



Role, Health, & Well-Being

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

A “By Us For Us” Guide (series 3-2)

introduction

This By Us For Us (BUFU) guide is the second in a series of helpful resources written BY and FOR partners in care of those living with dementia. A partner in care can be anyone including a spouse, child, sibling, grandchild, extended family member, neighbour, legally appointed representative, member of a community with whom a person with dementia may be associated (e.g., spiritual group, ethno-cultural group), and so on.

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 who were interviewed and several more involved in the research, development, and editing process. Please refer to the back of this guide for a complete list of titles in this series.

This guide outlines some roles that partners in care may assume and the potential impact on both the partner in care and the person living with dementia. Tips and strategies are offered to assist you with understanding, supporting, and maintaining your health and well-being. Partners in care share with you the positive insights they have gained along their journey.

In this guide you can find valuable information about:

- 1) The many roles that partners in care take on.
- 2) The difficulties and challenges experienced by partners in care.
- 3) Effective strategies from partners in care for managing and coping with difficult and challenging experiences.
- 4) Stories of positive experiences along the journey.

Emma, Charlene, Jack, Karen, Lisa, Kimberly, and Jessica
BUFU Partner in Care Committee

wearing of many “hats”

“My role has evolved from being a secondary caregiver, primarily giving advice when my father was alive and able to care for my mother and in the early stages of dementia when my mother was quite independent, to being the primary caregiver who has to make all financial decisions, and many caregiving decisions on behalf of my mother.” (Partner in care)

For those living with a form of dementia, loss and changes in abilities are expected. When the disease begins to affect specific abilities of a person living with dementia, the partner(s) in care will most likely need to take up these responsibilities. As such, the role of the partner in care changes accordingly. Being a partner in care does not just mean providing hands-on care to persons with dementia. Being a partner in care means taking on new and multiple roles. These roles continually change and can impact the health and well-being of the partner in care. When some partners in care take on new roles, they find it challenging and overwhelming, while others talk about it as being rewarding and providing opportunities for personal growth.

Some of the new and unexpected roles that a partner in care may take on can be easier or more natural to fill than others. This may depend on the relationship with the person with dementia, past experiences, the level of support needed by the person with dementia, stage of the journey, or available resources. For example, you may find yourself cooking or managing finances for the first time.

You may find yourself helping with personal care, assisting the person living with dementia with tasks such as dressing, bathing, and grooming. These tasks are often referred to as “Activities of Daily Living” (ADLs). Your role may expand to being a coordinator, who plans appointments and meetings related to healthcare, social, and leisure activities. You could find yourself being an educator, teaching family, healthcare professionals, the public, and others about dementia. Individuals in the support circle, including persons with dementia, may also need you to provide emotional reassurance.

You may find yourself being an advocate. This role could consist of vocalizing the needs of the person with dementia when they are unable to communicate for themselves. It may also involve finding ways to help the person with dementia obtain the services and programs needed in order to maintain their well-being, comfort and dignity. If you are appointed lead decision maker (also known as “Substitute Decision Maker”), you may become legally responsible for making decisions related to finances and/or healthcare. This may involve decisions regarding real estate or medical treatment. Some partners in care take a more pro-active role by publically sharing their personal stories on how they live well in the face of dementia to challenge the stigma associated with dementia.

These roles contribute to an increase in your responsibilities and workload. Regardless of the roles you take on as a partner in care, **the most important thing to remember is not to lose yourself in this journey.** You need to maintain your own identity, and continue to look after your own health and well-being in order to provide the best care and support possible to your family member or friend living with dementia.

Use the space below to indicate how your role has evolved and what “hats” you wear.

impact of changing roles

“My role as a partner in care has gone from just being around for company for my partner, to having to check to see what he is doing fairly frequently... I have to drive him places, help him with the ATMs... and solve problems for him.” (Partner in care)

Changing roles may have an impact in many areas for partners in care. A caring role may lead to increased stress, illness, emotional and/or physical fatigue, and even decision fatigue. Decision fatigue can create feelings of inadequacy in making decisions, a desire to make decisions too quickly just to get it over with, or a sense of exhaustion. The following are several more areas that can be impacted.

Nature of relationships - Changes in your roles can sometimes affect the nature of the relationship between you and the person with dementia you are supporting. For example, an adult child may feel overwhelmed or uncomfortable by having to help a parent with dressing or bathing.

