



A BY US FOR US GUIDE

Before/Early Diagnosis

An inspirational guide for care partners
of people living with dementia

SERIES 3

Introduction

This By Us For Us (BUFU) guide is the first in a series of helpful resources written BY and FOR care partners of those living with dementia. Care partners are non-paid family members, friends, or volunteer companions who provide some aspect of care or support to persons living with dementia. The care partner series is based on the original series written BY and FOR people living with dementia. This new series is a collaboration of care partners, many of whom were interviewed and several more who were involved in the research, development, and editing process. Please refer to the back of this guide for a complete list of topics in this series.

This guide will provide help and reassurance for those who are concerned about possible changes associated with dementia and provides knowledge about the diagnosis, assessment and testing process. The information reflects the experiences of care partners. It also provides some suggestions on important activities that are best started early, but could still be relevant at any stage in the process.

As you make your way through this guide you will encounter some issues that have been faced by care partners, with whom we talked, throughout the diagnosis process. The voice of care partners is presented as a quote. Also present in each section is a list of “strategies to consider” and finally “my personal commitment”, which offers ways to be proactive in your role as a care partner. We recognize that each experience will be different; you need to adapt these strategies to your own situation.

Introduction continued

Becoming a care partner may feel overwhelming. This may be a major change in your life. Your role will evolve into one as a care provider and care manager. It may be up to you to set things in motion, by being proactive, making plans, providing support, becoming a life learner, etc. We hope that this series will provide some support for you in your role.

– Emma, Kim, Ken, Jack, Meredith, Ann Marie and Lisa
By Us For Us Care Partner Committee

Warning signs and changes

Dementia is a progressive decline in cognitive function due to damage or disease in the brain beyond what might be expected from normal aging. Alzheimer's disease is the most common form of dementia. Often people do not recognize the warning signs in themselves or others. This could be as a result of many things:

- Other possible illnesses;
- Denial or adaptation to cognitive changes;
- Changes being covered-up by the person living with dementia and/or the care partner;
- Other life changes, such as retirement and/or the death of a loved one;
- Long distance care being provided; and/or
- Lack of knowledge of the warning signs.

If you are noticing changes that are out of the ordinary for your partner (for example, difficulty performing familiar tasks, changes in mood, abstract thinking, and/or personality), or there is a history of dementia in the family, pay attention and take note of these changes. For a complete list of the 10 warning signs and also changes that are a part of normal aging, visit the Alzheimer Society of Canada website (www.alzheimer.ca), or your local Alzheimer Society. If you are noticing two or more of the warning signs it is imperative that you see a doctor for proper assessment and treatment.

Warning signs and changes continued

The Alzheimer Society is a good source of information even before a formal diagnosis is made. They can support you and help you get answers to your questions. They also offer education programs, a library of information, and online resources.

Often care partners find that they have more questions than answers when they first become aware of responses or actions that are out of the ordinary for their partner. In addition, care partners often think they should have seen the signs sooner. Keep in mind – you don't know what you don't know! It's important that you are now taking the next steps to getting help for your partner.

“In hindsight I believe I had noticed subtle changes for a few years.”

(Care partner)

Get involved

Education and learning

When searching for a diagnosis or if a diagnosis has already been made, get involved by taking an active part in the process. Learning about resources, support services, tests and treatments can be helpful. Finding resources you need may be challenging, especially if your efforts are met with resistance. When changes occur, it is often you, the care partner, who may have important information about the events that are occurring. There may be difficulties along the way, such as your doctor not addressing your concerns, or the person living with dementia denying or not recognizing the changes. Stress can be greatly reduced when we understand more about dementia, the treatment and how to deal with the changes.

Strategies to consider

- ✓ Visit your local Alzheimer Society and use the internet to gain information about: dementia, the diagnosis process, cognitive testing tools (such as the Clock Drawing test, Mini Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA)) and medication options.
- ✓ Understand the different terms related to dementia – Alzheimer's disease, Vascular dementia, Frontotemporal dementia, Lewy Body dementia, mild cognitive impairment, etc.

