

Losing Me, While Losing You

Caregivers Share Their Experiences
of Supporting Friends
and Family with Dementia



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Contents

Acknowledgements.....	ix
Foreword.....	x
Preface.....	xiii
Chapter 1: Introduction.....	1
Chapter 2: Noticing.....	14
Chapter 3: Responding.....	68
Chapter 4: Assistance and Support.....	110
Chapter 5: Observations and Recommendations.....	138
Chapter 6: Closing the Gap.....	163
Chapter 7: Losing Me.....	201
Appendix A: Questionnaire.....	205
Bibliography.....	207

Foreword

Alzheimer's disease and other related dementias have rightly gained importance in the academic milieu as well as our day-to-day society. In Nova Scotia alone, it is estimated that nineteen thousand people develop dementia every year. *Losing Me While Losing You* is an insightful entry into the lives of the people who care for persons with dementia. Caregivers have often been called the backbone of our health care system, supporting those who need assistance.

In Canada, 80 percent of the support provided to older people in need of assistance comes from family and friends. The care provided to persons living with dementia by their family and friends enables them to live far longer in the community than would be possible. Even when care needs become so great that nursing home admission is needed, family continue to provide essential emotional and physical support and contribute to their quality of life. The knowledge gained through interviewing caregivers is critical to help improve support for both the caregivers and the persons with a dementia diagnosis.

The organization of this book follows the stages of the journey as seen through the eyes of the caregivers: Noticing, Responding, Assistance and Support, and Observations and Recommendations. Chapter 6 is a compendium of resources and supports available to caregivers. There are many strengths to the content — one is diversity of the caregivers interviewed. They represent different ethnic and cultural experiences, and they have a variety of living arrangements, geographies, education and relationships with the person they are caring for — be they wives and husbands, mothers and fathers, from large families or small.

Not so long ago, it was taboo to speak about our experiences of dementia — the “noticing stage” that the authors bring to life through the words of the caregivers help us to identify the multiple ways in which the disease is first manifest. In the recent past we would have been in denial of the

disease, afraid that by speaking about it we will it to happen or somehow it is the fault of the person with dementia. Indeed, some groups may still be in denial because of fear, because they feel that nothing can be done to turn the tide of dementia progression. Nothing could be further from the truth. Some types of dementia can be stabilized through medication. For others, the knowledge of cognitive impairment provides an opportunity for family and the person with the diagnosis to discuss future plans and preferences. Rather than hide behind closed doors, the thirty-five caregivers in this book offer insights into the process of noticing, how they responded and their encounters, good and bad, of seeking assistance and support.

The wealth of information on support and resources throughout the book will be beneficial to anyone who is currently a caregiver or is studying how to support people with dementia and their caregivers. Caregivers provide insightful recommendations on lessons learned, coping strategies and what government can do to best support caregivers. The positive personal growth caregivers experienced through their journeys is another valuable lesson from the book — one that is often overlooked in research literature.

From the personal to the societal response, the authors' descriptions of the caregivers' experiences reveal a patchwork of programs and services in Nova Scotia. This is in contrast to the long history of national dementia strategies across the globe and across the provinces within Canada. The chapter on resources is comprehensive in its examination of leading-edge initiatives such as dementia villages, dementia-friendly communities, memory care facilities, geriatric clinics and a host of other initiatives. It also tackles the under-recognized topics of the impact of race and ethnicity on dementia care. Understanding the intent and scope of these resources is essential for anyone working in this field.

Losing Me, While Losing You brings to life essential knowledge to support family and friend caregivers in caring for persons with a dementia diagnosis. I am very grateful to the thirty-five caregivers who shared their stories with us and the insights they have for others who find themselves on this dementia journey. Finally, thank you to the authors who chose a narrative approach to write these reflections and organized the vast material in an accessible way for all to read.

