



living and transforming with loss & grief

An inspirational guide for persons with
early-stage memory loss and their partners in care

A "By Us For Us" Guide

introduction

"My life changed overnight," said a person recently diagnosed with a dementia. From this time onward the thoughts of both the person with a dementia and the primary care partner may be dominated by anticipated losses and a sense of grief. If not recognized and validated, the person experiencing grief must suffer in isolation and may feel guilt, confusion, depression, or even anger. This guide provides tips and strategies offered by persons with dementia and their partners in care in the hope that these will help others experiencing feelings of loss and grief.

Dementia involves losses, including short term memory, an occupation, hobbies, social associations, independence, privacy, and personality. The losses are usually incremental, perhaps spread over months and even years, but they affect a person's sense of past, present and future. *"With my husband's illness, we have lost so many things. We have lost our dreams."* For persons on the dementia journey, a fear of the future may loom large. Questions arise: Will long term care be needed? Will we have enough money? Will we be able to stay in our own home? How will we cope with the inevitable changes?

The sense of loss and grief may change. One woman said, *"When my husband first received the diagnosis there was at first disbelief or denial followed later by anger and resentment and eventually acceptance."* And one newly diagnosed man said, *"I felt hopeless. I was scared and became very depressed. I gave up; however, with the help of others I came to realize that I still had a future."* Each person's journey is unique. In a sense, for both partners, there are many "small deaths" as time passes. Indeed, the only thing that is certain is that there will be change – *"grief means great loss that has changed my life beyond my control"* – and we are always trying to adjust to "a new normal," as one woman with dementia calls it.

The goal of this booklet is to help you – whether a person with a dementia or a partner in care – live and transform with loss and grief as you seek a place of greater acceptance, hope, and strength.

David and Janet Knight
Person living with memory loss and partner in care

experiencing loss and grief

Grief is a natural human experience we all feel with loss. While most people associate loss and grief with death and dying, for persons with dementia and partners in care, loss and grief become a significant part of life. Persons with dementia experience the continued loss of abilities, loss of employment, loss of meaningful relationships and activities, and more. Care partners can experience a loss of connection with their loved one, the loss of the loved one's personality as they know it, loss of hopes and dreams, and the anticipated loss or death of their loved one. This section of the guide outlines a variety of issues related to loss and grief as experienced, after diagnosis, by persons with dementia and partners in care. These include: the emotional and physical impact, the sense of who we are as persons, the way we feel connected to others, and more practically, finances.

emotional impact

You may experience a range of emotions and reactions after a diagnosis of dementia that are unique to each individual, and can vary greatly in intensity, from one situation to another, and over time. As reflected in the sentiments of both persons with dementia and partners in care, the emotional impact may come in the following form:

- shock and denial

I see others in denial and I don't want that.

- anger or resentment

I'm angry and so resentful about this damned disease.

- fear

I fear that all too soon I'll not be able to look after myself.

- feeling overwhelmed

I sometimes feel overwhelmed with having to deal with and organize daily events and schedules.

- loneliness

There are days when I feel very alone.

- depression

I am sad and depressed.

- acceptance

I accept the inevitable and enjoy life as much as possible.

These emotions and reactions are all part of the grieving process. Grief associated with dementia, however, is often ignored or misunderstood because it does not follow the accepted pattern of grief following the loss of life. As one partner in care stated, “*Stigma [and misunderstanding] associated with the diagnosis of dementia and its consequences*” intensify these emotions. For example, the stigma associated with the disease – the loss of mental capacity – leads others and individuals themselves to believe they are no longer productive members of society, which may result in a sense of worthlessness.

physical impact

For persons with dementia and their partners in care, loss and grief can result in physical disturbances. In turn, the physical challenges can also cause more feelings of loss and grief – it can be a vicious circle.

Both partners can experience such issues as:

- physical discomfort

Feels like being hit in the belly with a baseball bat.