Get involved continued

Strategies to consider

- ✓ Talk to others who are dealing with similar issues.
- ✓ Find out about dementia specialists in your community (geriatricians, neurologists, family physicians with specialty training) and where to access them (psychogeriatric clinics, primary care memory clinics).
- ✓ Talk to your family doctor and pharmacist.



My personal commitment

I will educate myself by searching for information about the symptoms that my partner is experiencing, the support services available, and seek professional advice.

“After researching I began to think that perhaps he had Alzheimer’s because it kept popping up during my research. At this stage I was okay with the information off the internet and I went to the Alzheimer’s Society to pick up some brochures.”

(Care partner)

Diagnosis

There can be many roadblocks to getting a diagnosis. For example, people age 55 or under may be seen as too young to be experiencing dementia, or the subtle changes in your partner are not taken seriously by medical professionals. Dementia can be a difficult diagnosis to make; the symptoms can develop very gradually and can mimic many other conditions. Some doctors may not have the specific experience or training to recognize the early symptoms of dementia. Dementia has its own language and jargon.

Not understanding the language and jargon of dementia can be a barrier when discussing with professionals. Your partner with dementia may not be aware of the changes they are experiencing. They may resist seeing a doctor due to a fear of job loss, how family and friends will react, and the impact it could have on their life.

Sometimes, a diagnosis happens because of a crisis situation. This is dangerous because there is likely no emergency plan in place. Getting a diagnosis can take months to years, due to:

- a person's age;
- challenges of the medical system;
- limited availability of specialists depending on where you live;
- the progression of dementia; or
- complications from other illnesses.

Therefore, it is important to start the process as quickly as possible. Benefits of early diagnosis include access to appropriate medications for symptom management, and in some cases potentially delaying the progression of dementia.

Diagnosis continued

Strategies to consider

- ✓ Be active in seeking a diagnosis – **sooner is better.**
- ✓ Keep a list of changes to present to your doctor and specialist.
- ✓ Obtain permission (Power of Attorney for Personal Care) to discuss your partner's medical issues with their doctor.
- ✓ Attend doctors' appointments with the person experiencing symptoms and also on your own.
- ✓ Ask your doctor to make a referral to a specialist or memory clinic.
- ✓ You have the right to insist on a second opinion.
- ✓ If you don't understand medical language, ask your doctor or specialist for clarification – take nothing for granted.
- ✓ Be assertive with your medical team – if this is not your nature, bring or include a family member or friend who can help you express your concerns.
- ✓ Be sensitive to what the person experiencing changes might be feeling. Explain your concerns in a sensitive way.

Diagnosis continued



My personal commitment

Even though getting a diagnosis of dementia can be a challenging process, I will be proactive and seek medical attention as soon as possible. Early diagnosis will lead us to the best possible resources, treatment and support so we can deal with the dementia in a responsible way. This will help us to live life with dementia to the best of our abilities.

Notes

“When we initially met with my husband’s [doctor] to discuss [Alzheimer’s disease], she suggested that the 10 question[s], which he couldn’t answer satisfactorily, were NOT conclusive and she also suggested that she thought he wasn’t an [Alzheimer’s disease] candidate. But she did forward his name to the Memory Clinic at a hospital in Halifax, NS, where he was diagnosed just before Christmas 2009.”

(Care partner)

Diagnosis continued

Assessment and testing

Assessment and testing for dementia may be frightening or overwhelming when you do not know what to expect. The process will include a visit to your family doctor to present your concerns, some initial diagnostic testing such as blood work, discussion of personal and family medical history and current medications. Also, there may be cognitive testing (Clock Drawing test, Mini Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA), and possible imaging such as Computerized Tomography (CT) scans. Your partner may be referred to a specialist, such as a Geriatrician, or a memory clinic. Ultimately, assessment and testing are a process of elimination where physicians try to rule out other possible causes of the symptoms presented. These could include other medical conditions such as delirium, depression, metabolic causes, stroke (note: a stroke can sometimes lead to Vascular dementia), drug interactions, and other conditions. As a result, the assessment and testing process may be lengthy; however, it does vary widely. The diagnosis is dependent on symptom presentation and the results of cognitive testing, laboratory and imaging tests.