— Janice M. Keefe, PhD, professor and chair, Department of Family Studies and Gerontology, Lena Isabel Jodrey Chair in Gerontology, director, Nova Scotia Centre on Aging, Mount Saint Vincent University, April 2021

Preface

As older women moving about in our communities of family, friends, acquaintances and others, we became increasingly concerned about the numbers of persons we knew or heard about who had been diagnosed with dementia, including Alzheimer's disease. We also heard many stories about the challenging experiences of caregivers of persons living with dementia, usually within their own homes. As we are engaged advocates for ourselves and other older persons and because we have taught, researched, published and engaged in community development activities with and for older persons and their important ones in a variety of settings, we were interested in hearing more about how such work impacts the caregiver's sense of self in relation to the person with dementia. For example, in October of 2019, Jeanette had a conversation with a friend about her experience of caring for her husband with dementia. The friend said,

We have been married for forty-two years. I was his wife, his lover and best friend, mother of his children and confidant. I was also his memory keeper. Now he doesn't know who I am and it is like I have been erased from his life, and mine. So, I don't know who I am anymore either.

Another friend, who is caring for his wife who has been diagnosed with Alzheimer's disease, made the following remarks:

She has really bad memory lapses now, so sometimes she calls me Bob, who was her younger brother. He has been dead for years. Some days I am not sure who I am. I am so tired, so pretending to be Bob is easier to deal with rather than reminding her that it's me, her husband of all these years.

Diane has a friend whose mother died from sudden-onset Alzheimer's

disease twenty years ago. She said that the memories of this loss are as traumatic today as they were at the time:

Amid much criticism I had to put my mother in long-term care on doctor's orders. My severe shock came not long after when I arrived at the nursing home and my mother greeted me with "and who are you?" I was an only child and I couldn't believe what was happening. I was in total shock and started to shake all over. A nurse saw my reaction and led me out to the nursing station for comfort. The shock was so great. The woman who had birthed me, loved me, nurtured me had no idea who I was? At that time there was very little help for family members or caregivers to deal with this type of shock and bewilderment. These feelings are just as clear to me today as they were then. I have not recovered from this pain.

In a 2019 Government of Canada report on dementia, data showed that more than 419,000 Canadians (65 years and older) were living with diagnosed dementia, almost two-thirds of whom were women. As this number does not include those under age 65 who may have a young-onset diagnosis nor those who have not been diagnosed, the true picture of dementia in Canada is no doubt somewhat larger (Government of Canada 2019).

Little did we realize when we began this journey of interviewing caregivers of persons with dementia, that we would do some of this work during a pandemic, when gaining access to potential interviewees would be challenging, especially when they lived in the homes of the persons who were diagnosed, so that entering the home to conduct an interview was not always possible. As a result, some of our interviews were conducted over the telephone and others via email responses to the questions we sent to informants. On other occasions, we conducted interviews outside residences where physical distance could be maintained; in other instances, family members conducted the interviews and then sent them to us.

The COVID-19 pandemic also introduced another component to the lives of caregivers and those they cared for as many experienced isolation, loneliness, anxiety and fear of rejection from neighbours and friends due to the stigma associated with dementia. In some cases, paid caregivers were not comfortable entering homes to provide care and support for fear of contracting the virus, which made caregiving by loved ones even more challenging. Further compounding the need for respite from the

twenty-four hours a day, seven days a week care that important ones provide, adult day programs, which offer respite relief for caregivers, were closed due to the pandemic, as were other long-term care facilities which have day programs. Some of the people we interviewed told us that they used to take their loved ones for regular doctor's visits for updates on their conditions, so, as one said, "At least we got to go for a drive for a reason and it was an opportunity to get out of the house." Due to COVID-19, doctor's visits were conducted over the telephone, once again isolating both patients and their caregivers from face-to-face social interaction.

Many with dementia diagnoses who lived in long-term care facilities were not allowed to have visitors, and if and when they were, they could only have a thirty-minute visit once a week by appointment only, and they were not allowed physical contact with their loved ones. For families with many relatives, especially in the case of parents with many children, partners and siblings had to decide when and who would visit, meaning that some did not see their loved ones for many weeks. If family members had others living in their homes who worked outside of the province and they had to self-quarantine for fourteen days when returning home, the entire family could not visit a long-term care home. Residents of such facilities with dementia diagnoses often told their loved ones that they felt rejected and orphaned by their families because they did not understand about the pandemic. In some cases, family members purchased cell phones and laptop computers so that their loved ones could see and talk to them virtually, but many times the person with dementia was unable to comprehend how to use the technology and staff were not always available to assist them with it. One particular story touched us deeply when a man, with six siblings and a 95-year-old mother who was blind, deaf and lived in a nursing home, decided on a creative solution to allow his mother to know which of her children was visiting. While living in her own home prior to her deteriorating health, every Christmas and birthday his mother knitted hats, toques and scarves for each of her children as gifts. He had an old sweater his mother had made for him some years ago, and he placed it in a bag and asked the attendant at the nursing home on his next visit if she would give his mother the sweater, which she agreed to do. When his mother placed the sweater to her face and smelled it, she seemed to know which son was visiting and she broke into tears, as did he and the care worker. We saw this as a sign of resilience and creativity in challenging times.