- sleep disturbance

When I was first diagnosed I experienced nightmares; I would wake up other family members because I would call out in my sleep.

- headaches

I feel as if I have a tight band around my head.

- weight loss or gain

My husband doesn't know when he is full; he will eat the whole serving dish of potatoes.

Both the person with a dementia and the partner in care may find themselves requiring medications such as sleep aids or antidepressants to alleviate some of the stress and anguish that comes with this disease. The partner in care is especially at risk due to neglecting his or her own needs by focusing almost exclusively on their partner's well-being. This self neglect can make a person much more susceptible to serious physical or psychological illnesses.

“I get so frustrated when I forget how to do things.”

– Person with dementia

psychological impact

Living with dementia can affect the very way we view or think about ourselves.

Persons with dementia have expressed:

- a sense of inadequacy
I feel inferior now, not as in control. I feel like my wife's puppy.
- a loss of independence
Losing my driver's license has made me dependent on my husband.
- a sense of being incapable
I am unable to do food preparation, find my way in the kitchen, or manage money.
- loss of pride
I feel bad that I can't go out and get the car for my wife; a man does that.

Partners in care have expressed:

- a sense of inadequacy in providing care
*I don't know how to handle this.
I have a lack of sufficient patience.*
- a loss of freedom
I have no time for myself. All my time is spent tending to her needs and keeping her safe.
- a loss of sense of self beyond caring
No more life of my own as I knew it, just a caregiver.
- a sense of ever increasing, overwhelming responsibility
I am more responsible for his needs and he depends on me more and more.
- a sense of loneliness with their partner's change in personality and loss of companionship
The spark is gone in the person I knew over 30 years.

For both partners these changes can lead to a withdrawal from friends and activities. There can be a feeling of resignation where there is a loss of hope and motivation. Many may feel a loss in their faith or in their God or just a loss in the sense of peace, purpose, and meaning in life.

Part of your being (soul, spirit) is taken away leaving a vacancy, and dreams are shattered.

Loss of understanding, serenity of mind.

social impact

Having a dementia or caring for a person with a dementia can alter the way we feel connected to people who are important to us. For example, one may experience:

- change in the nature of relationships

Feelings of being alone and not being able to share with your partner on a personal basis and losing the love for one another.

She doesn't want to do things with me, our interests have changed. I don't have the courage to say, you hurt me.

- isolation – other people may withdraw from you and you may withdraw from others

My colleagues at work shunned me, as if they thought Alzheimer's was contagious.

The thing that made it most difficult to deal with the issues and feelings was my isolation from friends and having few relatives to talk to.

- change in view and role related to sexuality

- Views about being sexual with your partner may change as the disease progresses. In our society we have been conditioned to avoid this topic and this confounds the difficulties people have in their sexual relationship.

The loss to me means no more husband, no more lover and best friend to talk to and enjoy life with.

- The way we define male and female roles can sometimes lead to more loss and grief. For example, women traditionally do cooking, men do finances, but role reversals may occur due to the disease.

A man should look after his family. I don't know how I can do that now.

- loss of physical contact

- There may be recurring thoughts about what the future may bring when the person with dementia will no longer be living at home or may die.

“The loss of contact that dementia causes is physical, spiritual, and mental loss.”

– Partner in care

It may be difficult to discuss anticipated feelings such as loss of connection with your partner or the ultimate loss that occurs at death.

The thing that bothers me most is that I must leave my wife at some point, where she will have to cope with life alone.

financial impact

Worries and fears related to financial matters can greatly increase feelings of loss and grief. There are several aspects of this issue that may be relevant depending upon each person's situation.