Diagnosis continued

The time leading up to diagnosis may bring additional frustration, stress, conflict or confusion. The testing process may provide the first opportunity to openly discuss the possibility of a dementia diagnosis. You may find that your doctor and family members don't share your concern about the changes you are witnessing, and therefore don't feel that testing for dementia is necessary. Initially, depending on your experience, you may feel little urgency to put your partner through the extensive testing process. Taking a "we'll do it later" approach may prevent a baseline from being established and delay treatment. However, waiting to get tested may not be a choice but a necessity due to long waiting lists for specialists and testing because dementia is on the increase. Testing and comprehensive evaluation leads to diagnosis and treatment, enabling greater control in your life by providing choices based on knowledge and understanding and opportunities to plan ahead.

Strategies to consider

- ✓ If your partner is experiencing any of the 10 warning signs be persistent with your requests for testing, even if they are met with resistance.
- ✓ Develop a plan while waiting for the appointment with the specialist or memory clinic. All of us, including the person who is experiencing symptoms, will benefit from keeping intellectually stimulated, eating a nutritious diet, exercising regularly and keeping active socially.

Diagnosis continued

Strategies to consider

- ✓ Be prepared with questions to ask the doctor and specialist before testing and at the time of diagnosis (see questions at the end of this section).
- ✓ Ask the doctor and specialist how to prepare for testing day. For example, bring in all medications (including herbal, eye drops, inhalers, and non- prescription medications), and assistive devices (including eyeglasses, contact lenses, hearing aids, canes, walkers).
- ✓ If you are unsure, ask the doctor to explain the tests that the person experiencing symptoms will undergo, what is involved, preparations for the tests, how long the tests take, and what the results mean.
- ✓ If after a diagnosis the person living with dementia experiences new changes, seek further assessment and testing.



My personal commitment

I will ask my doctor to make a referral in order to get the tests my partner needs – we will remain active and engaged until that time and will take measures to ensure that we are prepared for testing day. I will ask questions if I feel like I don't understand the testing process.

Diagnosis continued

The following are questions, developed by care partners, to help when discussing diagnosis with your doctor and specialist. The Alzheimer Society of Canada has also published list of questions.

Questions to ask the doctor or specialist before testing

- What is involved in the process of making a diagnosis of dementia?
- What tests do we need to have done and where will they take place?
- What other disease(s) are you trying to eliminate in the testing process?
- What else could these symptoms signify?

Questions to ask the doctor or specialist upon diagnosis

- Can you explain this diagnosis to us please?
- What do we do now?
- What does this mean to me as a care partner? What does it mean to my partner who has been diagnosed?
- What can we expect?
- What medications or treatments are available?
- What resources are available to help us?
- What is the follow-up process?

Diagnosis continued

Notes

“I found a new doctor and he ran the mini-mental test on my partner and then referred him to a geriatric doctor. My partner was then given some more tests by the specialist and he said that he was 99% sure my partner had Alzheimer’s. The geriatrician then prescribed Exelon.”

(Care partner)

Medication

Although medication is important to manage symptoms, it can also be an area of concern throughout the progression of the dementia. Once you have been diagnosed and medication has been prescribed, it is important to know and understand intended effects and possible side effects. The side effects of medication can also create adherence issues – if medication causes side effects, the person with dementia may not take the medication. Medication can also create safety concerns for reasons such as mistakes in proper dosage and timing of taking medications. For as long as you can, allow the person with dementia to keep control of taking their meds. However, there will come a time when the care partner needs to monitor and eventually assume responsibility for ensuring the person living with dementia is taking their medication properly.

Strategies to consider

- ✓ Keep a medication journal to record effects of the medication. Use this for ongoing discussion with health care professionals.
- ✓ Make a list (map) of when the person with dementia needs to take medication (part of an emergency plan) and keep the list updated.
- ✓ Use pill organizers, such as dosettes and blister packs.
- ✓ Have one person responsible for the medication.
- ✓ Speak to a pharmacist about any questions you have concerning medications and possible drug interactions (try to go to the same pharmacist).