In spite of our challenges, we continued undaunted with our research and the result is a group of narrative accounts on the experiences of some caregivers of persons diagnosed with dementia, including Alzheimer's disease, in various parts of Nova Scotia. We are grateful to all of them for sharing their difficult and sometimes rewarding experiences with us.

As well as the interviews with caregivers, we conducted a literature search of the material available on this topic, and we also reviewed the demographic and statistical material. Jeanette was asked to discuss this research to a group of university students enrolled in a course on death and dying. In November of 2019, the students were sent background material on the topic and asked to complete a set of questions about dementia. They returned the responses to Jeanette prior to her online discussion with them, and in some cases we have included their responses in the book.

Introduction

To help provide some context for our research on the topic of dementia in Canada we thought it useful to provide some historical and demographic details.

Historical Background of the Terms

The term dementia comes from its Latin roots *demens*, which means out of one's mind. Although this term has been used since the thirteenth century it was not until the eighteenth century that medical practitioners in European countries used it to diagnose patients. In the nineteenth century "senile dementia" was originally seen as a separate disease from Alzheimer's but as medical knowledge increased and expanded it became recognized as one of many neuro cognitive disorders (Assal 2019: 118–126).

Alois Alzheimer was a German psychiatrist and neuropathologist who in 1906, noticed changes in the brain tissue of a woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems and unpredictable behaviour. At that time Alzheimer diagnosed his patient as having presenile dementia. Later his colleague Emil Kraepelin would define this condition as Alzheimer's disease (Alzheimer's Disease International n.d.a). Alzheimer's disease is the most common condition resulting in dementia. In 2013 the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) noted that their preferred term for this disorder was "major neurocognitive disorder" in an attempt to help reduce the stigma associated with both the word dementia and the conditions that it refers to. This term has not yet gained popularity even among organizations serving individuals with this diagnosis (Warchol n.d.).

According to the Public Health Agency of Canada,

Dementia is a fatal, progressive and degenerative disease that

destroys brain cells. It is caused by neurodegenerative and vascular diseases or injuries. It is characterized by a decline in cognitive abilities and can impact mood and behaviour. The cognitive abilities that can be impacted include:

- memory
- awareness of person, place and time
- language
- basic math skills
- judgement
- planning. (Government of Canada 2019)

Demographics

In 2015, the Nova Scotia Department of Health and Wellness reported: “Today, more than 17,000 Nova Scotians are living with dementia. In the coming years, we expect that number to double as our population continues to age. While the numbers are significant, the impact on the individuals affected and their families can be devastating” (Nova Scotia Department of Health and Wellness 2015: 1).

Alzheimer’s Disease International, located in the United Kingdom, notes that more than 50 million people worldwide have been diagnosed with Alzheimer’s disease. It is believed that one in four people with the disease have not been diagnosed <Alzheimer’s Disease International. n.d.a>.

By 2030 the Alzheimer Society of Canada estimates that the number of Canadians living with dementia will be 912,000. Every year 25,000 more Canadians are diagnosed with dementia. This organization estimates the annual costs of care for persons with dementia is over \$12 billion.

Indigenous and Black Canadians, including those living in Nova Scotia are three times more likely to be diagnosed with dementia. For more information on this topic see the report *Alzheimer’s Disease and Related Dementias in Indigenous Populations in Canada: Prevalence and Risk Factors*, produced and written by Julia Petrusek MacDonald, Valerie Ward and Regine Halseth, for the National Collaborating Council on Indigenous Health in January 2018, and also the website of the Alzheimer Society of Canada (alzheimer.ca).

Of those diagnosed with dementia, including Alzheimer’s disease, 65 percent are women; women make up two-thirds of the caregivers for persons with dementia, and approximately 34 percent of them are aged

65 or older. One in five Canadians have experience in caring for someone living with dementia.

Although the literature on gender differences in Alzheimer's disease diagnoses is scant, there is research to support that factors such as depression, life-long exercise, age and sleep can have an impact on the development of dementia.

