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A BY US FOR US GUIDE

# Living Safely

An inspirational guide for people living  
with dementia and care partners

SERIES 2

# Introduction

The importance of safety is rooted in our everyday life: in driving, cooking, visiting places, etc. In situations involving heightened emotions, such as frustration or anxiety, safety becomes more important for people living with dementia. For example, you may feel upset about a negative comment you read online or stressed about the lack of respect from certain individuals. All of these negative encounters stimulate your emotions, fog your thinking and limit your attention to your personal safety or the safety of others around you. Sometimes you may also find yourself totally focused on completing a task that you neglect your own safety.

In this guide, the following safety concerns are explored: driving, living at home, keeping people living with dementia safe when alone, living in the community, personal identification, use of technology, health and medication, physical and financial safety. Practical strategies and resources are offered to assist you in enhancing your understanding of safety and opening up lines of communication with family and friends.

Even though safety is extremely important, it is critical to draw a distinction between safety and over-protection. For people living with dementia, be sure to communicate with your care partner your feelings and concerns. For care partners, recognize and appreciate the abilities of people living with dementia and avoid making decisions for them. Instead of working for people living with dementia, **work with** them and include them in all decision-making processes.

Lastly, remember, these safety tips are not meant to limit you, but to give you the freedom to enjoy life with some peace of mind.

– Faith Brender, Harry and Donna Gutoskie,  
Ron and Anne Hopewell, and Brenda Hounam  
By Us For Us Planning Committee

# Driving

It is often a misconception that once a person is diagnosed with dementia, they should no longer drive. In fact, the diagnosis has little to do with safety concerns.

The following safety concerns, however, were expressed by people living with dementia and their care partners:

- Visual and spatial problems, such as the ability to see or interpret traffic signals and signs.
- Getting lost.
- Slow reaction time.

Some people living with dementia voluntarily give up their license; others may be advised by their doctor to stop driving. In either case, this change may cause a sense of loss of independence in people living with dementia or stress for the care partner because of the added responsibility of being the only driver.

## Medical review process

In Ontario there is a medical review process put forth by the Registrar of Motor Vehicles, Ministry of Transportation for individuals age 16 or above whose driving ability may be impaired due to a medical or visual condition. It is important to understand this process. Refer to the Resources section at the end of this guide for a website with more information.

Since procedures and resources do vary depending on where you live, you should verify with the Department of Transportation in your area.

# Driving continued

## Adapting and coping, on or off the road

The progression of dementia will lead to changes in skills and abilities that may result in an increased safety risk when driving: safety of the person living with dementia and the safety of others. It is important to respect the opinions and decisions of medical professionals and care partners with regards to their concerns and responsibilities to obey the law and protect the safety of others. The Ministry of Transportation makes the rules about driving, not care partners or physicians. The following are suggestions to help adapt to and cope with changes in skills and ability with respect to driving.

### Suggestions for those who no longer have a valid license

- ✓ Arrange for someone to drive you to places (e.g., family members, friends, volunteer drivers, neighbours, etc.). This would be very important in rural communities.
- ✓ Use public transit, taxi services, or transportation for people living with disabilities (e.g., Mobility Plus).

**“Before I got into the vehicle, I would ask myself if this was a good day: Would I drive today if I had my grandchild in the car?”**

(Brenda Hounam, person living with dementia)

# Driving continued

## Suggestions for those who no longer have a valid license

- ✓ When using public transportation, take direct routes and minimize transfers.
- ✓ Avoid being a “back seat” driver - it can be a distraction to the person who is driving.

## Suggestions for current drivers

- ✓ Drive defensively.
- ✓ Avoid driving in unfamiliar places.
- ✓ Use a Global Positioning System and/or map out your route.
- ✓ Park at the end of a row to find your car more easily or make a note of where you parked.
- ✓ Brush up on driving skills with lessons offered by a certified driving school.
- ✓ Seek a 3<sup>rd</sup> party opinion regarding your driving abilities.