Medication continued



My personal commitment

Medication will be a part of our lives due to the diagnosis of dementia. I will become knowledgeable about medications and their administration, respecting my partner's independence using medication for as long as possible then I will be responsible for safely administering medication.

Notes

“My mother complied with some of the treatment but discontinued meds for dementia shortly after starting treatment as she claims it made her feel funny the way it had when she had tried this medication several years earlier (she had never actually taken the meds before, but could not be convinced otherwise).”

(Care partner)

Safety

Changes in personality, memory, communication, vision and judgement that occur with dementia can result in safety and well-being worries for those living with dementia and their care partner. Everyday tasks such as driving, cooking, bathing, managing medications and finances can become challenging, and issues related to physical and emotional safety can arise. Persons with the disease may not be aware that some of their actions may be risky or unsafe and they may be resistant to changing their activities to prevent dangerous situations. Driving is a good example. Be prepared to cope with the loss of a driver's license. Care partners need to identify risks and adapt in order to continue to provide a safe and supportive environment that encourages independence, social interaction and meaningful activities.

Strategies to consider

- ✓ Seek advice from an Occupational Therapist to assess safety in the home.
- ✓ Provide resources to support a person with dementia so that they can maintain independence. Register for the MedicAlert Safely Home® program through the Alzheimer Society of Canada (www.safelyhome.ca).
- ✓ Talk to your doctor about the regulations around driving and dementia.
- ✓ Create a plan for changes that will occur as your partner's dementia progresses over the months and years to come.

Safety continued

Strategies to consider

- ✓ Restrict unaccompanied travel to unfamiliar settings; familiar environments contribute to comfort and security.
- ✓ Talk to your partner with dementia about their needs and concerns



My personal commitment

I will identify potential risks, prepare for future changes and develop a plan to ensure that I am equipped to maintain safety and well-being for my partner. I will make sure that I let others know of potential issues so they can assist me in providing an environment where my partner with dementia can remain safe and supported. I will always respect the independence and dignity of my partner with dementia when making changes and include them in decision making.



For more tips on staying safe in the community refer to the By Us For Us guide: **Safety When Out and About** and **Living Safely**.

“If I am injured or hurt in any way that I can’t use the phone – is a constant dread of mine. That problem I am still working on.”

(Care partner)

Communication

Communication is a vital element of how our relationships develop. For the care partner, several types of verbal communication are worthy of attention. One is with the person living with dementia; a second is how we talk to ourselves. Refer to the By Us For Us guide “Enhancing Communication”, written by persons living with dementia. It is a great way to learn about communication from the perspective of people living with dementia!

Unfortunately for many care partners, the words “I should” or “I should have” creep into our daily language, with expectations of doing more or doing better. Such self-talk can have the effect of increasing the level of guilt that is felt by the care partner. Typically, unrealistic expectations reduce one’s ability to provide adequate care; therefore, it is not unusual that the result is a decrease in the overall quality of life for the person living with dementia.

Strategies to consider

- ✓ The effectiveness of one’s communication can be enhanced significantly by using good listening skills, by reflecting and repeating back what you think you have heard and what you understand.
- ✓ Don’t contribute to your own guilt level by telling yourself “I should” or “I should have” messages.

Communication continued



My personal commitment

I will obtain and read the By Us For Us guide “Enhancing Communication” written by persons with dementia. I will be wise in how I talk to myself and remind myself of the effort that I am making and the skills that I have and that I am acquiring are the best that I can do!

Notes

“I wish I had known earlier that I shouldn’t try to reason with my husband when he gets stubborn. Since, I have stopped trying to reason with him, our conversations are much more congenial and pleasant. When I disagree with him, I just shrug it off and move on to another topic.”

(Care partner)

Support and self-care

Professional and support services

The quality of care and support you provide your partner is highly dependent on the amount of care you are giving yourself. It is very important to reach out and get help. This initial effort may be uncomfortable because it is a new situation that requires exploration and learning. You will encounter many health care professionals – consider them part of your support team. This includes family doctors, neurologists, therapists and personal support workers.

Learn what help is available and how to access these resources. And don't be afraid to ask for help!