There is general agreement among authors that twice as many women as men in North American and European cultures live with depression and that depression can be a precursor to dementia. This is not to say that men do not experience depression, but that women are more likely to seek medical assistance when they do. Another reason posited for the differences is that women, especially in later life, do not exercise as much as men in formal settings such as gyms, hockey stadiums, soccer fields and other community-based sports venues. Because age is also a factor involved in diagnoses of dementia, the fact that women live longer than men is another potential reason why more women than men are diagnosed.

Types of Dementia

There are over two hundred sub types of dementia, according to Dementia UK (n.d.). However, the most commonly diagnosed six are the following:

1. Alzheimer's disease is the most common form of dementia. It is a chronic neurodegenerative disease that destroys brain cells, causing thinking ability and memory to deteriorate over time. Alzheimer's disease is not a normal part of aging and is irreversible.
2. Vascular dementia is the second most common form. It occurs when the brain's blood supply is blocked or damaged, causing brain cells to be deprived of oxygen and die.
3. Lewy body dementia is caused by abnormal "Lewy bodies," which are deposits of protein called alpha-synuclein inside of the brain's nerve cells. This type of dementia shares many similarities to Parkinson's disease.
4. Frontotemporal dementia (also known as Pick's disease) is an umbrella term for a group of rare disorders that primarily affect the areas of the brain associated with personality and behaviour.
5. Young-onset dementia is the term used to describe people under the age of 65 who are diagnosed with this disease. It can also be called early-onset dementia.

6. Mixed dementia is the term used when people have more than one type of dementia.

Limbic-predominant age-related TDP-43 (LATE-NC) is the most recently identified form of dementia, noted for its close similarity to Alzheimer's disease. When TDP-43 accumulates in an area located in the mid-brain known as the limbic system, it affects learning, memory and emotion, resembling symptoms of Alzheimer's disease, the most common form of dementia. This suggests that people may exhibit symptoms mirroring those of Alzheimer's but may not involve the same changes to the brain caused by the disease. Currently, LATE-NC is not diagnosable with standard tests. Because people are typically diagnosed with certain types of dementia based on the symptoms they experience, LATE-NC will not be easily distinguished from Alzheimer's due to overlapping symptoms. Further research is required to improve diagnosis in identifying the different diseases that can lead to dementia, including LATE-NC. Investigators are currently trying to understand how to identify and diagnose LATE-NC clinically. The discovery of LATE-NC speaks to the growing umbrella of different dementias and the complexity of these diseases (Alzheimer Society of Canada 2019b).

The Research

In order to collect the experiences of caregivers of persons with dementia we used a snowball sampling technique. We each knew people who acted in these roles and they knew others in similar situations, either through being involved in research initiatives attempting to find cures for dementia, such as the True North Medical Research Clinics, through adult day programs, where they received respite care, or through word of mouth when discussing their situation with others who shared their experiences. We also posted information about the research on social media and contacted Alzheimer and dementia support group leaders, some of whom passed on the information to groups that were meeting online during the pandemic. As well, some of the students with whom Jeanette interacted said that they had experiences with loved ones with Alzheimer's and agreed to participate in the research by completing questionnaires online.

The Questionnaire

We asked a total of twenty-two questions (See Appendix A). The first set of questions asked for basic information such as the name, sex, age and race of the interviewee and the person they were caring for as well as their relationship status, such as parent, partner, child, friend and so on. We wanted to know when they first noticed changes in the behaviours of the person they were caring for and what they did about it; when the person was first diagnosed and their age at the time; what roles the person and the interviewee played in their relationship with each other; if the roles for each changed during the progression of the disease and if so in what ways; if any respite care was provided to the caregiver and if so, who provided the care; if the caregiver experienced stress or burnout or felt overworked as they pursued their caregiving responsibilities; how the role changes have impacted their lives; whether or not their incomes were affected; and how the community, other family members and friends have responded to the person's dementia. We asked if the caregivers learned anything about themselves as a result of their experiences caring for an important one, as well as whether they perceived benefits due to this work. We asked if their faith contributed to their experiences, what coping strategies they used to assist them in these challenging roles and how the experience has affected how they feel about themselves. Finally, we asked if the caregivers had any recommendations they could provide to others in similar situations and whether or not there were other issues we had not dealt with that they would like to expand upon or share.