- As the dementia journey progresses, the financial burden can increase due to the cost of drugs, in-home support, assistive devices, transportation, respite care, and long term care.
- There may be the loss of employment or a decrease in earnings for the person with dementia or the partner in care. As a result, there will be a loss in future earnings from investments or savings.
- Some people may find they have inadequate or no insurance coverage making it difficult to purchase new or additional coverage because the diagnosis of dementia makes it unaffordable.
- It will eventually be necessary for the person with dementia to relinquish control over finances to the partner in care or another person.
- For some, there will be financial burdens on other family members and this extra strain can impact future generations.

Even with good planning and adequate resources, it can be a challenge to make the plans flexible and be able to anticipate all the eventualities.

"I don't feel I am the same person I once was."

– Person with dementia

living with loss and grief

Diagnosis can be overwhelming; you may find yourself paralyzed, not knowing where to turn for support. Isolation may occur due to denial of the disease or a lack of understanding of the ebbs and flows of loss and grief. There may be a lack of understanding of the grieving process: it doesn't have a time frame, it is perceived differently by individuals, and some are able to adjust while others struggle. You need to be mindful that everyone grieves in their own way and at their own pace and that loss and grief are ongoing throughout the process of the disease. This section deals with coping strategies that we hope will help you adjust.

share your grief

Upon diagnosis you need to allow yourself time to think. Be honest with yourself about the disease. This will help in communicating and sharing your grief with others. Take some time to think about what you are going to say about the disease, and how and with whom you are going to share this information.

Tips for communicating and sharing with others:

- find a person who was always there for you and talk to them – use them as support and let them know that you “just need to talk”
More grief may occur if you tell the wrong person; they pull away and don't acknowledge your feelings and experiences.
- put others at ease by being open and honest about the disease
I'd rather tell them that I have Alzheimer's disease than be embarrassed.
- don't presume that people know what you need; help them, tell them what you need
- share advice – this may give you a sense of value, contribution, and being proactive
We're pretty much the same and dealing with the same issues and if not we exchange tips on how to deal with them.

For more information on communicating with others refer to the *By Us For Us* Guide: Enhancing Communication.

stay connected

Denial threatens connections with family and friends. The following tips may prevent isolation, loss and associated grief.

- enhance existing relationships

My emotional reactions are tolerated very well at this point by family and friends. They are very supportive!! Hence, my frustrations are minimal!!!

- rebuild relationships where possible

I have talked to my mother honestly about my feelings and we have settled whatever grievances there were between us.

- commit to maintaining relationships and finding new ways to be together

We still dance – we do chores together – we entertain when we can.

seek out support

As the disease progresses both the partner in care and the person with dementia can benefit from and will need increasing emotional and physical support. Support can come from a confidant, professional organizations (such as the Alzheimer Society, day away and respite programs), and/or a professional counsellor.

- include family in the process of diagnosis and disease progression; they can provide immeasurable support

The support of our daughters has been phenomenal.

- attend support groups

An early stage support group has been a blessing. These people with dementia understand me like nobody else can. We now have sessions for the newly diagnosed.

The support group helped me know I wasn't alone.

- build new support networks

My husband has a respite worker who he enjoys being with.

“You can only completely deal with loss and grief if you're completely honest with everyone including yourself.”

– Person with dementia

take care of yourself

Self-care can enhance your ability to deal with the disease and feelings of loss and ensuing grief. Caring for yourself may cause feelings of guilt, but know that focusing on your own health and well-being is critical in order to deal with loss. As one person with dementia stated to her daughter, “*Look after yourself dear, or we’re all in deep trouble*”. The following may be helpful:

- deal with depression first
- recognize the reality of what the losses mean to you and acknowledge them
- do not judge your grief – do not judge others’ grief
- know it is okay to cry, to feel sad, to take the time you need to grieve
- treat yourself – you may not want or feel like doing something good for yourself, but it is important to level the scales – it is okay to grieve but you have to balance good with bad
- give yourself permission to take a break
- keep humour in your life – don’t forget to laugh
- try to focus on the good things
- accept the new normal – you are the same person but your life is taking you in a different direction
- try to stay focused on today and enjoy the moment

draw on spirituality

Turn to your beliefs for help – this can mean living life with basic fundamental core values and those things that give you inner peace. You may find it helpful to turn to your spiritual leaders or communities, and to use prayer or meditation to cope.

