

Supporting Parents with Alzheimer's:

Your parents took care of you,
now how do you take care of them?

Tanya Lee Howe



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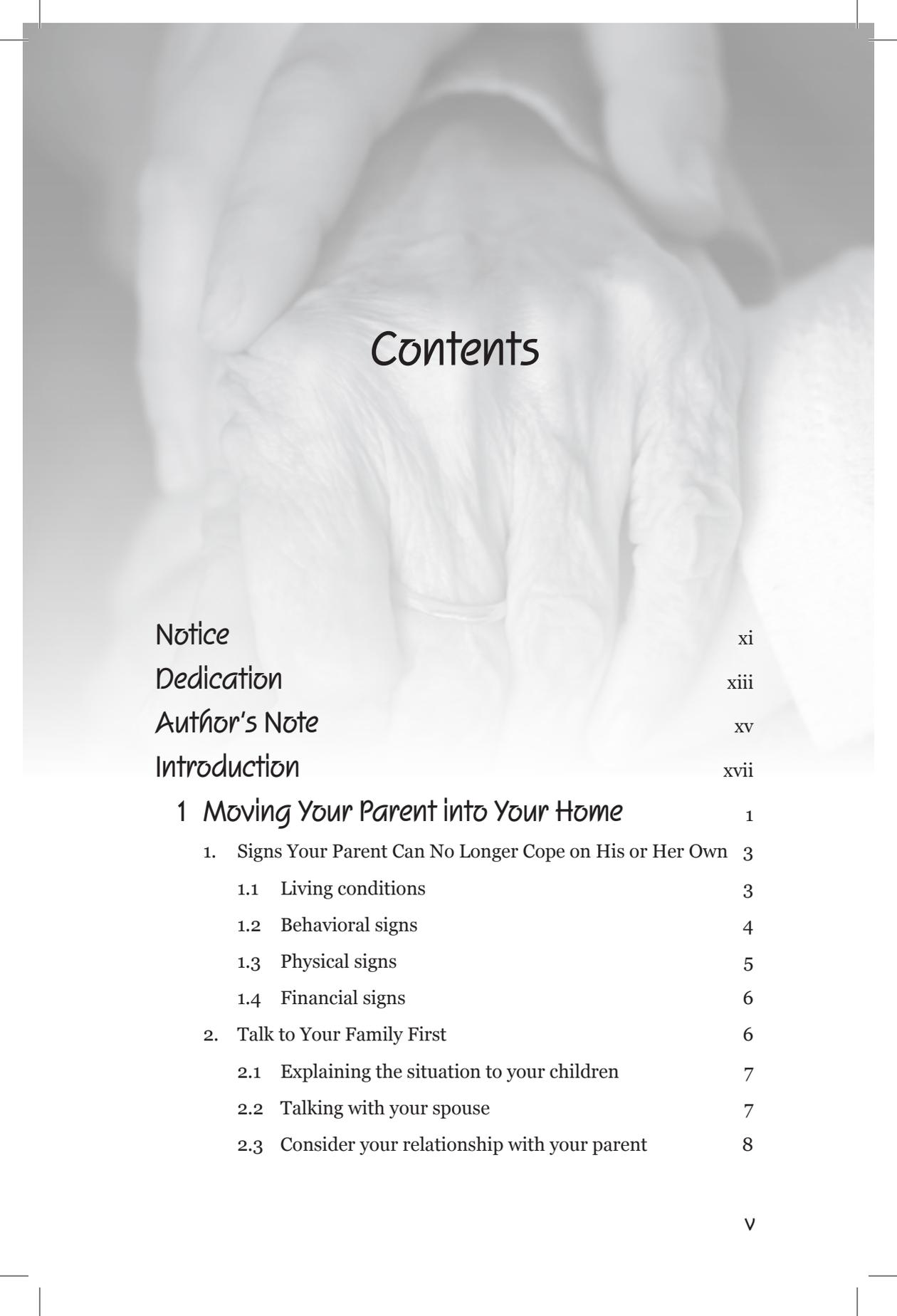
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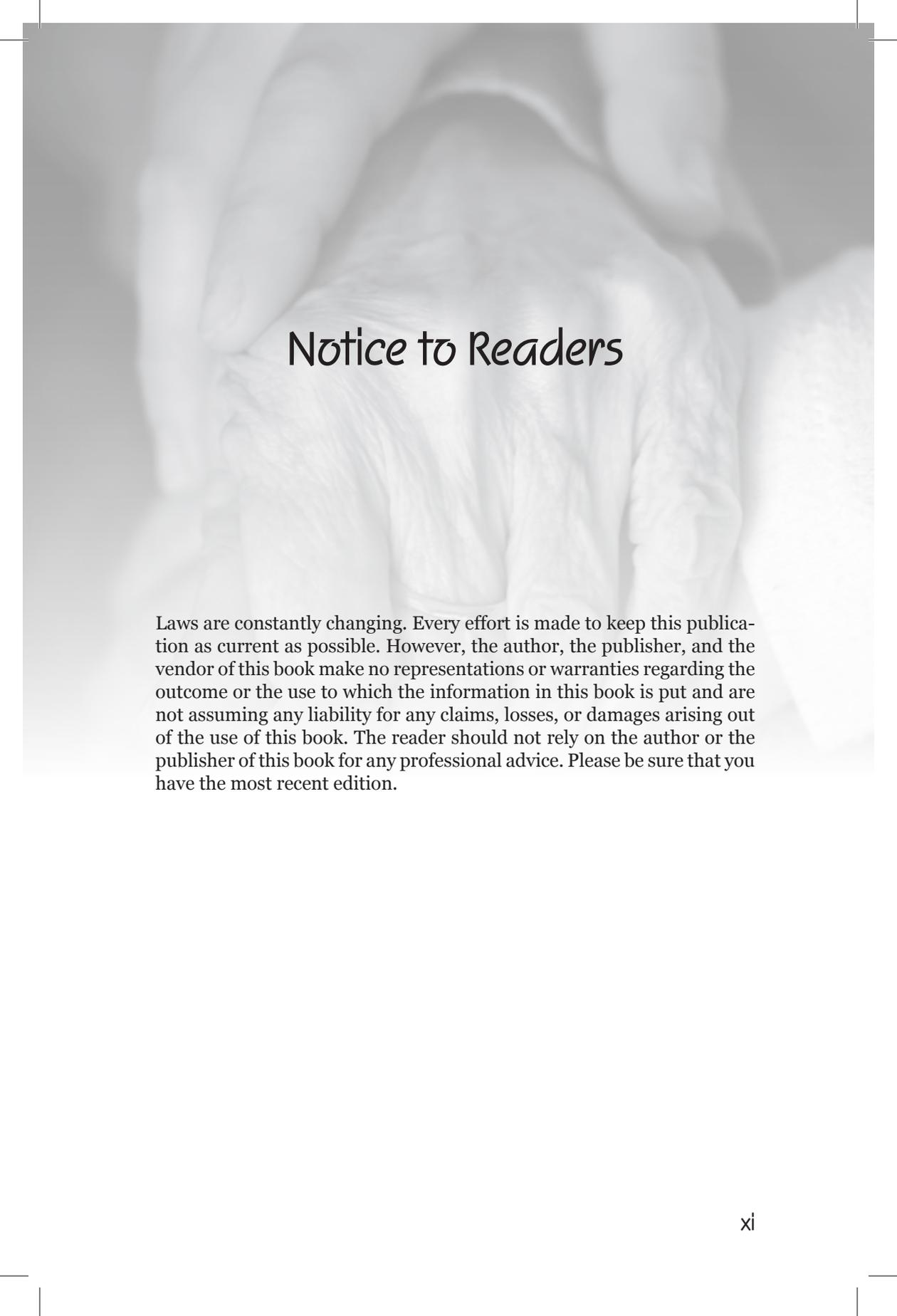
