetables, 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 intake to avoid becoming overweight, and if you can't, provide as much healthy food as possible (fruits, yogurt).

Possible changes	Helpful strategies to try
Decreased judgment A person with dementia may not recognize utensils on a table or food items on a plate. They may use a knife to pick up food instead of a fork, or put food on their fork and not know what do with it. They may try to drink from a plate rather than a cup.	 Cue the person with words or actions. The person might be able to mimic your motions for eating, such as putting food on a utensil and bringing it to their mouth. Use simple, step-by-step instructions. If necessary, place the utensil in the person's hand, put your hand over theirs and guide food to the mouth. They may be able to continue eating independently after a few tries. If they are obviously struggling with a task, be respectful and ask if they would like assistance, rather than making this assumption.
Concentration Eating can involve carrying out a series of complex skills, such as cutting up food, moving a utensil or hand towards 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.	 Limit distractions: Serve meals in a quiet place so that the person can focus on eating. Turn off the television, radio, telephone ringer and mobile notifications. Simplify the setting. Remove flowers, centrepieces and condiments. Use only the utensils needed for the meal. Serve the meal one course at a time. This prevents the person from getting overwhelmed. Try to keep the environment as calm and relaxing as possible. Try to be flexible. If the person does not want to be with other people while eating, don't force them to eat with others. If they want to stay in a different room where they are comfortable, allow this. It may be difficult for them to change routines. Use a tray as needed to help with clean up.
 Refusing food or spitting food out A person may refuse or spit out food if they: Have forgotten how to eat, chew or swallow Need help to eat Dislike the taste, texture or smell Don't know it's time to eat Are trying to tell you something, such as the food is too hot or cold, or they are not feeling well 	 Check the temperature of the food to ensure it is neither too hot nor too cold. Offer the person's favourite foods. If the person doesn't know what to do with food after it is chewed, remind them to swallow. 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.

Possible changes	Helpful strategies to try
Possible changes Visual and motor abilities A person's vision can change as their dementia progresses. So can their ability to understand where objects are in relation to each other. This may make it difficult to distinguish items on a plate, table or place setting. It can also affect movement and co-ordination.	 Provide a sharp colour contrast between the plate and the surface it is placed on. Avoid patterned dishes, tablecloths and placemats because they might confuse or distract. 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 utensils 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.
	 Offer the person only one utensil. Spoons with large handles, texture or colour are easier to identify and use. Cups and mugs with larger handles may be easier to use; ones with lids can prevent spilling. Avoid using sharp knives or fragile dishes. Ensure dishes are stable; use mats or even a wet cloth underneath to prevent slipping. Use a clothing protector or consider using a large napkin so that any mess can be taken away without too much distress for the person. Cut food carefully into bite-size pieces (about the size of a
	 quarter). Remove all bones, garnishes and non-edible items. Provide finger foods or everyday foods that are easy to pick up and be eaten with the hands. These foods help maintain independence. Some finger-food ideas are: cheese cubes, small sandwiches, small pieces of chicken, sliced fruits and vegetables, potato wedges, chicken strips and fish sticks. Fruit can be peeled if preferred, but the peel may make it easier to grip the fruit, especially if it's slippery.

Possible changes	Helpful strategies to try
Changes in behaviour	• Present only one food item at a time.
Pushing food away or refusing to eat may be caused by:	• Don't rush the meal. The person may start and stop eating many times.
 Type and progression of dementia Type and progression of dementia The environment Frustration because of changing abilities and memory changes Needing help to eat Inability to sit through an entire meal Side effects of medications Depression, delusions, hallucinations or delirium Pain or other conditions Changes in ability to communicate Inability to recognize a caregiver Being rushed An unsupportive routine or care approach 	 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 that medication, mental health or a physical issue may be causing a change in behaviour.

