



before/early diagnosis

An inspirational guide for partners in care
of people living with memory loss

A "By Us For Us" Guide

introduction

This *By Us For Us* (BUFU) guide is the first in a series of helpful resources written BY and FOR partners in care of those living with dementia. Partners in care are non-paid family members, friends, or volunteer companions who provide some aspect of care or support to persons with dementia. The BUFU Partner in Care series is based on the original BUFU series written BY and FOR persons living with dementia. This new series is a collaboration of partners in care, 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 symptoms of dementia and provides knowledge about the diagnosis, assessment and testing process. The information reflects the experiences of partners in care who have travelled this journey. It also provides some suggestions on important activities that are **best started early in the process**, but could still be relevant at any stage.

As you make your way through this guide you will encounter some issues that have been faced by partners in care, with whom we talked, in the early stages of dementia and throughout the diagnosis process. The voice of partners in care is presented at the beginning of each section 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 partner in care. We recognize that each journey will be different; you need to adapt these strategies to your own situation.

Becoming a partner in care 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
BUFU Partner in Care Committee

warning signs & symptoms

“In hindsight I believe I had noticed subtle changes for a few years.”
(Partner in care)

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;
- symptoms being covered-up by the person experiencing the changes and/or the partner in care;
- other life changes, such as retirement, and/or the death of a loved one;
- long distance care being provided; 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, or 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 chapter. If you are noticing two or more of the warning signs it is imperative that you see a doctor for proper assessment and treatment.

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

Often partners in care find that they have more questions than answers when they first become aware of behaviour that is out of the ordinary for their partner. In addition, partners in care 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.

get involved

education and learning

“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.”
(Partner in care)

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 the resources you need may be challenging, especially if your efforts are met with resistance. When symptoms occur it is often you, the partner in care, who may have important information about the changes that are occurring. There may be difficulties along the way such as your doctor not addressing your concerns or the person with dementia denying or not recognizing the changes. The stress related to dementia can be greatly reduced when we understand more about the disease, the treatment and how to deal with the symptoms.

Strategies to consider:

- Visit your local Alzheimer Society chapter 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 (such as Ebixa®, Aricept®, Exelon®, Reminyl®).
- Understand the different terms related to dementia – Alzheimer’s disease, Vascular dementia, Frontotemporal dementia, Lewy Body dementia, mild cognitive impairment, etc.
- 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.

My personal commitments:

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

diagnosis

“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 & 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.” (Partner in care)

In the early stages 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, like other diseases, has its own language and jargon. Not understanding the language and jargon of dementia can be a barrier when discussing the disease with professionals. Your partner with dementia may not be aware of their symptoms. 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 1 month to 3 years, due to the fragmentation of the medical system, the limited availability of specialists depending on where you live, the stage of the disease the person is at, and complications from other diseases. 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 delayed progression of the disease.

Strategies to consider:

- Be proactive – take an active and participatory role in seeking a diagnosis – **sooner is better**.
- Keep a list of symptoms and 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 doctor's 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 the person experiencing symptoms, as well as your doctor or specialist – 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.

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.

assessment and testing

“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.” (Partner in care)

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, MMSE, MoCA), and possible imaging studies such as Computerized Tomography (CT) scans. Your partner may be referred to a specialist, such as a Geriatrician, or a memory disorder clinic. Ultimately, assessment and testing is 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 results of cognitive testing and laboratory and imaging tests.

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 symptoms you are witnessing, and therefore don’t feel that testing for dementia is necessary. Due to the low impact the symptoms may have on your lives *initially*, 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.
- 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 with dementia experiences new symptoms, 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.

The following are questions, developed by family partners in care, to help when discussing diagnosis with your doctor and specialist. The Alzheimer Society of Canada also has a 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 partner in care? 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?

medication

“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).” (Partner in care)

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 meds. 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 partner in care needs to monitor and eventually assume responsibility for ensuring the person with memory loss 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).
- Keep timing of giving the medication consistent.

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.

safety

*"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."
(Partner in care)*

Changes in personality, memory, communication, vision and judgement that occur with dementia can result in safety and well-being worries for those with the disease and their partners in care. 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. Partners in care 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 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 symptoms progress over the months and years to come.
- 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.

communication

“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. (Partner in care)”

Communication is a vital element of how our relationships develop. For the partner in care, 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 BUFU guide on communication, written by persons with dementia. It is a great way to learn about communication from the perspective of persons living with dementia!

Unfortunately for many partners in care, 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 partner in care. 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.

My personal commitment:

I will obtain and read the BUFU 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!

support and self care

professional and support services

“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.” (Partner in care)

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 on this journey – 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).

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.

community and family support

"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." (Partner in care)

Despite declining cognitive abilities, people 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 untapped 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 partner in care, 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 with dementia and they need to know how they can effectively help. Everyone copes differently with memory loss. Sometimes the person with dementia is in denial and may reject help, not want to acknowledge that they have dementia, or recognize changes are happening. Beneficial support to be garnered from family and friends can greatly reduce the partner in care's stress level and increase their capacity to provide effective care.

Strategies to consider:

- Inform persons in your community that your partner has an illness that causes memory loss and confusion, ensuring that it is done in a way that respects the dignity of the person 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 where you are in the journey 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.

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 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 with dementia and my needs are met.

financial/legal issues

"[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." (Partner in care)

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

Things to note and 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 in the illness 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 POA is the substitute decision maker when the individual no longer has the capacity to do so. Persons with dementia should continue to be included in decision making.
- If your partner with a 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 POAs.
- Keep passport updated – it can be used as identification when an individual no longer has a driver's license. Alternately, request that the driver's license card be kept for the purposes of photo identification.
- 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 partners in care in your province/country.

coping strategies

"I have been gifted with a faith background and have many friends and family support to sustain me." (Partner in care)

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 the 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 with dementia in decision making as much as possible.
- Avoid quarrels.
- Get counselling and support for yourself.