The interviews lasted between one to two or more hours. Most were held in caregivers homes, but due to the COVID-19 pandemic we also conducted interviews in the grounds of long-term care facilities, over the telephone, through emailed questionnaires and via friends who were sent the interview questions and then conducted the interviews, transcribed them and returned them to us. In some cases, caregivers showed us photographs of their weddings, grandchildren, awards the person with dementia had received and other evidence of their lives together. Our youngest interviewee showed us woodworking projects he and his grandfather had worked on when he was well.

In order to ensure confidentiality, we have not used the real names of interviewees, unless they specifically said we could, which happened in a few cases. Instead we asked them to choose a pseudonym, and most did, including some who made comments like "I have never liked my name

and am happy to choose another,” or “I have always liked the name X and wanted to call my daughter that, but my husband wanted her to have his mother’s name.”

The interviews were at times deeply emotional for the caregivers as well as us and tears were often shed when remembering better times. COVID-19 further complicated the situation as it was not clear when family could visit again, when a nursing home bed might become available as the person with dementia’s condition deteriorated and when respite or home care would become more readily available.

We were very moved and thankful that in these times of the pandemic people were willing to share their experiences with us — in some cases the person with dementia would be present during the interviews so there were stoppages in the conversations as they needed to be attended to. In spite of their work as caregivers, we were often provided with cups of tea, baked goods and even, on a few occasions, lunch. Due to the pandemic and the feelings of loneliness and isolation experienced by some of the caregivers, some said our presence provided a friendly and caring visit and change of pace for them.

The Interviewees

Age Range of Participants

In total we conducted full interviews with thirty-five people; the majority were female, and five were male. The ages of caregivers ranged from 11 (the youngest) to an 89-year-old (the oldest). The majority were in their sixties, seventies and eighties, and some interviewees did not supply their age as they did not consider it significant to the questions asked.

Race and Ethnicity of Participants

The majority of our interviews were conducted with persons who self-identified as Caucasian. We also conducted one interview with a Chinese couple, four with people who identified as African Nova Scotian, three with people who identified as Indigenous and one as East Indian. In order to further discuss the situation regarding Indigenous and African Nova Scotians we relied on a literature search and recent material (2020) compiled by the Alzheimer Society of Nova Scotia and the National Collaborating Centre for Aboriginal Health in Prince George, British Columbia. Some of this material is discussed later in the book.

Diagnoses

The majority of people we interviewed were caring for persons who had been diagnosed with Alzheimer's disease. Others were diagnosed with unspecified dementia, vascular dementia, frontal lobe dementia, Parkinson's disease dementia and dementia with Lewy bodies. In addition, one caregiver shared that her mother's dementia was the result of medication, and in another case the dementia was brought on by radiation of the brain.

Who Was Being Cared For

The majority provided care for their mothers. Others provided care for their husbands, wives, fathers, mothers-in-law and grandfathers. One provided care for a father-in-law, one for herself, another for a grandmother and another for a friend.

Location of Care

The majority ended their caregiving journey providing care in a long-term care facility, such as a nursing home. Fourteen were providing care in their own homes or the home of the individual living with dementia, and two stories involved admission into hospitals where the individuals awaited transfers to long-term care homes when beds became available.

The Geographic Locations of Interviewees

The interviews were conducted in a variety of settings across the province of Nova Scotia with the majority being in the HRM (Halifax Regional Municipality) and Kings County. Interviews were also conducted in Cape Breton, Mahone Bay, Preston and Shelburne, and others identified as living in "rural areas." Some interviewees preferred not to provide their location to protect their anonymity.

Present Caregiving Situation or Remembering Ones From the Past

The majority of interviewees were providing care to their important ones at the time of the interviews and had been doing so from one to five years or more. In some cases, the person with dementia had died and the person interviewed was recalling their experiences and reflections since the death of their loved one from one to eighteen years ago, with the majority in the past five years.

The Themes

In order to present the narrative accounts of providing care to an important one living with dementia, we broke the interviews down into four distinct themes. The first we call “Noticing,” which addresses the warning signs caregivers observed when their loved ones started to experience memory loss, confusion, agitation or other symptoms associated with various forms of dementia. In this theme caregivers share their experiences of being in denial, resisting the new roles imposed on them by the disease and their attempts to get a proper diagnosis.