**“Driving is a privilege, not a right.”**

(Ron Hopewell, person living with dementia)

# Driving continued

## Suggestions for care partners

- ✓ Plan ahead and discuss when driving should stop.
- ✓ Use a positive approach when communicating driving safety with people living with dementia (e.g., let them know that it is not their fault that they are no longer able to drive; it is because of their changing abilities caused by dementia).
- ✓ If the person living with dementia is having difficulty with the idea of not driving, talking about the practical consequences may help with their adjustment (e.g., point out the financial cost if they were to have an accident or the personal cost if they were to injure someone).
- ✓ Involve people living with dementia when they are a passenger:
  - Be flexible and allow the person living with dementia to choose the route home.
  - Ask the person living with dementia to be the navigator and provide them with a map.
  - Allow them to fill the gas tank, if appropriate.

**“Remember, it is the disease that causes a license to be revoked, not the doctor or care partner.”**

(Harry Gutoskie, care partner)

# Safety at home

Many people living with dementia and care partners find that the need for closer supervision at home has increased as dementia progresses. For instance, people living with dementia may find it harder to be alone at home for longer periods of time, and may experience problems with balance resulting in difficulty walking or climbing stairs. It may be necessary to make modifications to the home to ensure everyone's safety. It is important for care partners to communicate with people living with dementia throughout the process and introduce modifications gradually - only modify what you need to, when you need to.

## Physical environment

Although home is usually a comfortable place to rest and relax, many areas can be falling hazards that are often overlooked, such as:

- Stairs.
- Uneven front walkway.
- Bathroom shower or bathtub.
- Loose rugs or mat.
- Change in position (e.g., sitting in or getting up from a chair).
- Obstacles or clutter.
- Flooring (e.g., moving from light to dark flooring may cause tunnel vision, or changes in elevation - tile to carpet may be a falling hazard).
- Low lighting in hallways or during night time.

# Safety at home continued

## Kitchen

Cooking can be a fire hazard affecting the safety of people living with dementia and their care partners. For example, a person living with dementia may forget to turn off the stove or other appliances.



For tips on kitchen safety, refer to the By Us For Us guide: **Food and Mealtime**.

## Adapting at home

The following modifications may not work for everyone, but they serve to demonstrate how small changes can dramatically increase home safety.

## Kitchen

- ✓ Use appliances with an automatic shut off function.
- ✓ Monitor appliance or tool use when necessary.

**“Reducing clutter – ‘what you keep to yourself you lose, what you give away you keep forever’.”**

(Anonymous, care partner)



# Safety at home continued

## Bathroom

- ✓ Use bath mats.
- ✓ Install grab bars beside the toilet and in showers.
- ✓ Install a raised toilet seat for getting up and down easier.
- ✓ Remove bathroom door locks, or have a bobby pin ready for unlocking the door in case of an emergency.
- ✓ Remove electric appliances (e.g., hair dryer, curling iron) on the bathroom counters or near the bathtubs.

## Living room

- ✓ Use blocks or platforms as raisers for chairs or sofa.
- ✓ Reduce clutter (e.g., use smaller furniture in high-traffic areas).
- ✓ Consider making more space to move around (e.g., re-arrange furniture).

## Outside

- ✓ Seek help with lawn maintenance and snow removal.
- ✓ Use manual (push) rather than gas or electric lawn mower.
- ✓ Keep walkways clear.

# Safety at home continued

## Stairs

- ✓ Use different coloured strips of tape on stairs to identify where a step ends.
- ✓ Have sufficient lighting (e.g., install nightlights throughout the house or LED lights on stairs with automatic light sensors).
- ✓ Professionally install gates at the top of stairs.
- ✓ Stair lifts may be a reasonable adaptation in some situations.

## General

- ✓ Contact your local health team to arrange a home safety assessment or an occupational therapist.
- ✓ Use signage or cues in the bathroom or kitchen (e.g., hot and cold taps, turn off the stove, etc.).
- ✓ Use calendars, reminders, written lists, and note pads at visible location (e.g., on the fridge).
- ✓ Have a flashlight handy or an emergency flashlight/nightlight that plugs in to the wall.
- ✓ If stairs are challenging, consider moving your bedroom to a main floor room or area.
- ✓ Have a care partner's phone number on speed dial.
- ✓ Check the fire alarm, smoke detector and carbon monoxide detector twice a year, when daylight savings time starts/ends.