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

endorsement for the guide

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.

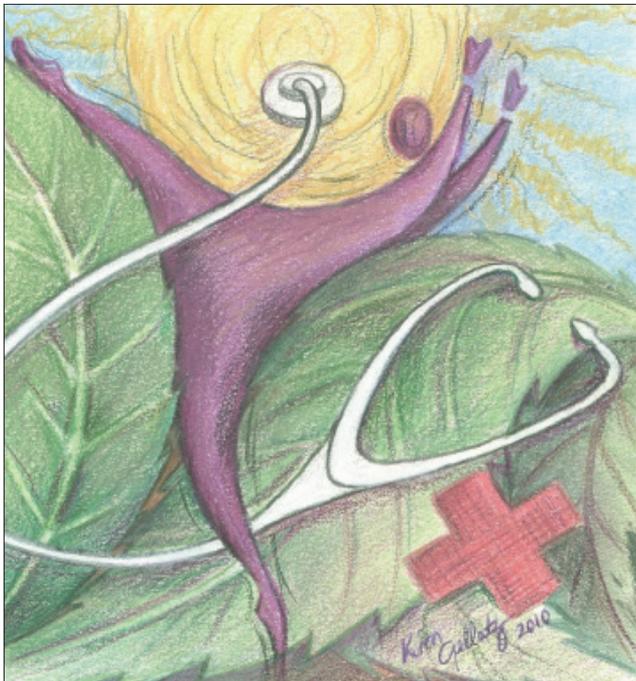
*Linda Lee, MD, MCIsc (FM), CCFP, FCFP
Director, The Centre for Family Medicine Memory Clinic
Assistant Professor, Department of Family Medicine, McMaster University*

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

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.



acknowledgements

By Us For Us Partner in Care Committee:

Emma Dundon, Kim Gellatly, Ken Hancock, Jack Henderson, Meredith McGinnis, Ann Marie Wilson and Lisa Loiselle

For their personal contributions, we would also like to thank:

Those who took the time to fill out the questionnaires distributed by MAREP

Thanks also to:

- Sherry Dupuis, Rachel Morrison, Shannon Knutson and Stephanie Bates – MAREP
- Guide Endorsements: Dr. Lee and Dr. Ingram
- Cover Graphics: Kim Gellatly
- Creative Services, University of Waterloo

Funding for this project was provided by the Homewood Foundation and the Murray Alzheimer Research and Education Program (MAREP), a major division of the Schlegel – UW Research Institute for Aging (RIA), Faculty of Applied Health Sciences, University of Waterloo (www.marep.uwaterloo.ca).



This is the first of many guides in the BUFU Partner in Care series.

Other topics will include:

Role & Health of Partners in Care
Supporting Quality of Life
Responsive Behaviours
Accessing Supports for Services
Financial & Legal Issues
Long-Term Care
Food and Mealtimes

Please pass the guide along to someone else who may need it.

other resources

From the Alzheimer Society (accessible on www.alzheimer.ca):

10 Warning Signs – Information includes a list of the 10 warning signs to look for, in addition to information on what is part of normal aging. © Alzheimer Society of Canada 1997-2010

The Progression series – Information includes a discussion about each stage of the disease, typical challenges that often come with each stage, and strategies for responding to them. © Alzheimer Society of Canada 1997-2010

Physician's Corner – Information includes what a “dignified diagnosis” looks like from the voice of people with dementia who reflected on how their diagnosis could have been improved. Also there are checklists for doctors as well as for the individual and how to prepare for the doctor’s visit. © Alzheimer Society of Canada 1997-2010

Getting a diagnosis – Information includes the process of getting a diagnosis, the family role, and a list of questions to ask your physician. © Alzheimer Society of Canada 1997-2010

First Steps for Families – Information includes coping strategies for family partners in care. © Alzheimer Society of Canada 1997-2010.

From MAREP (www.marep.uwaterloo.ca):

“By Us For Us” Persons with Memory Loss Series

I’m Still Here DVD and Teaching-Learning Guide

From other sources:

Canadian Caregiver Coalition (www.ccc-ccan.ca)

ACE – Advocacy Centre for the Elderly (www.advocacycentreelderly.org)

Ability4Life (www.ability4life.com)

Brenda's story – the inspiration behind the “By Us For Us” series

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for persons living with early stage memory loss. The dominant perception was that persons living with memory loss could no longer learn and be involved in their own care. Brenda knew differently. She was inspired to address this gap – to develop a series of resources specifically designed by and for persons with dementia. In 2006, she approached two of her peers with her idea and was astounded 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 at the University of Waterloo, Brenda connected with various persons 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 memory loss. Since the publication of the first guide, “Memory Workout,” and subsequent guides focussed on issues raised by persons with dementia, the project has evolved to include a guide researched and developed in partnership with persons with dementia and family partners in care, and a series dedicated to the needs of family partners in care. The philosophy of the project remains steadfast – the BUFU series places 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 and without her determination and perseverance, this project would not exist nor have the international recognition that it does.

we welcome your input

If you are a partner in care or have been diagnosed with early-stage memory loss and would like to comment on this guide or suggest topics for future guides, please contact MAREP at marep@uwaterloo.ca.

For more information about this project, or to order additional copies of this guide, contact:

The Murray Alzheimer Research and Education Program
University of Waterloo
Waterloo, ON, Canada N2L 3G1
1-519-888-4567, ext. 32920
www.marep.uwaterloo.ca

OR

Your local Alzheimer Society:



Permission is granted to make an enlargement of this guide to suit the visual needs of individual readers.

© BUFU/MAREP 2011