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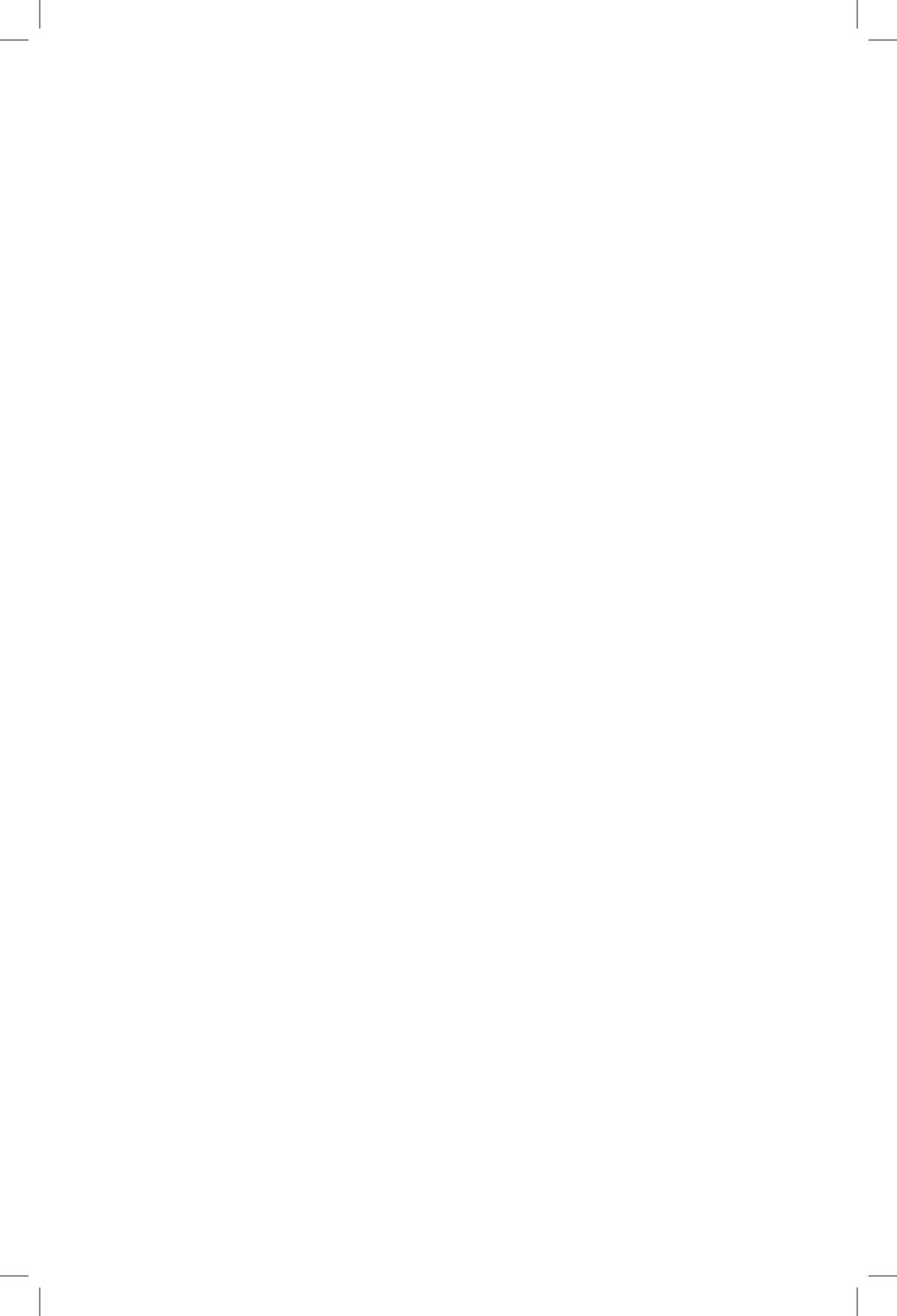
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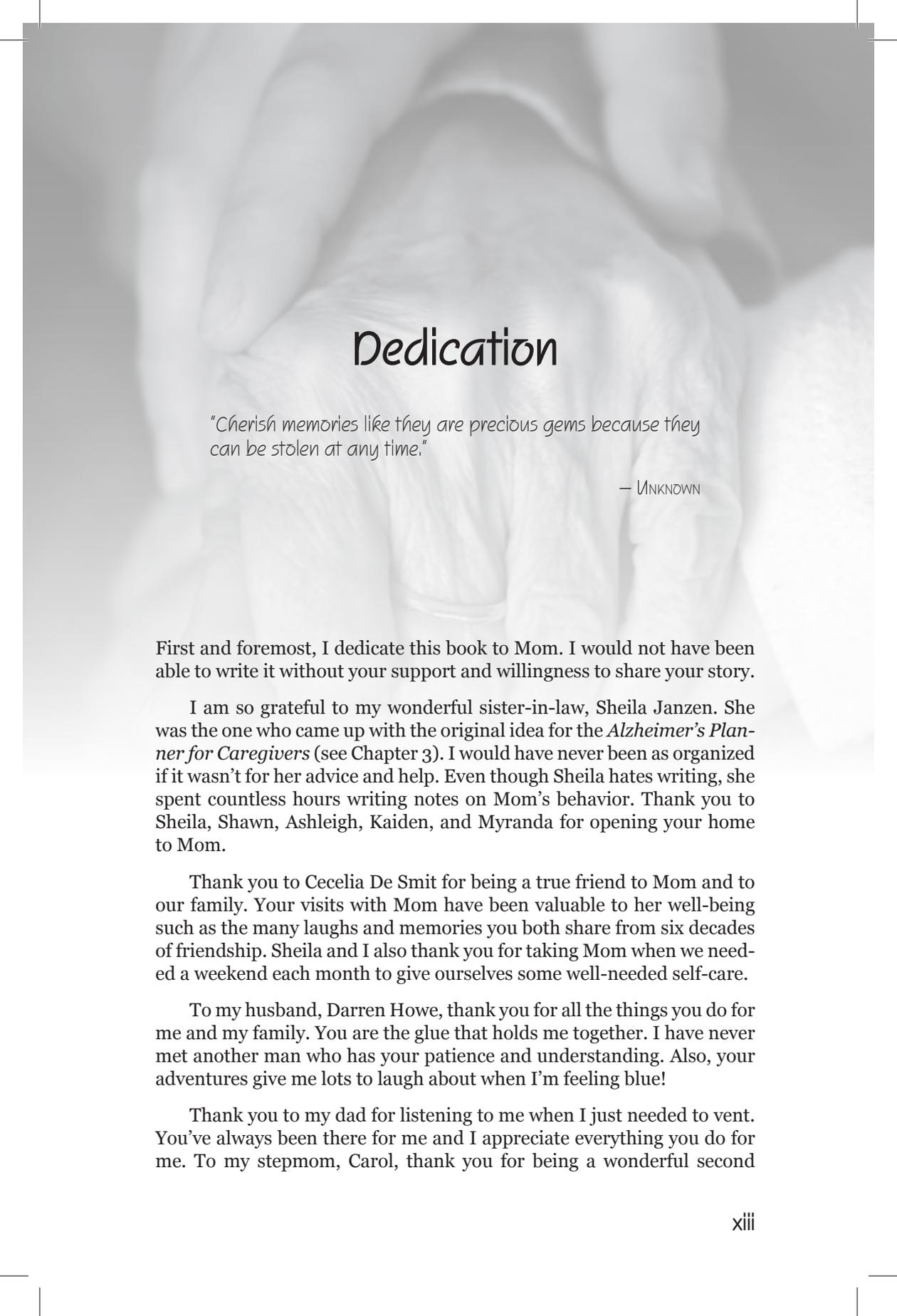
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Dedication