# Safety at home continued

- ✓ Ask someone to do home repairs (e.g., fix loose rugs).
- ✓ Remove mats on carpet.
- ✓ Lower the temperature of the water heater, if possible.
- ✓ Install hand rails on both sides of stairways and front entrance.
- ✓ Avoid stocking feet at home; wear non-slip slippers, shoes or even go barefoot.
- ✓ Watch out for loose cords or extension cords.
- ✓ Watch out for slippery ground.
- ✓ Review 911 procedures and put 911 sticker(s) on the phone and refrigerator.
- ✓ Store all hazardous chemicals safely.
- ✓ Use home monitoring (e.g., ADT).
- ✓ Install a home security system/motion detector if night-waking is a safety concern.

**“My brain has become my Achilles Heel, but I have to make the best of it when I’m out there.”**

(Anonymous, person living with dementia)

# Safety in the community

A diagnosis of dementia should not automatically stop people living with dementia from being in and enjoying their community. They can still enjoy many hobbies, such as shopping, travelling, going for a walk, and so on. To support continued involvement in the community, develop strategies before leaving your home and adapt these strategies as needed. The Alzheimer Society of Ontario's **Finding Your Way** program offers practical tips to stay safe while staying active (refer to the Resources section for more information).

## Shopping trips

Busy, noisy and crowded stores can over-stimulate people living with dementia. Visual safety hazards, such as overly bright or dim lighting, change in floor colours, uneven ground, and change of height on a walkway may increase the risk of tripping and falling. People living with dementia may also find it difficult to navigate in an older building because it is often not accessible to wheelchairs or may have poor hand railings, stairs are not marked with reflective tape, and music can be disorienting. Consider the following strategies to make your shopping trip safer.

- ✓ Plan out your trip, shopping time, and stores you will visit.
- ✓ Plan your route making use of accessible intersections (e.g., curb cuts), crosswalk islands or using intersections where there is a crossing assistant (e.g., crossing guard).
- ✓ Use family washrooms whenever possible and where appropriate.

# Safety in the community continued

- ✓ Use a Velcro strap to loop all bags together to avoid forgetting anything in the store or on the bus.
- ✓ Keep your wallet in the same area of your purse.
- ✓ Do not take your wallet out of your purse and only open it enough to take out money or card(s); this will minimize the risk for theft.



For more tips and strategies when grocery shopping, refer to the By Us For Us guide: **Food and Mealtime**.

## Physical safety

Extra emphasis should be placed on physical safety because this is where harm and injuries are most likely to occur. Staying well-rested is critical for preventing bodily harm because being tired affects a person's concentration and the person may overlook some safety issues. Likewise, anxiety, frustration and over-stimulation affect concentration and can distract people living with dementia from paying attention to safety concerns. To remind yourself of the importance of being well-rested, consider putting a sign on the exit door or at a visible place by the door that says "Are you too tired today to safely engage in the community?" Knowing your own mental or emotional state helps you decide whether you should go out or not that day.

# Safety in the community continued

Suggestions for staying safe:

- ✓ Wear a helmet when cycling.
- ✓ Walk in familiar and safe areas.
- ✓ Use crosswalks.

## Weather-related issues

People living with dementia may not be as aware of the external environment and as a result may dress inappropriately for the current temperature. Addressing issues such as the weather (e.g., rainy weather makes the ground slippery), temperature and seasonal concerns (e.g., heat in the summer, icy roads in the winter) is critical for safety and enjoyment in the community. Consider the following tips when dealing with weather related issues.

- ✓ Dress appropriately for the weather.
- ✓ Apply sunscreen and bug spray in the summer.
- ✓ Always use railings on stairs when available.
- ✓ Call your city about snow removal or icy roads.
- ✓ Use grippers on boots or cane.

# Safety in the community continued

## Loud, busy environment

A loud, busy environment, for example, shopping during the holidays, affects concentration and makes it more difficult to think clearly and make decisions. The following are strategies to help avoid or manage loud, busy environments.