Strategies to consider

- ✓ Get assistance through the local Alzheimer Society, local caregiving agencies and government supported services. Speak directly with a representative by telephone to establish a contact and to get help as soon as possible.
- ✓ Inquire about education, support groups, and programs for yourself and your partner.
- ✓ Ask about how to arrange for care inside AND outside of the home (e.g., respite and day away programs).

Support and self-care continued



My personal commitment

I will seek help from many sources so that I don't have to face this alone. I will take the initiative to get professionals working to help us. I will seek help from professionals to look after my own health so that I can provide care to the best of my ability.

Notes

“I am fairly resourceful so we plod and I am finding out things and trying to do what we can. I think a lot of stress could have been avoided though by having someone assigned to a “newly diagnosed family” to help them manoeuvre the system – like even where to get help with transportation so they can maintain some of their activities.”

(Care partner)

Support and self-care continued

Community and family support

Despite declining cognitive abilities, people living with dementia usually have a number of years of active life to live within the community. If you encounter stigma associated with dementia, do not let it become an obstacle to accessing help. There may be many unused support networks available that can be used.

Dementia is an invisible disability. People in service positions (for example, bank tellers, grocery clerks, and pharmacists) may not realize when customers are living with a dementia so, as a care partner, you will have to let them know so they can help. Many people are able and willing to help their customers overcome difficulties if they know what obstacles they are dealing with.

Losing a driver's license is a major loss of freedom and can be traumatic depending on the circumstances. Often there are volunteers in a community willing to help with transportation. Accessing transportation in these situations can help offset the loss encountered.

The reaction from family and friends can fall into two groups: those who are willing and able to help and those who turn and run. Those who are able and willing are the ones who deserve your attention. For them to be effective they need to know what is happening with the person living with dementia and they need to know how they can effectively help. Everyone copes differently with memory changes. Sometimes the person with living dementia is in denial and may reject help, not want to acknowledge that they have dementia, or recognize changes are happening. Beneficial support from family and friends can greatly reduce the care partner's stress level and increase their capacity to provide effective care.

Support and self-care continued

Strategies to consider

- ✓ Inform persons in your community that your partner has dementia that includes memory loss and confusion, ensuring that it is done in a way that respects the dignity of the person living with dementia.
- ✓ Arrange for delivery of groceries and medication.
- ✓ Arrange for automatic payment of bills.
- ✓ Take an optimistic approach to find new ways to deal with challenging situations.
- ✓ Look for help within the community to build your personal support network.
- ✓ Contact community associations for transportation options to get to appointments, meetings and social functions (for example, senior's associations, service clubs, city transportation and faith community).
- ✓ Seek beneficial support from family members and friends. Set up a formal plan with them so you can have some time for yourself.
- ✓ Educate family and friends about what you are experiencing and what will be helpful now.
- ✓ Don't be afraid to ask for help.
- ✓ Don't neglect your own needs. Take time to enjoy activities you find meaningful.

Support and self-care continued



My personal commitment

I will inform service providers about the current challenges that the dementia is causing and have a discussion with them on how to support the person living with dementia to complete daily tasks in a way that will respect their dignity. I will work with family and friends to make sure that the needs of both my partner living with dementia and my needs are met.

Notes

“I found myself astonished by the supportiveness of people like the manager at the bank who visits my mother and who has set up bill payments for her. It really is above and beyond regular banking support, but clearly recognizes the human in the customer. Long before any diagnosis that I knew about, people were taking into account my mother’s confusion and desperate desire to get things right, and helped her to do so.”

(Care partner)

Financial and legal issues

Legal and financial issues are important to consider early on. Seek professional advice from a lawyer, banker or financial advisor, and get answers to your questions related to planning for the future.

Strategies to consider

- ✓ It is wise to establish a Power of Attorney (POA) for Personal Care and Continuing Power of Attorney for Property before a diagnosis of dementia. POAs can only be established when the person has capacity to decide and make choices for themselves. Later, when the person becomes unable to make decision, it becomes a difficult and long process for the family to go through the courts to establish a substitute decision maker.
- ✓ Recognize the Power of Attorney is the substitute decision maker when the individual no longer has the capacity to do so. Persons living with dementia should continue to be included in decision making.
- ✓ If your partner living with dementia is your Power of Attorney, make the appropriate arrangements to have them removed and replaced.
- ✓ Avoid the do-it-yourself approach when it comes to establishing wills and Power of Attorney.
- ✓ Keep passports updated – it can be used as identification when an individual no longer has a driver's license. Alternately, check if you can request a photo identification card.