Spouses may experience a sense of loss of companionship as the disease progresses and roles begin to change. Sharing life experiences with the person with dementia may become more difficult as the disease progresses. Maybe you used to plan and share holidays together and are no longer able to do so. This can be accompanied by frustration and a feeling of sadness or grief about this loss, making the situation hard to accept. As a result, it can be more difficult for you, as a partner in care, to provide the care the person with dementia requires.

Financial impact - There may be financial changes such as the need for additional paid support, medications, tests, and long-term care fees. For families, income may also be reduced due to early retirement, loss of employment or modified work.

Lifestyle changes - You may experience a loss of freedom. You could be faced with your own physical and/or mental challenges. Some of your friends may distance themselves if they are uncomfortable with the disease and its effects.

Feelings, mood and emotions - Travelling the journey with someone living with dementia can trigger a large range of emotions including sadness, anxiety, fear, and frustration. For the partner in care, these can be a natural consequence of changing roles.

Feelings of frustration and anger about changes in the capabilities of the person living with dementia, or the increased need for support, can also affect the health of the partner in care. You may not know which steps to take or you may lack confidence about managing unfamiliar skills. Friends and family may offer a variety of solutions for the challenges you are facing. However, they may lack understanding or provide unrealistic solutions; you could be left feeling isolated or trapped.

A person living with dementia becomes increasingly aware of your tone, mood, and body language and may have challenges interpreting your spoken words. Your mood and body language can significantly affect a person living with dementia. If you are positive, they are likely to reflect that and be positive themselves; if you are negative, they are likely to reflect that and be negative themselves. This is known as the “plasticity” of dementia. It can be difficult to regulate one’s own attitude, especially when the person living with dementia is a spouse.

Sometimes you may feel frustrated that the person with dementia does not understand what you’re saying, so you automatically raise your voice. However, this is a challenging situation as the problem may actually be comprehension and not hearing.

A loss of a capability, even a small one, causes grieving. Denying a loss just makes the feelings surface somewhere else in a less manageable way. Your friends may not have much experience with grieving the kinds of gradual losses that occur when a person is living with dementia. They may have more experience with grieving a sudden loss, such as a death, for example. This may make it more difficult for them to grasp your feelings of loss and isolation.

*“When things turn around to more bad days, things change and it becomes very worrisome and you start to fatigue. That’s when you feel the most pressure and alone in the world.”
(Partner in care)*

Compassion fatigue (CF) is a term used to describe a form of burnout that helping professionals, volunteers and partners in care can develop while helping others in need. Helping professionals are individuals such as nurses, doctors, police officers, and social workers. Partners in care, volunteers, and helping professionals may find that over time they feel less sympathetic or patient with the stories they hear from the people they work with, and become less compassionate towards their friends and family. Partners in care may extend themselves beyond their own capabilities and may not be able to recognize their own limitations, making them less effective in the quality of care they provide. With CF, partners in care, helpers, and volunteers start feeling very emotionally and physically exhausted. Those with compassion fatigue can lose their enjoyment of the task and develop a more negative view of their world.

It can be challenging to find a balance between your own life and the responsibilities associated with your new roles. One of the weaknesses of our amazingly capable human body is our poor ability to detect very gradual changes in ourselves. As the roles for the partner in care shift and responsibilities increase, you may continue to think that you are adapting well to handling the load. You may find yourself defensive about how you are doing. The phrases, "I'm OK" or "I'm fine and handling things well" may be your answer. Others observing you may be better able to see your stress level, your exhaustion, or the effects of your feelings of isolation.

Use the space below to indicate how your role has evolved and what "hats" you wear.

general tips and strategies

It is important to understand that this journey may be life altering (i.e., physically, emotionally, intellectually, spiritually, etc.). Once you're in a place of acceptance, it becomes easier to continue through your journey.

Do not wait until a crisis happens to seek support for yourself! It will help if you develop a good understanding of dementia and the journey that both you and the person with dementia will share. Educating yourself and planning ahead can help you not only cope better, but will allow you to maintain a sense of well-being despite all the changes that you experience.

The following are some general tips and strategies that can help you cope with the changing roles and minimize the impacts to your health and overall well-being.

understanding our health & well-being and the journey ahead

“Struggles are there on your journey and by getting educated and reading, talking about it seems to help.” (Partner in care)

- 1) Educate yourself and others** – Become more knowledgeable about the illness. Talk to your doctor and/or your local Alzheimer Society. Information found on the internet and through support groups can also be beneficial. However be careful about the information you find on the web; it may not always be from a reliable source.
- 2) Do not take changes personally** – There are many factors that create changes in the person with dementia including physical well-being, social changes and his/her environment. Their actions and words change because of the disease process and are not meant to hurt you, but rather as a result of the disease process. It is important to put the blame on the illness NOT the person.