- ✓ Choose less busy times and stores to shop.
- ✓ Ask for directions or help.
- ✓ Pay attention to non-verbal cues and listen to your own body as to when you have had enough.
- ✓ Avoid pushing limits - go home when things start to become overwhelming.
- ✓ Make a shopping list.
- ✓ Shop with company.
- ✓ Wear ear plugs, when appropriate, and when safety is not a concern (e.g., do not wear ear plugs when walking through a parking lot).
- ✓ Take frequent breaks.
- ✓ Invite people to your own home instead of going out.
- ✓ If shopping, bring clothes home from the store to try on or shop online.

# Safety in the community continued

## Travel

It is possible for people living with dementia and their care partners to continue travelling, with pre-planning. Pre-planning can help adjust to the changing needs of the person living with dementia and alleviate frustration. The following are strategies to consider when travelling.

## Road trip

- ✓ Get an accessible parking permit through Ministry of Transportation (a doctor's signature is required).
- ✓ Travel with another couple who also has an understanding of living with dementia. This can be very useful for washroom visits.
- ✓ Allow lots of time for frequent rest stops.
- ✓ Use a calendar and day planner to help stay on track.
- ✓ Keep to a routine.
- ✓ Give your travelling companions space and time to be on their own.
- ✓ New bathrooms may be a problem. Use a family washroom or wait outside the washroom door in case your assistance is needed.
- ✓ Stay hydrated; drink lots of water.



# Safety in the community continued

- ✓ Alert staff at the resort or destination to special circumstances.
- ✓ Allow plenty of time for orientation to new surroundings.
- ✓ Avoid planning too many activities for one day.
- ✓ Make cards with the hotel name, address and room number.
- ✓ Have proper ID in your wallet.

## Airport travel

Customs can create problems because people living with dementia may get separated from their care partners. The following are tips for air travel.

- ✓ Inform the airline of special circumstances.
- ✓ Stay close to the people you are travelling with.
- ✓ Get in the same Customs line as your care partners.
- ✓ Carry companion card and copy of your Power of Attorney (POA) and ask to go through Customs together with a care partner.
  - If you cannot go through Customs with your care partner, go through the Customs line first.
  - If you are travelling with two care partners, go through Customs in between your care partners.

# Safety in the community continued

- ✓ Keep a list in your purse or wallet of medications, Power of Attorney and any other medical problems you may have.
- ✓ Stay calm if you get separated from your group and ask airport staff for assistance.

## Personal identification and use of technology

Computers and technology have become an important part of our society. For people living with dementia, who may have fewer opportunities to socialize (e.g., live in a rural community), computers can be a way to connect with others (e.g., through chat rooms). Touch screen technology has made using a computer easier, eliminating the challenge presented by having to use a mouse. Although computers may frustrate some, they are very useful to exercise the brain and memory by playing computer games.

**“The important thing to remember is: don’t be afraid to travel, particularly if you have someone to travel with and is able to provide support.”**

(Anne Hopewell, care partner)

# Safety in the community continued

The following strategies may not be relevant for everyone, but may serve as topics for open dialogue for families as dementia progresses.

- ✓ Consider establishing an agreement with your care partner that neither you nor your partner will share personal information online without letting the other person know.
- ✓ Place a sign by the computer and/or phone as a reminder to never give out personal information.
- ✓ Make arrangements to block anonymous callers to avoid “scam” calls.
- ✓ Consider screening your phone calls to minimize the likelihood of speaking with a telemarketer, or let your calls go to the answering machine.
- ✓ Consider using caller ID so that you can identify familiar people calling.
- ✓ Register your phone number on the National Do Not Call List (refer to the Resources section for more information).



To learn more ways to exercise your brain, refer to the By Us For Us guide: **Memory Workout**.

# Health and medication

It is important for families to establish a plan in case of an emergency, the care partner gets sick or is taken to hospital, and the person living with dementia who is left at home will need support. Consider creating a 3-3-3-3 emergency plan. Decide whom you can rely on to be a first responder (within the first 3 minutes of an emergency); within the first 3 hours of an emergency to replace the first responder; if the situation lasts more than 3 days, or for a longer period (e.g., 3 weeks or more). Also consider different care options for the person living with dementia in case they cannot be supported at home.