For more information on enhancing emotional health refer to the *By Us For Us* Guide: Enhancing Wellness.

become knowledgeable

For some, anxiety and fear of not knowing about the progression of the disease can stall the grieving process. Education can provide a sense of control over the situation. As one person with dementia stated, “*Knowledge is power*”. Some people may choose to quickly seek out all types of information on the disease and the possibilities of what is to come. Others may want to take information gathering more slowly. Here are some strategies:

- seek out information on how to live positively with the disease
- find **reliable** and **multiple** sources of information
- be **critical** of the information
- recognize that some information will suit individual situations better than others
- talk to others who are experiencing memory loss or are partners in care
- learn more about how to live and transform with loss and grief

plan ahead

It is often said that you should plan for the worst, hope for the best, and you’ll always be ready. The development of a realistic plan can help you deal with the unknown, which can be frightening. The following are suggestions for the planning process:

- recognize that we may not have control over the progression of the disease but we can control other aspects of our lives
- plan for inevitable losses which will prepare you for dealing with situations and eventualities – this could include home care and, possibly, placement in a long term care facility
- set a realistic goal every day; for example, exercise, play with the grandkids, go grocery shopping, run an errand like getting gas
- set goals for the next day the night before
- give yourself incentives for meeting your goal – make sure it is something that you like
- do something positive everyday
- plan for the future, but don’t dwell on it – revisit your plan as necessary

transforming with loss and grief

Although the process of dealing with loss and grief can be difficult and ever present in the dementia journey, many individuals have been able to transform their loss and grief and find a “silver lining”. This reminds us all that it is still possible to have joy, love, laughter, and hope while living with dementia. This section will highlight the positive outcomes that some persons with dementia and partners in care have experienced in transforming with loss and grief.

positive outlook

Acceptance with respect to a disease that can affect every part of your life may seem difficult, but growing into a new reality can make room for meaningful new possibilities. As illustrated below, some individuals have been able to keep a positive outlook.

I learned – be patient, remain calm, adjust and accept.

I still have a very positive attitude. My favourite saying is, “I am still on the right side of the grass”!! I went to friends’ funerals this year and they are not here to enjoy life!!!

Here and now are most important along with lots of laughter. I also make time to do things I like and renew my spirit so I can continue to stay in the moment.

personal development

There is opportunity to learn and grow in all situations. In some cases, experiencing an illness such as dementia or caring for someone with a dementia can result in:

- learning to value self

I still attend local meetings of the Alzheimer Society and feel I have something to contribute.

- becoming more compassionate

I view myself now as a person with more compassion

- developing inner strength and confidence
I feel stronger than I ever thought I could or would have to be and doing a great job.
- developing new skills
I have better self-esteem because I have accomplished some new skills like handling the finances.
- being open to new avenues for learning
It was worth the expense for learning new strategies and techniques.

growing amid loss

As the saying goes “when a door closes a window opens”. Some people stop looking for the good things – we need to keep reaching for our goals – keep enjoying the little things in life, the “golden moments”. Here are some ways that persons with dementia and partners in care are growing amid their loss and grief.

- Express your grief – many people find it helpful to express their grief in a way that is meaningful for them. This can involve expressing through tears, but can also involve other ways such as through:
 - writing – songs, poetry, sayings, stories
 - painting or other art forms
 - capturing one’s biography – written, audio- or video-recorded
 - creating a memory box/album
 - reminiscing with others
 - engaging in other valued activities, such as golfing
 - journaling
 - listening to music or dancing
- Start your day with an affirmation. Post your affirmations on the fridge or mirror in the bathroom to remind yourself throughout the day. Some examples of daily affirmations include:
 - I understand that change is inevitable. I welcome change and adapt myself to change.
 - I am grateful for all that I have received.
 - I can do it.
 - I am not alone