The second theme we identified as “Responding.” In this chapter of the book the caregivers share the ways in which they attempted to access resources; the impacts on their own health and wellness; the challenges they faced in regard to loneliness, fear, exhaustion and assuming new roles; and how these changes impacted their images of self.

In the third theme, “Assistance and Support,” the caregivers focus on the support they did, or did not receive from others, including professionals, and the lessons they learned as they conducted their work. They also talk about what they would have done differently had circumstances allowed and the ways in which the health care system needs to change to support caregivers more adequately.

The fourth theme focuses on “Observations and Recommendations” and is where the caregivers share with us which strategies they found helpful in the care they provided, as well as the recommendations they would make to government and others in similar situations.

In Chapter 6 we examine some of the gaps that have existed in dementia care locally, in the Canadian context and internationally, and we discuss ways in which these gaps are being addressed. We conclude the book with a brief chapter titled “Losing Me.”

Introducing the Caregivers

Rather than repeat the information about each caregiver as we discuss their experiences, we thought it best to introduce you to them at the start of their narratives. In each case we give you the name of the caregiver, age (where provided), name of the person being cared for and their relationship to the caregiver. We also provide the location of where they were living when the interview was conducted. Rather than provide specific geographic locations we identify them more generally to provide

confidentiality — for example the greater Halifax Regional Municipality, or a small town in Kings County, or Cape Breton, unless the interviewee specifically asked for their location to be made known.

In addition to in-depth interviews with the thirty-five caregivers, we also gathered information from a class of students at a Halifax university and three Indigenous women who provide care professionally as well as providing support to family members with dementia.

The Text Within

Because the caregivers we interviewed were so willing to share their experiences with us, we felt it appropriate that we also share our personal stories of family and friends who have experienced and do experience dementia.

Diane's Story

As I took part in interviews with folks taking care of loved ones with dementia I had time to reflect on my experience with family members who lived with dementia in their later years.

My paternal grandmother, a widow and former missionary in India, developed dementia later in her life. She took to singing off key while playing a piano and later on had hallucinations. My uncle and his wife arranged for my grandmother to be admitted to a Roman Catholic long-term care facility and then left to retire to British Columbia. My mother and father had been in a horrific accident and had left the city to live in rural Nova Scotia. At the time of Grammy's developing dementia I was left as the only living relative in the city. I was newly married and expecting our first child. For several years I only got to visit my grandmother several times a year. I had no idea what was really going on. It was several years later on a visit that I discovered that my grandmother was given antibiotics for several cases of pneumonia. By this time she was a living "corpse" and not able to function on her own in any way. I was horrified that she was being kept alive. I objected to the use of antibiotics and finally Grammy died peacefully.

Then my uncle developed dementia, having served in World War II. I remember on my last visit to him in BC, we went for a walk and he stated to me, "It is so disturbing to realize my brother's (my father's) body is totally wearing out but his mind is still intact while my body is strong and my mind is going."

I remember his wife leaving notes around the house and my uncle buying bricks of ice cream. The freezer was full of ice cream (his love on returning from the war).

At the time of our last visit I was a volunteer palliative care worker in the Valley. I was particularly upset as Joy (his wife) continued to insist my uncle stay at home. I remember her telling me at times she would curl up in the middle of the floor to avoid my uncle's rage. When he was finally admitted to long-term care she still insisted he be force-fed! I was mortified! Finally members of the palliative care team talked to her and explained what would be most beneficial for her loved one. My uncle finally died in peace several months later.

I am now 82 and had major surgery last August from which I am recovering. When I forgot a name at first I would worry that I was developing dementia, but now I have come to realize stress doesn't help. I simply laugh now and say to myself, "Oh well, I will remember a little later" and I usually do! I am doing okay living alone through this COVID-19 pandemic!

Jeanette's Story

I have been fortunate to not have anyone in my immediate family be diagnosed with dementia, to my knowledge. However, I have had very good friends and neighbours diagnosed with dementia over the years. In fact, it was the experience of one such friend which piqued my interest and concern about the experience of being the caregiver for a loved one with dementia. I watched this couple first deal with the husband's diagnosis after he had several memory tests that showed he had a slight decline in memory, to a year later him being diagnosed with dementia and then experiencing a fast decline as the disease progressed. I watched his wife of forty-two years struggle with trying to find appropriate care for her husband, especially respite, which was booked but then cancelled after a three-month wait. In the end, their son who lives in Scotland convinced them to leave Nova Scotia and go and live there so that they could receive better care. They did do this, in spite of living in this province for twenty-five years after moving here from the UK.