With respect to medication, people living with dementia may want or need support early on with such things as organizing medication, dispensing medication, and reminders to take their medication. There are many effective ways to manage your medication safely.

- ✓ Use blister packs.
- ✓ Observe the compliance label on packaging.
- ✓ Keep pills in the same place, such as the dining area, ensuring they are out of reach of children.
- ✓ Put a list of medications on the fridge.

It is important to consult your pharmacist about your diagnosis and the medication you are taking, as dementia medication can cause problems with existing medical conditions. Current medications can also affect your dementia. Always seek the advice of your pharmacist.

# Health and medication continued

Care partners are encouraged to observe any problems with taking medications (e.g., missing doses) and become knowledgeable about your partner's medications. If problems arise, the care partner may need to offer more support.

Along with effective medication management, regular physical check-ups are also important to monitor the progress of dementia and other general medical issues. See your doctor at least once a year. Schedule your annual physical during your birth month to make it easier to remember.

## Change in medication

Any changes in medication can increase risks for safety. Side effects may be minimal and are different from person to person, so it's important to be observant in the first couple of weeks when your medication is adjusted. Below are some points to keep in mind with regards to change in medication.

- ✓ Watch for any side effects, like changes in symptoms or mood, visual changes, balance/stability, light-headedness, etc.
- ✓ Update the changes in your medication on a medication card, fridge list, MedicAlert, etc.
- ✓ Maintain your routines to allow the medication to work into your day-to-day life.
- ✓ Wait a few days for medication to stabilize in your body before taking long journeys.

# Health and medication continued

- ✓ Avoid going out when you are drowsy or unable to concentrate.
- ✓ Consider how your existing medical conditions affect safety as well –ability to concentrate or see and hear clearly, etc.
- ✓ Visit the doctor if something is out of the ordinary - not all new medical issues are related to dementia.

## Timing

Knowing and remembering when to take medications may not be easy for some people living with dementia, especially if medications are to be taken at odd times or with or without food. Consider the following tips for taking medications.

- ✓ If appropriate, consider using a medication dispensing service (e.g., Philips Lifeline Medication Dispensing Service).
- ✓ Follow all instructions from your pharmacist or doctor.
- ✓ Take your medications as prescribed.
- ✓ If medications are to be taken at odd times, establish a routine for taking them.

**“We need to be honest with each other and our partners.”**

(Anonymous, person living with dementia)

# Health and medication continued

- ✓ Take your medication as soon as you receive a medication reminder or you may risk forgetting.
- ✓ Use a scheduler on your phone or computer and consider adding reminders there.

## Working with the same pharmacist

Building a relationship with a pharmacist by consistently going to the same one is helpful to manage medications. For instance, you may be able to request the pharmacist you are working with to “red-flag” any medication concerns. Here are some tips in working with the same pharmacist.

- ✓ Be your own advocate.
- ✓ Choose a pharmacy that has all your records.
- ✓ Pharmacists can and will do consultation.
- ✓ Ask your pharmacist before you take any over-the-counter medications, including vitamins.
- ✓ Let your pharmacist know what over-the-counter supplements you are taking - some ingredients in supplements may not be suitable for you.

**“Glasses are a part of you, just like the disease –  
you deal with it.”**

(Anonymous, person living with dementia)

# Health and medication continued

- ✓ Make a list of medications and print it on a small card to be carried in your wallet or purse at all times.
  - Include any vitamins or other supplements.
  - Keep the list updated.

## Medication for related or other health conditions

If you are experiencing any side effects from a drug you are currently taking, your doctor may prescribe additional drugs to treat these side effects. This is known as “prescription cascade” and it occurs more commonly in people taking multiple medications for existing health conditions. In this case, be aware of the drugs you are taking and any side effects, and work with your doctor and pharmacist to optimize your medications. Here are more tips for handling medications for other health conditions.