- Designate a location, such as a favourite chair, and at the end of each day take up position in this favourite location and reflect on the positive aspects of your day and what you are grateful for. By doing this before you go to sleep, it will end your day on a good note.
- Appreciate the special people in your life.

new purpose

Having a purpose makes all of us feel as though we have meaning and each morning, a day of endless promise. The type of contribution you make may have changed but what hasn't changed is the potential value you give to others and yourself. Persons with dementia and partners in care have found new purpose in:

- spending more time with family and friends
- taking on the role of educator by being an advocate for people with dementia and partners in care in order to change misunderstandings and reduce stigma
- being proactive about creating a life plan and focusing on the factors and details that require special attention – relationships, finances, learning about the disease
- recognizing the need to support others and becoming a volunteer

“I have spoken at the annual general meeting of the Alzheimer’s Society and the volunteer appreciation night – something I never thought of or could do.”

– Person with dementia

peace of mind

Sometimes taking solace in having someone or something to turn to can help us lighten the burden of our own heavy thoughts and hearts. Some positive outcomes of living and transforming with loss and grief include:

- knowing that you are not alone

I learned that the journey is a long process, so it gives me a lot of confidence that life will be longer than I expected. I put an article in the newspaper expressing my feeling and the improvement in my everyday lifestyle. I had a lot of feedback from my church, friends, and strangers by phone.

The Lord has helped me knowing I am not alone.

- developing a greater understanding

Joining a group and meeting with people with Alzheimer's disease and still able to lead a normal life, with help, helped to quell many of the preconceived visions I was harbouring. It has helped me to believe the future is not so scary.

support

With a diagnosis of dementia comes the potential and opportunity to build, re-build and strengthen support systems. This can come in the form of physical support, emotional support, assistance with decision making and sharing responsibilities, as suggested below.

Our youngest daughter who shares Power of Attorney for finances visits most weekends.

My husband is very supportive. My three children have helped me very much and have encouraged me.

“Try to stay positive. If you can't laugh you'll cry, so I try to keep a sense of humour.”

– Person with dementia

questions to reflect on

The following is a list of questions to think about in living and transforming with loss and grief:

- What are you feeling?
- What do you fear?
- Where do you feel your grief?
- What do you need others to know about what you are feeling?
- Who can you talk to, openly and honestly, about your feelings?
- What do you need?
- How can others support you?
- How can you express your grief in a way that is meaningful for you?
- What aspirations do you have?
- How can you support others as they work through their grief?
- How can you be truly present for others experiencing grief?
- How can you support others in achieving their aspirations?

Use the space below to record your thoughts and feelings.

final thoughts

Dealing intentionally with loss and grief can provide opportunities for growth. As one partner in care stated, *“To me grief is a sadness that involves crying and wanting alone time to reflect. It is a way for the body and mind to recognize loss, express the feelings so that the body and mind can then resume normal balance.”* Initial reaction to a diagnosis of dementia can be to zoom all the way to end of life; however, getting a diagnosis is not a death sentence – there are many years to live. Do not make any big decision without careful reflection. Here are some other thoughts to reflect on:

- Do not be afraid to speak honestly and openly about what you are feeling.
- Be present and listen carefully and compassionately to the feelings and thoughts of others.
- Share your suffering with a trusted other; it can make you aware of the love in your life.
- Breathe deeply and connect with the innate wisdom of your body and soul.
- *“Through acceptance of reality, of oneself and the other, one develops the power to affirm life, and grow.”* (Dr. Brenda Shoshanna)
- *“Persons with dementia have not really lost their personality nor their memories. They have just lost access to it.”* (Oliver Sacks)
- *“I bow in reverence before the emotions of every melted heart. We have a human right to our sorrow...A morality which rebukes sorrow, rebukes love. When the tears of [loss] have their natural flow, they lead us again to life and love’s generous joy.”* (James Martineau)
- *“The greatest degree of inner tranquility comes from the development of love and compassion. The more we care for the happiness of others, the greater is our own sense of well being.”* (Tenzin Gyatso, 14th Dalai Lama)

“All we have enjoyed, we can never lose. All things we love deeply, become part of us.”