"Cherish memories like they are precious gems because they can be stolen at any time."

— UNKNOWN

First and foremost, I dedicate this book to Mom. I would not have been able to write it without your support and willingness to share your story.

I am so grateful to my wonderful sister-in-law, Sheila Janzen. She was the one who came up with the original idea for the *Alzheimer's Planner for Caregivers* (see Chapter 3). I would have never been as organized if it wasn't for her advice and help. Even though Sheila hates writing, she spent countless hours writing notes on Mom's behavior. Thank you to Sheila, Shawn, Ashleigh, Kaiden, and Myranda for opening your home to Mom.

Thank you to Cecelia De Smit for being a true friend to Mom and to our family. Your visits with Mom have been valuable to her well-being such as the many laughs and memories you both share from six decades of friendship. Sheila and I also thank you for taking Mom when we needed a weekend each month to give ourselves some well-needed self-care.

To my husband, Darren Howe, thank you for all the things you do for me and my family. You are the glue that holds me together. I have never met another man who has your patience and understanding. Also, your adventures give me lots to laugh about when I'm feeling blue!

Thank you to my dad for listening to me when I just needed to vent. You've always been there for me and I appreciate everything you do for me. To my stepmom, Carol, thank you for being a wonderful second

mom to me. I'm also grateful for your help with my research; you have sent me valuable information that has contributed to this book.

I also want to say thanks to Jocelyn Rawleigh for putting her life on hold to help me promote a cause. We both have lists of "100 Things to Do before We Die" and I'm happy that a couple of the items on our lists just happen to coincide!

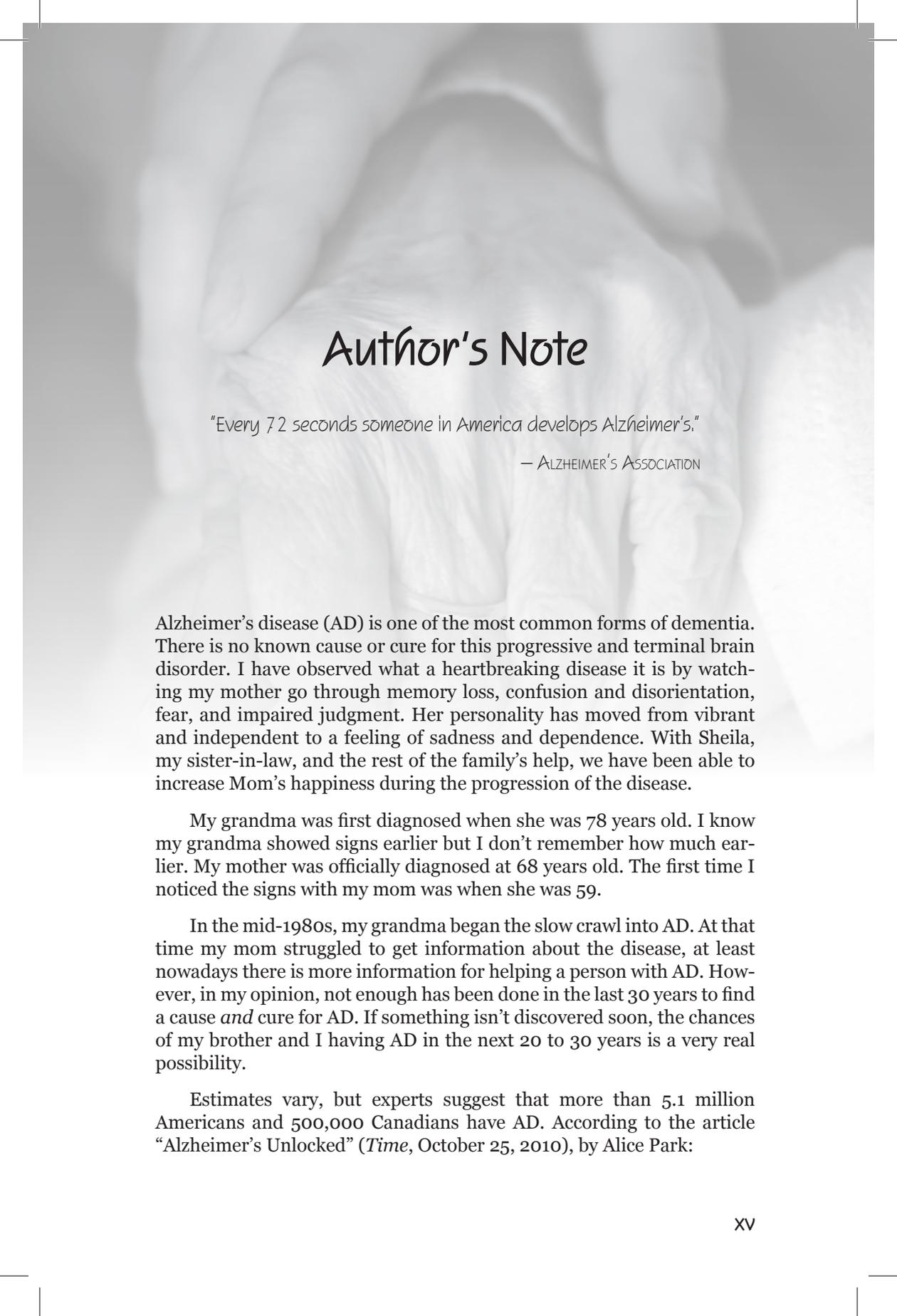
Thanks to Eileen "Madam Editrix" Velthuis for helping me to make my dreams come true. You have given me wonderful advice as both a friend and business associate. I can fly again and that is because of you!