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

Late stage

In the late stage of dementia (also referred to as "severe" or "advanced"), people experience more cognitive and physical changes. Here are some of the changes that a person living with dementia may experience, and tips and strategies that could help:

Possible changes	Helpful strategies to try
A person living with late stage dementia may often lose their appetite, be unable to feed themselves and have difficulty swallowing, which	• Cook vegetables so they are soft to eat. Remove any hard pieces or skins.
	• Serve soft foods such as applesauce, pudding, yogurt, cottage cheese, gelatin, oatmeal and scrambled eggs.
can cause choking.	• Breakfast cereals soaked in milk will soften the texture.
	• Fresh fruit can be peeled and mashed. Canned fruit is often softer.
	• Focus on the person's quality of life rather than eating healthy. 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 easier for a person living with late stage dementia. Protein milkshakes, smoothies 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.

Learn more about the progression of dementia at <u>alzheimer.ca/stages</u>.

Dining out: Tips and strategies for people living with dementia and caregivers

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 a person living with dementia and their caregiver, both of whom can feel socially isolated if alone at home. Going out to eat allows a person with dementia to continue to be part of their community.

Dining out can be a positive change, but it can also present challenges. Planning ahead can help. Here are some tips:

- Going out earlier in the day may be best, to avoid becoming 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.
- Show (using a card) or tell service staff that you are living with dementia or are supporting a person living with dementia and may need extra support.
- Eat in places where the menu and staff are familiar and where servers understand your needs.
- If the menu is long and complex, narrow the choices for a person living with dementia. Menus with pictures can help with selections.
- Write down a list of favourite foods and drinks beforehand. This will help you remember preferences or you can show the server.
- Consider previewing the menu online and deciding what to eat before going to the restaurant. This will help you not feel rushed or pressured to make a decision.
- Ask the wait staff for a written copy of the specials instead of having them listed verbally.
- 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, or any other members of your group, use a walker or wheelchair.
- Consider the type of dining or type of restaurant and seating that might work best. (Is a buffet easy to walk around with a cane, walker or wheelchair? Would sitting in a booth be a problem for mobility?)
- Consider going to family restaurants or coffee shops; they are less formal and have more fingerfood items on the menu.
- When paying the bill, offer assistance if the person living 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.
- Some people living with dementia experience changes in their inhibitions and judgment and may act differently while eating a meal. Try to identify if a health condition, environmental factor or social situation might be causing changes in the person's behaviour. Learn more tips and strategies at alzheimer.ca/behaviour.

Alzheimer Society 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, telephone ringer and mobile notifications. 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 setting by removing centre pieces and condiments. Avoid patterned tablecloths, dishes 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! 1-855-705-4636 (INFO) alzheimer.ca

Dining out tips for caregivers

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

- Go out during non-peak times so the person living with dementia won't feel rushed.
- Dine at a restaurant with family washrooms if the person uses a walker or wheelchair.
- Request a table in a quiet corner to avoid noise and distractions.
- Show (using a card) or tell service staff that you are caring for someone living with dementia and need extra support.
- Ask for it in writing: Ask the server for a written copy of the specials instead of having them listed verbally.

1-855-705-4636 (INFO)

<u>alzheimer.ca</u>

Alzheimer Society

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 alzheimer.ca.

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Help and support from the Alzheimer Society

For information and support, visit <u>alzheimer.ca/find</u> to find your local Alzheimer Society.

Additional resources

Alzheimer Society of Canada. All about me. <u>alzheimer.ca/allaboutme</u> Alzheimer Society of Canada. Brain health. <u>alzheimer.ca/brainhealth</u> Alzheimer Society of Canada. Communication. <u>alzheimer.ca/communication</u> Alzheimer Society of Canada. Changes in behaviour. <u>alzheimer.ca/behaviour</u> Alzheimer Society of Canada. Conversations about decision-making. <u>alzheimer.ca/decisionmaking</u> Alzheimer Society of Canada. Meal time. <u>alzheimer.ca/mealtimes</u> Canadian Association of Occupational Therapists. Find an occupational therapist. <u>caot.ca/site/findot</u>

This resource is informed by research and the experiences of people living with dementia and their caregivers. We thank Dr. Heather Keller and her research team for their generous contribution to the development of this resource. To provide feedback on this factsheet, please email <u>publications@alzheimer.ca</u>.



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