- ✓ Double check what your pharmacist gives you when you are on multiple medications.
- ✓ Avoid recognizing drugs by size, shape or color - always check labels.
- ✓ Be aware that generic medications may look different by brand.
- ✓ Consider using blister packs if a dossette is confusing.
- ✓ Store different types of medications separately (e.g., flu medications, pain medications, cough medications, etc.).



# Health and medication continued

## Doctor's visit

People living with dementia may not express their thoughts clearly to their doctors, affecting their medical management. Here are some strategies for doctor's visits.

- ✓ Have someone accompany you to your doctor's visit.
- ✓ Let the doctor know if you are willing to have your care partner join you for the appointment.
- ✓ Prepare notes, such as a list of concerns and questions, ahead of time to discuss with the doctor.
- ✓ Have a list of medications to share with your doctor, including vitamins and other supplements.
- ✓ Learn the meaning of commonly used medical vocabulary to accurately describe symptoms.

# Supporting safety and dignity

Respecting the dignity of people living with dementia is equally important in establishing safety measures and minimizing risks. At any stage of the journey, remember to respect the capabilities of people living with dementia in making decisions, and avoid excessive protection that often disables and devalues people living with dementia. Below are some suggestions to support people living with dementia in living well and safely.

## Suggestions for people living with dementia

- ✓ Establish a routine with your care partners early on – trust grows and evolves.
- ✓ Find out what other people living with dementia are doing and learn from them.
- ✓ Participate in peer support discussion.

## Suggestions for care partners

- ✓ Create a system TOGETHER with people living with dementia - something that works for them.
- ✓ Keep people living with dementia updated on all changes.
- ✓ Be aware that how we communicate matters - use positive language (e.g., “Let’s do this together”).



For more tips on communication, refer to a By Us For Guide: **Enhancing Communication.**

# Staying alone at home (short term or long term)

There may be times when people living with dementia stay alone at home for as short as a couple of hours or for a longer period, such as several days or perhaps a week. Whatever the reason, it is important to develop a personal checklist of requirements and/or practices when home alone and implement these practices as a routine. **For care partners, it is important to keep in mind, these practices are meant to enable independence rather than over-protect people living with dementia for the goal of safety.** Remember, you are **working with** people living with dementia and **not for** them. For that reason, maintaining open communication with people living with dementia is essential. Below are some practices to help people living with dementia stay safe while alone.

- ✓ Write down the care partner's information on a whiteboard or in an established location (e.g., where they are, telephone number, when they will return).
- ✓ Have someone check-in in the morning and at night for medication reminders and make sure things are fine.
- ✓ Find out if there are any local "check-in" services available in your region.
- ✓ Consider having someone visit or phone you depending on necessity.
- ✓ Have enough convenient or microwaveable food, or arrange food delivery.
- ✓ Communicate your normal routine with your family members so that they don't check-in when you are away.

# Staying alone at home (short term or long term) continued

- ✓ Set up speed dial if necessary or make a list of contacts for any emergency situations.
- ✓ Have emergency systems in place if necessary (e.g., 3-3-3 plan as described in the Health and Medication section above).
- ✓ Let your neighbours know if you are going to be away from home for a longer period of time than normal.
- ✓ Consider establishing a sign or signal that will let your neighbours know if you need help, such as flashing a light or opening and closing curtains or blinds.
- ✓ Consider the value of Lifeline or other home monitoring services.

**“I can’t give up.”**

(Anonymous, person living with dementia)

# Financial safety

Finding ways to maintain independence safely in financial matters is critical because the ability to manage your own finances gives people living with dementia a sense of control. Below are some strategies to manage finances safely.

- ✓ Be aware of phone or internet scams – “if something is too good to be true, it probably is!”
  - Never give out any personal or financial information over email - financial institutions will never request personal information via the web.
  - When banking or shopping online, make sure the webpage is secure. Look into applications or software for added online security.
- ✓ Be extra cautious in answering the door for salespeople.
- ✓ Talk to a trusted person if you are not certain.
- ✓ Talk to a lawyer and get them to fully explain to you how having a Power of Attorney works.
- ✓ Limit maximum daily spending amount and reduce maximum credit available on your credit cards.
- ✓ Use preloaded store cards for popular stores or preloaded debit and credit cards, with a small amount of money for payment.
- ✓ Use small bills when purchasing inexpensive items.
- ✓ Carry just enough cash when going out.