Thank you to Self-Counsel Press, and especially Richard Day and Diana Douglas, for publishing two books with topics that meant a lot to me to be able to share with the world.

Thank you Dr. Derman (and his wonderful staff) for your kind words, and for being a doctor who treats his patients with respect and care. I wish every person was lucky enough to have such a wonderful doctor.

Thank you to Conny Schipper, Janet Cook, Heather Mueller, Christine Ratkai, Travis Asplund, Lisa Barrett, and Lynn Crackel for taking the time to answer my questions and to donate words to these pages. Thank you to Trudy Curtis for making me laugh on the days when I thought laughter wasn't possible.

Finally, to my dearest Orph, for making me realize life is too short to waste. I miss you buddy.



Author's Note

"Every 72 seconds someone in America develops Alzheimer's."

— ALZHEIMER'S ASSOCIATION

Alzheimer's disease (AD) is one of the most common forms of dementia. There is no known cause or cure for this progressive and terminal brain disorder. I have observed what a heartbreaking disease it is by watching my mother go through memory loss, confusion and disorientation, fear, and impaired judgment. Her personality has moved from vibrant and independent to a feeling of sadness and dependence. With Sheila, my sister-in-law, and the rest of the family's help, we have been able to increase Mom's happiness during the progression of the disease.

My grandma was first diagnosed when she was 78 years old. I know my grandma showed signs earlier but I don't remember how much earlier. My mother was officially diagnosed at 68 years old. The first time I noticed the signs with my mom was when she was 59.

In the mid-1980s, my grandma began the slow crawl into AD. At that time my mom struggled to get information about the disease, at least nowadays there is more information for helping a person with AD. However, in my opinion, not enough has been done in the last 30 years to find a cause *and* cure for AD. If something isn't discovered soon, the chances of my brother and I having AD in the next 20 to 30 years is a very real possibility.

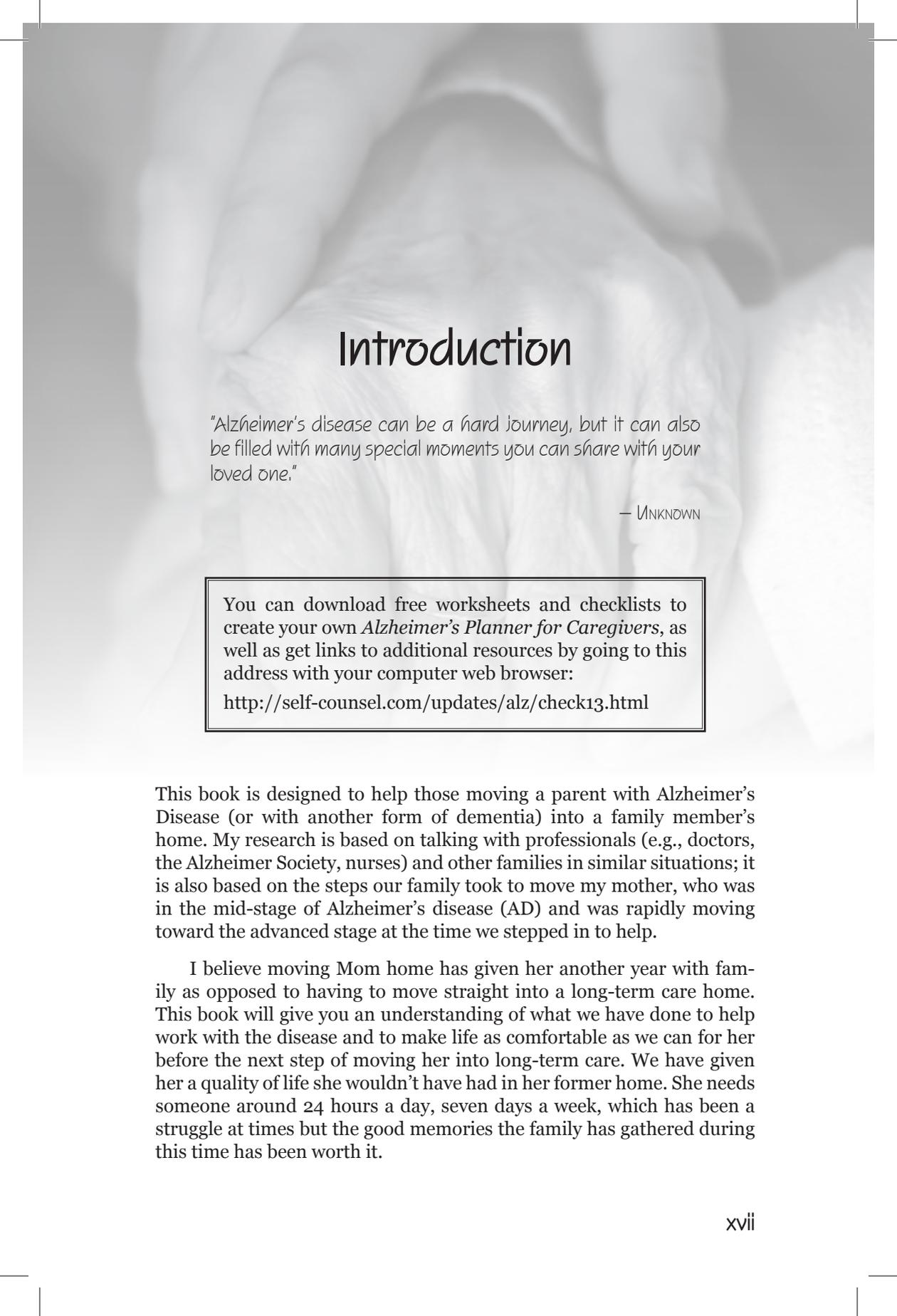
Estimates vary, but experts suggest that more than 5.1 million Americans and 500,000 Canadians have AD. According to the article "Alzheimer's Unlocked" (*Time*, October 25, 2010), by Alice Park:

“We spend \$5.6 billion a year funding cancer studies, \$1 billion a year on heart disease ... and \$500 million to study Alzheimer’s,’ said Dr. Ronald Petersen, director of the Mayo Clinic Alzheimer’s Disease Research Center.’ Yet what is going to get most of us in the next few years is Alzheimer’s.”

Two years later, in a news release on May 12, 2012, it was announced that President Obama’s administration had presented the National Plan to Address Alzheimer’s Disease (aspe.hhs.gov/daltcp/napa/NatlPlan.pdf). The plan includes making additional funding available to support research, provide clinicians with more education, and spread public awareness about the disease. There will also be funding for new research projects and easier access to information for support caregivers.

If your loved one is showing signs of AD, please learn as much as you can about the disease and spread awareness. The more people who know about it means more funding will go toward this disease and a cure will be found. In the United States, contact the Alzheimer’s Association (www.alz.org); and in Canada, the Alzheimer Society (www.alzheimer.ca) to see what you can do to help fight Alzheimer’s disease.

This book is written from the research and experience of our family. Every situation is different, but I hope that some of the information in this book will help you and your family on your journey with your loved one.



Introduction

"Alzheimer's disease can be a hard journey, but it can also be filled with many special moments you can share with your loved one."

— UNKNOWN

You can download free worksheets and checklists to create your own *Alzheimer's Planner for Caregivers*, as well as get links to additional resources by going to this address with your computer web browser:

<http://self-counsel.com/updates/alz/check13.html>

This book is designed to help those moving a parent with Alzheimer's Disease (or with another form of dementia) into a family member's home. My research is based on talking with professionals (e.g., doctors, the Alzheimer Society, nurses) and other families in similar situations; it is also based on the steps our family took to move my mother, who was in the mid-stage of Alzheimer's disease (AD) and was rapidly moving toward the advanced stage at the time we stepped in to help.

I believe moving Mom home has given her another year with family as opposed to having to move straight into a long-term care home. This book will give you an understanding of what we have done to help work with the disease and to make life as comfortable as we can for her before the next step of moving her into long-term care. We have given her a quality of life she wouldn't have had in her former home. She needs someone around 24 hours a day, seven days a week, which has been a struggle at times but the good memories the family has gathered during this time has been worth it.

It's a personal decision that family members need to discuss before moving the parent. I'm fortunate to have a sister-in-law, Sheila, who feels like a blood sister to me. This experience has made our families grow closer, which is something Mom has always wanted for us.

In our situation, my house does not include an extra bedroom; instead, Sheila offered her and my brother's home. My oldest niece, Myranda, had moved away, so they had a room to spare. I have to commend my sister-in-law because she stepped up without hesitation.

Our journey with Mom began in the summer of 2011. Mom drove from Saskatoon, Saskatchewan, to Lethbridge, Alberta, for a surprise visit. It had been a couple years since I had seen her, which was not unusual for us — we've always been close by phone. Her surprise visit wasn't unusual either because over the years, when she wanted to go for a short vacation she would just hop in her car and show up on our doorstep.

Mom was two hours late when I received a frantic phone call from her. She told me she was at a corner store, but when I looked at the call display on my phone, it named another store. I calmly asked her to put the manager on the phone, which turned out to be someone I knew. The manager kept an eye on her as she paced in front of the store until I got there.

When I drove up to the store, she didn't recognize me until I said, "Mom." Relief washed over her face and she rushed to my passenger car door trying to open it. "Mom, where's your car?" She looked at me confused and attempted to open the passenger door again. Again, I asked her where her car was. Her face showed a moment of clarity and then she marched across the parking lot to her car, and then she drove behind me to my home. She was slightly confused and anxious for the rest of the evening.

This book describes the steps and information Sheila and I had to learn in order to help Mom with the transition of moving. It was hard for all of us because we didn't have a clue about what to do or who to contact. It was so overwhelming for me, because the person I turned to for advice was now depending on me to give her advice and make decisions for her. Being that I've never had children, I knew very little about taking care of someone who was dependent. It is a huge responsibility but also an honor that Mom trusted us to take care of her during this time.

While this book was mainly written for sons and daughters looking for answers on how to deal with their parents who may now be going into early to mid-stage AD or dementia; in this world of blended families more and more adults are having to help uncles, aunts, stepparents, and even elderly siblings with cognitive impairments. AD doesn't affect just seniors; there are cases of people in their 30s, 40s, and 50s with the disease as well.

When a person you love begins to lose the ability to think properly, remember what happened yesterday (or even an hour ago), formulate ideas, or concentrate on a simple task, what do you do? How do you convince someone he or she can no longer take care of himself or herself? Chapter 1 discusses signs that your loved one needs someone to step in and help him or her. It also includes information on how to talk with the person about the move.

There are many good books dedicated solely to the topics of power of attorney, enduring power of attorney, living wills, and health-care directives; however, you will need to know some basics about these important documents. Chapters 1 and 5 include information about the necessity of having this paperwork in place before you begin moving your elderly relative.