Financial and legal issues

continued

Strategies to consider

- ✓ Have a conversation with key personnel at your financial institution about your partner's diagnosis.
- ✓ Look into the disability pension. This is related to employment and there may be some time sensitivity to accessing this support.
- ✓ Investigate insurance responsibilities related to driving and out of country travel.
- ✓ Investigate with your insurance company what they cover with respect to medication and home care, such as, the services of a private duty nurse and purchase of assistive devices.
- ✓ Consider placing a dollar limit on credit and debit cards.
- ✓ Be aware of changing legislation for support of care partners in your province/country.

“[My mother’s doctor] has been very protective of her independence and has made it clear that she is his patient, and that she is still legally competent. Therefore [her doctor] has said that he will not talk to me or any of the people at the community where she lives, unless [my mother] gives him permission.”

(Care partner)

Financial and legal issues continued

Coping strategies

Below is a list of coping strategies for family partners in care:

- ✓ Take one step at a time, one day at a time.
- ✓ Ask for help when you need it.
- ✓ Share your concerns with someone close to you.
- ✓ Talk to others who may be in the same situation.
- ✓ Take a break by doing something you enjoy to keep yourself well.
- ✓ Plan ahead – create a plan recognizing that you will need to revise it as your partner's dementia progresses.
- ✓ Engage in self-care – eat well, rest, exercise, maintain your social and spiritual connections.
- ✓ Take measures to reduce your stress by being proactive and using relaxation techniques.
- ✓ Learn as much as you can about dementia.
- ✓ Involve the person living with dementia in decision making as much as possible.
- ✓ Avoid disagreements.
- ✓ Get counselling and support for yourself.

Financial and legal issues

continued



For more information on coping refer to the By Us For Us guide: **Transforming with Loss and Grief.**

Notes

“I have been gifted with a faith background and have many friends and family support to sustain me.”

(Care partner)

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

Website: www.alzheimer.ca

Refer to the 10 warning signs

World Health Organization

Website: www.who.int

Advocacy Centre for the Elderly

Website: www.advocacycentreelderly.org

1-855-598-2656

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

Endorsements

As a physician and educator in dementia care, I wish to congratulate the “By Us For Us” team for the development of this valuable resource for persons with dementia and family members dealing with early stages of memory loss. Knowing what to expect can significantly reduce the suffering associated with these conditions. Based on the experience and wisdom of persons living with dementia and health care providers working to improve care, this guide provides a wealth of practical strategies for navigating the care system and for managing common day-to-day challenges. I have seen very few resources available for patients with early memory loss that are as concise, understandable, and useful as this. This guide is highly recommended reading for persons and family members dealing with early stages of dementia and other memory disorders.

Linda Lee,

MD, MCISc (FM), CCFP, FCFP Director,
The Centre for Family Medicine Memory Clinic
Assistant Professor, Department of Family Medicine,
McMaster University

This quick reference is a great starting point for family partners in care. I especially like the proactive approach, with the emphasis on being active. Being actively involved in decisions, in your social network and your families is so important. Focus and foresight, friends and family become a powerful recipe for successful management of any challenges ahead. Enlarge your own personal circle of trust to make life's changes workable and warm.

Dr. K.J. Ingram,

Geriatrician Founder, Kawartha Regional Memory Clinic
Consulting Geriatrician for Ontario Shores Centre for Mental
Health's Memory Clinic

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Front cover concept

The cover art for this guide was based on the idea that a dementia diagnosis is a journey that requires motivation, movement, and progression. In the pursuit of answers, individuals or families may be required to use a number of actions to navigate the systems in place: requesting, bypassing, promoting, flexing, pursuing, and connecting.

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

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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Murray Alzheimer Research
and Education Program