# Financial safety continued

- ✓ Use cues to help you remember passwords and PIN numbers on debit and credit cards – do not carry the password or PIN number in your wallet. Alternately, speak with your bank or financial institution about safety features for debit/credit cards.
  - No pin necessary for smaller purchases – just tap your card.
- ✓ Set up automatic bill payments from your bank account to avoid missing payments or late fees.
- ✓ Be aware of elder abuse, especially family or friends taking advantage of people living with dementia.
- ✓ Let your family members know where you are spending your money, even if it's for family members or friends.
- ✓ If you are thinking of getting a companion credit card, ensure it is being used by someone you trust and multiple people are aware of the account activity.



For more information on financial and legal issues, refer to the By Us For Us guide: **Before/Early Diagnosis.**

# Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the By Us For Us (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.

## Resources

### **Alzheimer Society of Canada**

Toll-free telephone: 1-800-616-8816

Email: [info@alzheimer.ca](mailto:info@alzheimer.ca)

Website: [www.alzheimer.ca](http://www.alzheimer.ca)

### **Elder Abuse Prevention Ontario**

Providing public education and training of professionals/service providers and families of seniors, to raise awareness around elder abuse issues.

Website: [www.onpea.org](http://www.onpea.org)

### **Finding your Way**

A program that offers practical tips for people living with dementia to stay safe while staying active.

Website: [www.findingyourwayontario.ca](http://www.findingyourwayontario.ca)

### **Government of Canada Get Prepared**

A campaign that encourages Canadians to be prepared to cope on their own for at least the first 72 hours of an emergency.

Website: [www.getprepared.gc.ca](http://www.getprepared.gc.ca)

### **Ministry of Transportation**

Refer to the Medical Review Process.

Website: [www.mto.gov.on.ca](http://www.mto.gov.on.ca)

### **National Do Not Call List**

Website: <https://lnnte-dncl.gc.ca>

Telephone: 1-866-580-DNCL (3625)

### **Project Lifesaver**

Provides law enforcement, fire/rescue, and caregivers with a program designed to protect, and when necessary, quickly locate individuals who have gone missing.

Website: [www.projectlifesaver.org](http://www.projectlifesaver.org)

### **World Health Organization**

Website: [www.who.int](http://www.who.int)

We also suggest that you check for other local, national and international resources.



## Endorsements

The focus of this “By Us For Us” guide offers some helpful and simple strategies to consider to promote safety. Safety is not something that can be simply defined and this guide covers a commendable breadth of areas from driving, to home safety, to internet use and financial areas, all of which are important to managing life. When we think of safety for people with dementia, a first approach might be more over-protective than is necessary. This guide provides a nice balance of suggesting strategies to consider while ensuring that people are given the opportunity to take risks and engage in activities that they enjoy and offer them meaning. The guide offers a good starting point for thinking about safety and suggests resources and supports when more complex safety issues arise.

**Lori Letts**, PhD, OT Reg. (Ont.)

Occupational Therapist Assistant Dean, Occupational Therapy Program, & Associate Professor

School of Rehabilitation Science, McMaster University

One of the most important things for all of us is to ‘feel safe’. We know that dementia can cause a number of changes in the brain and body that may affect a person’s safety. It is important for a person with dementia and their partners in care to take steps to improve their safety. The information and practical tips in this “By Us For Us” guide will hopefully prevent injuries and help all people feel more relaxed, less overwhelmed. The best living environment for a person with dementia is one that helps them to be as happy and independent as possible. This “By Us For Us” guide will be a wonderful help for people with dementia and their partners in care.

**Cathy Conway**

Director of Quality Management & Education

Alzheimer Society of Ontario

# Acknowledgements

**Creator of By Us For Us Project:** Brenda Hounam

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# About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

## **People Living with Dementia: Series 1**

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

## **Partnership: Series 2**

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

## **Care Partner: Series 3**

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

**To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:**

**[www.the-ria.ca](http://www.the-ria.ca)**

## **We welcome your input...**

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

# Connect with us!

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