We discovered the value of the Memory Book from Mom. She had been writing in memory books for the previous seven years. It wasn't so much a journal, but a book to keep track of what she was doing from day to day. She included shopping lists, trips to the doctor, social events, and sometimes her mood swings and fears. When we mentioned this to her new doctor in Alberta, he said, "You have inspired me to encourage my other patients with memory issues to create their own memory books." This in turn, gave Mom a big boost of confidence knowing she had inspired a doctor. (I owe Dr. Derman a big thank you for all the kindness, patience, and understanding he has given to both Mom and me.) Chapter 2 goes into the benefits of having your loved one create his or her own Memory Book.

Sheila and I divided our caretaking duties, but we kept all the information in one book that we passed back and forth between us when we took Mom to different appointments. We called this the *Alzheimer's Planner for Caregivers*. This was one of the most important tools for us to stay organized. It also helped us to reduce our caregiver stress. (See Chapter 3 for more information.)

You will find in the following pages help for transitioning the person with AD to your home. There are many reasons your parent may need to move in with you. In some areas there are long waiting lists for long-term care homes, and in some situations, the person cannot afford to move into a care home so the only option is to move the person into a family member's home. The biggest challenge is helping the person adjust to the new living environment (see Chapter 4), but it can also be a big adjustment for the caretakers.

What you and I deem organized and logical will not always be so with a person suffering from AD. You may find important paperwork

stashed in books, boxes, kitchen cupboards, or nowhere at all, so where do you begin? What do you do with all the stuff in storage or the knick-knacks that won't fit in the new place? Chapter 4 discusses the problems and solutions for going through someone's personal items.

There are many important government agencies you will need to contact as well as doctors and other experts who understand AD. If your parent is no longer fit to drive, how do you approach this topic? This can be a touchy subject because most people consider a license as a form of independence. Chapter 5 will take you through the steps to dealing with these important topics.

Chapter 6 discusses your loved one's finances, how to find all the accounts, organizing the bills and paying debts, and closing or transferring accounts.

Chapter 7 discusses some ways to help your parent cope with the disease. As a caregiver, you will need to understand AD as best you can in order to help your parent go through the progression of it. You may find your parent becomes difficult when it comes to bathing or changing his or her clothes. You will find tips in Chapter 7 to help you with difficult behavior.

You will need to find meaningful activities at the appropriate skill level for your relative with AD. Chapter 8 will give you suggestions of things to do with your loved one as well as solo activities. It is important that your parent is socially and physically active, which will help him or her be happier.

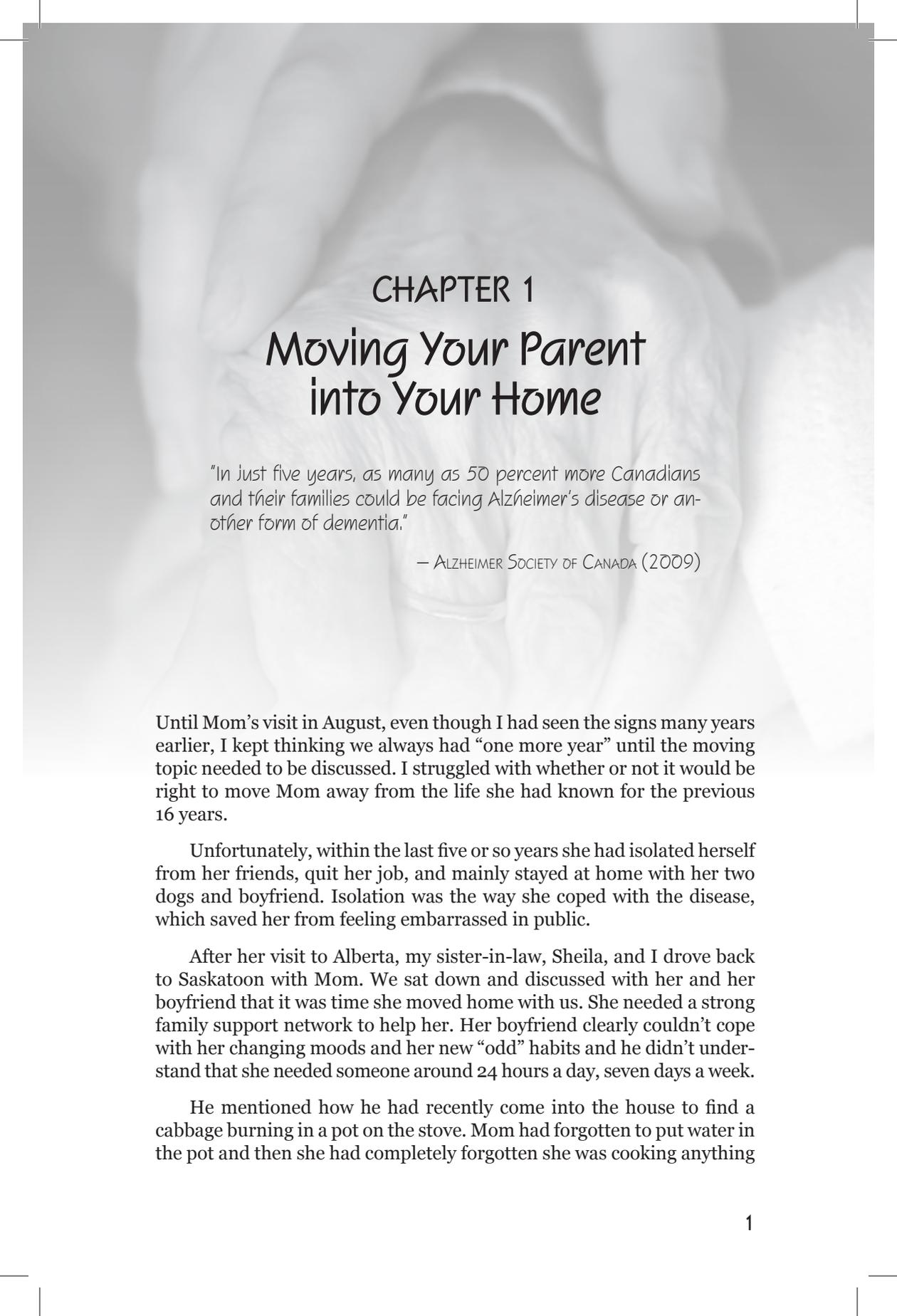
This book does not cover later stages of elder care, such as removing the elderly person from a long-term care home or abuses in a long-term care home environment. However, Chapter 9 discusses the complex issue of removing your relative from a bad home environment such as an abusive spouse or partner, whether it is verbal, mental, or physical abuse. When you are dealing with a victim with such a delicate frame of mind, removing him or her from a familiar place is not an easy task.