3) Know your “breaking point” – “Breaking point” is the moment when stress gets so overwhelming that you can no longer cope or manage a situation. Your “breaking point” may sneak up on you because these changes can happen very gradually. Listen to the advice of your support network objectively. Use professional/counselling support services before you get to your breaking point. Remember, the quality of care that we can deliver is directly related to our own health.

4) Do advanced care planning – It is important to think about the future as early as possible in the progression of the disease to ensure that the wishes of the person with dementia will be taken into account later. The more familiar you are with the wishes of the person living with dementia, the easier it is to have confidence in making decisions on their behalf in the future. This could also reduce the risk of conflict with family members or others supporting the person with dementia.

- Draw on available informal supports – engage family, friends, neighbours, or anyone who can provide positive support to build your informal network.
- Search out available formal supports – there may be support services available in your community. Find a format that works for you (i.e., respite, support groups, etc.). Learning about them helps you plan and build your support network.
- Make financial plans – become familiar with financial options that can help manage future challenges, such as reduced employment income and costs for respite and long-term care.
- Discuss health care – talk openly about health care and support including preference for living accommodations (i.e., placement in a long-term care home, waitlists, etc.), quality of life choices, and end of life care (e.g., “Do Not Resuscitate (DNR)” orders, continuation of medication for other illnesses).

supporting health & well-being through positive behaviours

*“[You] ...need to be realistic. We cannot prevent the disease progression so how can we minimize impact – take care of yourself (physically, mentally, emotionally, and spiritually!)”
(Partner in care)*

- 1) Acknowledge and accept your feelings and emotions** - Don't blame yourself for the changes in your mood. Even for small losses, allow yourself to go through the grieving process. By doing so, partners in care often find themselves in a better place of acceptance and even develop a sense of peace and hope. You may wish to read the By Us For Us guide – Living and Transforming with Loss and Grief.
- 2) Take care of yourself** – Make sure to get plenty of rest, healthy nourishment, and exercise whenever possible. Taking good care of yourself is important in helping you to provide effective support for a person with dementia. It also reduces your risk of compassion fatigue.
- 3) Accept help from others** – When family or friends offer to help, it may be very valuable to accept their assistance. Sharing some of your roles with others allows them to become familiar with the situation. It also allows the person living with dementia to become comfortable accepting assistance from others. Drawing on people whose opinions you respect, those with more experience, or those you know well will help you to avoid decision fatigue.
- 4) Take time to get away and nourish your soul** – Try using adult day programs, respite services, and your support networks so you can maintain life outside the caring role. Avoid self-isolation by staying personally active (e.g., support groups, personal care, theatre, travel, shopping). This is not something that you should feel guilty or selfish about. You are doing it for the person with dementia so you can be a better partner in care.

- 5) **Adopt humour and a positive outlook in your daily life** –Take time to laugh. It is healthy to laugh at surprising situations. Taking on a positive attitude is a good thing. A cheerful voice, a smile, or some uplifting words can make a big difference. Appreciate the emotional connection you may have with the person with dementia. Focus on living in the moment and the quality time you have together.

maintaining health & well-being in a changing reality

“I have learned to be very patient and go with the flow. I try to make my partner’s days the best they can be by altering my behaviour to fit with the ‘new’ person I am living with.” (Partner in care)

- 1) **Recognize and support abilities** – It is important to recognize and support the changing capabilities and strengths of the person living with dementia. This will help foster a better quality of life through the journey. It is also important to try to understand their reality and let them live in it. Don’t argue or try to control their perspective.
- 2) **Be as flexible as you can** – Each day may differ. Things may not go as planned... that’s to be expected. Live in the moment and remember some things may be beyond your control.
- 3) **Use time saving strategies to balance hectic schedules** – As the dementia journey changes, your schedule may become busier. Many partners in care have found organizations to help them stay on track. Figure out what strategies work for you. It can be helpful to prioritize, make lists, or delegate tasks to others.
- 4) **Listen to respected opinions about your well-being** – If trusted family, friends, and neighbours are expressing concerns about your well-being, remember that they can often detect gradual changes in yourself better than you can.
- 5) **Recognize that you are not alone** - Many have experienced the same feelings and emotions you may be facing. Draw on their knowledge and expertise throughout the journey.

drawing on positive experiences of being a partner in care

***“From my care role, I have learned to appreciate the gift of my partner and the gift of all those who care and share our journey.”
(Partner in care)***

In the midst of the journey, positive experiences can be difficult to recognise. However, many partners in care talk about the rewards they have gained. In fact, focusing on the positive is a helpful way of coping. Some recognise the new skills, insights, and experiences that are learned along the way. Many of these skills can be transferred easily to other new life situations.