– Helen Keller

endorsement for the guide

“Living and Transforming With Loss & Grief” is an inspirational guide that acknowledges the many losses experienced by persons with dementia and their partners in care. By acknowledging losses that are invisible to others or silenced in society this guide may provide the understanding many long for. It affirms that it is okay to cry, feel sad and to grieve losses. This guide has the potential to offer solace for persons with dementia and their partners in care since they are guided to be present to their own experiences of loss and grieving and to not judge them but accept them. Many ways of living on with losses are described in creative ways. Persons with dementia and their partners in care who are grieving may feel less alienated and alone in their experiences of loss as they connect with the many people through the quotes provided in this guide. This guide also opens the door for others to enhance their understanding of, and sensitivity toward persons with dementia or their care partners who are grieving.

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“Living and Transforming With Loss & Grief” the latest instalment in the “By Us For Us” Guides is a gem. This booklet helps persons with dementia and their partners in care to recognize the diagnosis for what it is: a journey into the land of grief and loss. Like tourists dropped into a foreign land, persons with dementia and their partners in care must set about finding their way through a maze of unasked for challenges along the way learning to speak the language of grief and loss.

Wisely, the booklet tells the reader that loss and grief must be acknowledged. For only then can they fully engage in life experiencing the joys that can still be found amidst the pain and loss.

Unafraid to face the difficult challenges dementia presents, this booklet tackles topics that include among others, emotional impact, self-image, financial strategies, and that great taboo, sexuality.

Perhaps the booklet's greatest gift is the opportunity to learn from the masters – persons with dementia and their partners in care. The statements in the booklet ring true for they are hard won insights into the challenges and coping strategies one can employ in navigating dementia's terrible terrain in the most life-giving way possible.

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As a social worker for the Alzheimer Society of York Region and developer of the 3-A Grief Intervention Model, I commend the “By Us For Us” team on their hopeful approach to raising awareness of the loss and grief that families dealing with dementia experience. In this guide, the voices of people with early-stage memory loss and their partners in care are heard and their voices resonate well with the academic writings that have been done on this topic. They address the ambiguity by clearly acknowledging the grief reaction to losses commonly experienced such as the loss of the person with the illness, loss of independence and ideals which will not get achieved. Usually, dementia and grief carry negative connotations that are stigmatized. This guide, on the contrary, offers affirmative suggestions towards transforming the loss(es). For instance, the experience can be so much less isolating by seeking informal supports from trusted relationships and obtaining formal supports from organizations such as the Alzheimer’s Society. Based on my experience in the field of dementia for over 10 years professionally and personally, also doing research in this area, I recommend this guide as it provides a concise direction families can follow in establishing a “new normal” while grieving the uncanny losses of the dementia experience.

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front cover concept

When a diagnosis is first given you have a feeling of being very alone and in a place that may be darker than you have ever experienced before. There are people who are reaching out to you, but they don't always know what they should do, or you are keeping them at a distance. As you start to deal with the situation and learn to accept what is happening, your days will become a little brighter until you reach the time when your days will be much brighter and will outweigh the cloudy times. As the person with dementia and the support person gain insight and are there for each other, the difficult days represented by the clouds, will be easier to deal with. The losses will be ongoing but as you gain understanding and insight into each others needs you will be able to choose a path TOGETHER that leads you up a hill instead of a mountain.



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personal notes

Use this page to start to identify how you can modify the tips and strategies presented here to live and transform with loss and grief to meet your own personal needs.

we welcome your input

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

To order additional copies of this guide, contact:

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