Chapter 10 discusses self-care for the caretaker. It's not always easy inviting a relative to live in your home. There will be a period of adjustment. Depending on how far advanced the cognitive impairment is, it may be necessary that the person never be left on his or her own. So how do you make time for yourself? You will need to learn to avoid caregiver burn out. If you can't take care of yourself, it is extremely hard to properly care for someone else.

What I have found during this journey with Mom, Sheila, and the rest of our family is that the good moments we have are cherished more

now than they have ever been. Memories are repeated over and over, but I don't mind hearing Mom's stories again and again. They make her happy, which makes me happy. I wish you all the best on your journey with your loved one, and I hope this book helps you with the transition.





CHAPTER 1

Moving Your Parent into Your Home

"In just five years, as many as 50 percent more Canadians and their families could be facing Alzheimer's disease or another form of dementia."

— ALZHEIMER SOCIETY OF CANADA (2009)

Until Mom's visit in August, even though I had seen the signs many years earlier, I kept thinking we always had "one more year" until the moving topic needed to be discussed. I struggled with whether or not it would be right to move Mom away from the life she had known for the previous 16 years.

Unfortunately, within the last five or so years she had isolated herself from her friends, quit her job, and mainly stayed at home with her two dogs and boyfriend. Isolation was the way she coped with the disease, which saved her from feeling embarrassed in public.

After her visit to Alberta, my sister-in-law, Sheila, and I drove back to Saskatoon with Mom. We sat down and discussed with her and her boyfriend that it was time she moved home with us. She needed a strong family support network to help her. Her boyfriend clearly couldn't cope with her changing moods and her new "odd" habits and he didn't understand that she needed someone around 24 hours a day, seven days a week.

He mentioned how he had recently come into the house to find a cabbage burning in a pot on the stove. Mom had forgotten to put water in the pot and then she had completely forgotten she was cooking anything

at all. She had gone off to do something else and didn't even notice the smoke billowing from the kitchen.

We made plans to come back in a couple of weeks to talk to her doctor and find out the best way to go about the move. When we returned, Mom was suffering from shingles. We took her to the doctor and discovered that Mom had been to the doctor twice the week before. The doctor didn't understand why Mom returned a second time (and now a third time with us) when she had already been given medication for the shingles. As we talked to the doctor, we discovered she didn't know that Mom had Alzheimer's disease (AD). Mom had told us she was on pills for AD and had already been diagnosed; however, she hadn't been prescribed pills or diagnosed.

The doctor learned from our visit about Mom's situation and in the end the doctor said, "I realize after this visit with you, the family, that I need to get to know my patients better." This is a major problem nowadays, there are not enough doctors for patients, which makes it hard for doctors to really get to know their patients due to lack of time.

I cannot stress enough that when you take over the care of your parent, you need to keep on top of all medical situations. You need to get to know the doctors, nurses, and others in the medical profession and get them to know your parent. Even though this book isn't about long-term care, when your parent goes into a care home someday, you still need to stay on top of everything that concerns your loved one; otherwise, he or she may get lost in the system.

We were told that if Mom was to stay in Saskatoon, it may be up to a year until she was able to see a Geriatric Specialist. Mom's general practitioner doctor said that considering the circumstances with Mom, she should go home with her family because we could provide a better network of help for her. The doctor suggested to help Mom with the transition that she come stay with us for three weeks, return to Saskatoon for three weeks, and then back to our place for another three weeks.

We returned a couple of weeks later to gather Mom and her items. When we arrived, we discovered the shingles had spread and they had become severely inflamed. We immediately took her to the hospital, where she was diagnosed with the worst case of shingles the doctor had ever seen.

We took her home to Alberta the next day and for the next three weeks we nursed her back to health. We weren't set up for the Alberta medical yet so there was a lot of medical care we couldn't access without paying for it. The brunt of the care fell to our family. At the end of the three weeks, we decided to not follow the doctor's suggestion of moving

her back and forth for the next few months. We felt that moving her back and forth would cause her more stress and confusion, which is not good for someone suffering from AD.

This chapter provides you with the first steps of moving your parent into your home. Hopefully in your situation, you don't have to move your parent a long distance. If you are lucky, it is a matter of moving your parent from his or her home to your home within the same city as you.

1. Signs Your Parent Can No Longer Cope on His or Her Own

The signs your parent is not coping well living on his or her own may be obvious, but sometimes you have to do a little investigating to see the extent of what is really going on.

If possible, have a few family members or close family friends visit your parent. This way you can compare what you and everyone else discover. Sometimes close family members overreact from small behavior changes — your parent may need some in-home services as opposed to moving to another home or into long-term care. You may even be in denial, so having someone else observe the situation may give you a more accurate description of how your parent is coping.

Sheila helped open my eyes to how severe the situation was with Mom. I kept saying, “Just give Mom one more year before we rip her from her life.” Finally Sheila had to say to me, “She may not have one more year if we don't move her home with us now.” Sheila was right and I'm thankful for her honest insight.

1.1 Living conditions

The first sign that your parent is no longer able to cope on his or her own may be the state of his or her home. Your parent may have once been very clean and organized, but now the inside of his or her home is messy and disorganized. There may be dirty dishes piled in the sink or spread around the house, moldy food in the fridge, or no food at all. You may also come across dirty clothes, towels, and bedding. Appliances may be broken or beyond repair or the furnace may no longer work properly or at all. On the extreme side, there could be an infestation of bugs or mice.

Outside the house, the yard may be neglected with signs of many weeds and an overgrown lawn or flower beds. Minor or major maintenance of the home is not being kept up such as broken windows, a leaking roof, or peeling paint. Damaged sidewalks and walkways may cause the person to trip and fall.

Basically, anything around the home that is evidence of poor living conditions is a sign you need to talk to your parent and find out why his or her living conditions have deteriorated.

If the person has a pet, the pet may be malnourished or overfed. In the case of my grandma, she forgot to feed her dog until it was close to death. We had to remove the pet from her home, but the dog had to eventually be put down due to how poorly it was. In Mom's situation, her dogs were grossly overweight from being overfed and not exercised enough.