The following are some of the positive experiences or insights that partners in care have gained along the journey:

- Development of new skills, expertise, confidence, and a realisation of one's own limitations and when to ask for help.

“I have [now] become proficient at planning and preparing meals, doing the laundry, ironing, grocery shopping, shampooing, and setting hair, nails polishing, and learning [about] the [challenges] of sizing ladies bras and underwear.” (Partner in care)

- Continued appreciation of the person living with dementia and their strengths.
- Reflection on goals, priorities, and values in life.
- Moments of thankfulness and blessing.
- Enhanced ability to appreciate life and its many pleasures (e.g., sunrise/sunset).

“... [I] am learning to appreciate the small things, the times that we get along nicely, and to live [in] the present, and not to worry about the future, which I can't control (for the most part).” (Partner in care)

- Being present and sharing each other's company (i.e., warm smile, embrace, or holding hands).
- Strengthened faith or spirituality.

"Actually I praise God more and more for the wonderful wife He has given me and for all the opportunity that this disease had given me to love her more." (Partner in care)

- Improved quality of relationships with other care partners, family, and friends (e.g., stronger network or relationship repair).
- Stronger emotional connection with the person living with dementia (e.g., by listening to his/her stories, feelings, and experiences).
- A sense of accomplishment, resourcefulness, and pride in doing the best that you can.
- Greater acceptance of and sensitivity to others.
- Pleasure in being able to reciprocate love and care.

Partners in care can learn to appreciate all that people with dementia may have to offer and the joy in day to day life. This may involve relying on professional help, a change in mindset, a reliance on spiritual supports, or taking time to nourish the soul.



This is the second of many guides in the By Us For Us Partner in Care series. **Other topics include or will include:**

Early/Before Diagnosis (2011)
 Supporting Quality of Life
 Responsive Behaviours
 Accessing Supports for Services
 Financial & Legal Issues
 Long-Term Care

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

endorsement for the guide

When a spouse, family member or friend is affected by memory loss and dementia, many of us become partners in care. This role can be both deeply rewarding and very taxing. Over time, managing competing demands and the emergence of difficult symptoms in the person with dementia can lead to compassion fatigue (CF) in the partner in care. This is a normal consequence of being in the role of a partner in care. The sooner we can detect that we are experiencing CF, the better we can address it before it takes a toll on us and the person with dementia. Congratulations to BUFU for this compassionate and supportive resource guide that provides partners in care with concrete tools to navigate the challenging journey they face in caring for a person living with dementia.

*Françoise Mathieu, M.Ed. CCC.
Author of "The compassion fatigue workbook" published by Routledge in 2012*

At the age of 26 I became a secondary partner in care for my father who had been diagnosed with early-onset Alzheimer's. During this time, I found that information from individuals who have lived a similar experience to be the most useful. Watching my mother as the primary partner in care, I could see when she needed time to care for herself, but not all care partners have that kind of support. The BUFU guide reminds me how we dealt with so many different situations and I wish we had something like this during our journey. It is an excellent resource for persons living with dementia and their families.

*Chris Wynn
Family partner in care
Documentary Filmmaker*

front cover concept

The cover art for this guide was based on the idea that the partner in care role can bring life-altering changes in response to an environment that is sometimes fluid but often dynamic. We may need to reach out for others and stretch ourselves beyond our current knowledge or levels of comfort. Maintaining the partner in care's physical, psychological, spiritual or social wellness is an essential factor for providing the strength to face new challenges – renewing us with the energy to embrace the days ahead.



other resources

Living with Dementia: A Resource for Living Well

<http://www.livingwithdementia.uwaterloo.ca>

Forgetful not forgotten – Connecting and Supporting Canada's

Alzheimer's Caregivers <http://www.forgetfulnotforgotten.com/>

Compassion Fatigue Solutions <http://compassionfatigue.ca/>

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<http://www.marep.uwaterloo.ca>



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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. Brenda has been a true inspiration and role model to her peers and without her determination and perseverance, this project would not exist or 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 info@the-ria.ca.

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

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OR

Your local Alzheimer Society:



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

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