After their arrival in a small town in Scotland, the husband became agitated and angry and was using aggressive behaviour towards his wife. As a result, first he was placed in a hospital and then in a private nursing home; he has been institutionalized. Due to the pandemic and her own poor health, which she attributes to the stress of caring for her

husband, his wife was unable to visit him for three months. She is now able to do so for half an hour a week, all without being able to physically touch him with a hug or a kiss. She says his condition has deteriorated since he was first admitted into the care facility, to the point that he doesn't always recognize her, their son and his wife, or his three-year-old granddaughter.

Many years ago, a dear friend was diagnosed with young-onset Alzheimer's at 50 years of age. I watched as her partner of thirty years cared for her and tried to keep their life as "normal" as possible in spite of the many challenges involved in being a main caregiver. Two years after her diagnosis she was admitted into a care facility, where she died two months later.

I have several neighbours who have had partners diagnosed with dementia. Three have died — one very recently. I have observed and been party to the challenges all of these people have bravely taken on to ensure that their important ones receive the best care available to them, all while losing sight of the need to care for their own health in the process. In most cases the caregivers ended up needing care. As well, I have learned from them all that when a loved one has dementia and becomes invisible to themselves, and sometimes others, that the caregivers struggle with their own identity and self-esteem.

Recently a friend, whose husband died in a nursing home from Alzheimer's disease, said of her sense of self, "It's as if I look into a mirror which has broken and see shattered bits of myself all over the place since he has been gone. It used to be when I looked I saw a wife, mother, grandmother, dresser (I always dressed him as he had no sense of style otherwise), cook and cleaner. I was his constant companion and I would say his oldest and best friend. Now I look in the mirror and see so much is gone. So after losing him, I only hope I can find me again." These experiences are why I wanted to co-write this book.

Brenda's Story

I have worked with aging people and taught gerontology courses throughout my career. When I was younger the challenges presented by aging were opportunities to explore new approaches and new ways of doing things. I liked teaming with older people and learning from them as we conducted research and developed new programs. I had older people among my close circle of friends, and I admired their keen minds, fearless

advocacy efforts and commitment to make changes in their lives and their communities when needed.

I met my “Waterloo” when working (and living) with older people involved the challenge of dementia in my own family. Both my father-in-law and father developed dementia. My father-in-law had Parkinson’s disease, and in addition to changes in his cognitive functioning he lost his wonderfully expressive face which was replaced by a “Parkinsonian mask.”

My father had dementia which was originally diagnosed as Alzheimer’s disease but was likely vascular dementia. He died two years ago.

As I was growing up my father had a brilliant mind and was an eloquent speaker. His storytelling was always relatable and didactic. My mother was the first to notice that something was not right and that his forgetfulness might be more than what would be typical for his age. My father described his forgetfulness as “bobbing for apples” — you know they (the words) are in there and if you keep trying you will eventually bite into the right word and emerge triumphant.

As the dementia progressed his communication became more like attempting to put together a jigsaw puzzle. He appeared to see the total picture, but he only communicated with us in pieces and most often some of the key pieces were missing.

What I found more frustrating than my father’s reduced level of communication was the resignation that accompanied the dementia. He was still interested in the things happening around him, but he was not interested in, nor capable of, initiating things or making them happen. This had been the part of my father that I had always admired. He would come up with unique, cutting edge ideas and he would then do everything to move those ideas forward.

As I adjusted to my father’s changing capacities it reminded me of a fabulous sandcastle as the tide comes in. With each wave more and more of the castle is worn away until you are left simply remembering what the castle looked like in its glory.

So, I am sharing the concerns raised by watching the slow but progressive downward journey of these two important men in my life. What can we do to prevent dementia? What can be done to reduce the stigma of dementia? What can we do to ensure that caregivers supporting people with dementia are getting the support they need? What changes need to be made to maintain the personhood of those living with dementia in

long-term care? How can we best accommodate the end-of-life wishes of persons with dementia?

My starting point is to collect the perspectives, ideas and insights of the persons for whom adjusting to the demands of dementia has also been their lived experience.

EXCERPT