Another concern with pets is if they are not being kept clean and the elderly person is sleeping with the animals. The bedding may be filthy, the floors unwashed, or there is other animal damage to the home that should have been fixed. Foul odors are another sign due to dirty litter boxes or feces and urine on the floor and stains in the carpet.

1.2 Behavioral signs

Overmedicating can be a common problem with prescription medications as well as self-medicating (i.e., drugs, alcohol, smoking). New habits such as drinking throughout the day or picking up smoking after decades of being smoke-free are all concerns.

The person may be taking a number of medications prescribed by various doctors. Check the labels on your parent's medications for expiration dates and doctor names. If you noticed different doctor names, you need to find out why your parent has been going to so many doctors. Your parent may be forgetting that he or she has seen many different doctors and the medications may be conflicting which is making his or her memory worse. Talk to a pharmacist about the medications your parent is taking; he or she can give you advice and whether or not the medications conflict with each other.

We noticed with Mom that whenever she had a cough, she would take a swig of cough syrup straight from the bottle. We observed her doing this many times throughout the day. She had also begun drinking a bottle of wine every one or two days, which didn't help with her memory or balance. Mom had never been much of a drinker so this came as a big surprise for me. We later discovered the wine was a coping mechanism for her stress.

We also found a newspaper article that Mom had kept saying a daily glass of wine was good for a person, which translated into her telling us a doctor had told her to drink wine every day. We had to wean her from her wine addiction by eventually substituting nonalcoholic wine in the regular wine bottle. Eventually I talked to a pharmacist, with Mom

present, about the effects of alcohol mixed with her medication. When the pharmacist explained to Mom that alcohol didn't mix well with her medications, she stopped drinking all together. Hearing this from a professional instead of concerned family members helped her believe the wine was not necessarily good for her in her situation.

If your parent was once a social butterfly, but now he or she refuses to go out, he or she may be socially isolated. You might notice that his or her friends no longer come for visits or he or she no longer makes it to regular social events or clubs. For example, church or some other form of religious contact may have been a staple in your home growing up, but now you may notice your parent is no longer attending services, which could be a sign that all is not right.

Another sign is hoarding. In Mom's situation it was paper hoarding. She kept every scrap of paper she wrote on or notes others gave her for appointments. She did this because she thought it helped with her memory, but instead it confused her because she would refer to old notes and appointment times.

1.3 Physical signs

Has your parent lost or gained a significant amount of weight? In our situation, Mom was extremely skinny, which shocked all of us. She had always been a bit rounder, not overweight, but not skin and bones. We discovered that she no longer had an appetite and if it wasn't for her boyfriend insisting she eat at mealtimes (he was the primary cook in their household), she would have starved herself to death. Chapter 7 goes into more details about problems with eating.

Your parent may be bruised or have cuts or sores he or she can't explain. This may be a sign of falling or may even be a sign of abuse by his or her spouse or significant other. Note that sometimes partners have a hard time dealing with the negative cognitive changes in another person and may no longer know how to deal with the situation. Other partners may have been abusive all along but your parent may have at one time been better at hiding the signs of abuse. Your loved one may show mental signs of abuse by being timid around the person he or she is living with. Maybe he or she cringes when the other person raises his or her voice. (See Chapter 9 for more information about elder abuse.)

The abuse may be the other way as well. As tough as it may be to admit, maybe your parent is abusing his or her partner. Those suffering from the early to mid-stages of AD may inflict violence on those around them because they are confused or frustrated and no longer know how to deal with their emotions.

You may also note that your parent no longer dresses appropriately. For example, he or she may wear pajamas when walking the dog. Or wear a heavy winter jacket when it is the middle of summer or a t-shirt in the middle of a winter storm.

Your parent may be wearing soiled clothing due to incontinence. He or she may not realize that there are stains on his or her clothing or favorite chairs around the house.

Your loved one's driving may be dangerous or erratic. If you discuss this with your parent, you may find he or she becomes defensive or hostile about it. (See Chapter 5 for more information about dealing with driving issues.)

If your parent smokes, you may notice burn marks around the house that weren't there before. You might observe your parent falling asleep with a cigarette in his or her hand while sitting in his or her favorite chair in the living room.

1.4 Financial signs

Bank accounts may be drained with no explanation from your parent as to where the money was spent. Credit cards may be maxed with odd purchases. Junk mail may be piled around the house with requests for donations from legitimate and non-legitimate charities. Mom was giving to every charity known to man, which was depleting her resources slowly and building up the junk mail collection in her filing cabinet.

If there are strange new people in your parent's life who seem to hang around for no reason you can understand, you need to find out who they are and why they are hanging around your parent. There are many people who prey on the elderly with contractor scams, phone scams, and the like. (See Chapter 6 for information about fraud.) If you notice cherished items missing from your parent's home, find out what happened to these items.

You may find bills unpaid or utilities have been turned off due to disregarded or misplaced bills. Or bill collectors have been calling, which can be causing your loved one major stress because he or she doesn't understand why he or she is receiving these calls.

2. Talk to Your Family First

Moving a parent into your home means your life will change. It is a big decision and not one to be taken lightly. You need to discuss it with your spouse and children before you talk to your parent because everyone in your home will be affected.

You should also include your siblings and any other extended family who may have concerns for your parent. Don't force other family members to help if they are not willing or comfortable to do so. It can create resentment, and it may even cause ill-treatment of your parent. Sometimes it is better without family members interfering with their own agendas. The family members that are resistant may get over their resistance in time, but the key is not to pressure anyone. The important thing to remember is that this is about your parent's welfare and not about anyone else's old grudges or unresolved family issues. At this time, past hurts need to be forgiven and everyone needs to move forward for your parent's sake.

2.1 *Explaining the situation to your children*

This may be a great opportunity for the children to get to know their grandparent; however, you will need to explain the situation to your children about what to expect when Grandma or Grandpa moves in. The Alzheimer Society has some wonderful illustrated children's books that you may be able to borrow from your local organization. By using the children's books, and explaining the disease, it will make it easier for your children to understand when their grandparent has an "off" day.

Your children may need to take on extra chores to help their grandparent. You will want to make sure your children don't resent your parent because of these extra duties. Explain to the children that it not only helps their grandparent, but also helps you and your spouse as well.

Try to make it a positive experience, such as explaining to your children that they are getting older so you are "trusting" them to do more "adult" duties. This may make them feel more responsible and excited to be able to help. It may be as simple as taking Grandma for a walk with the dog every day, or spending time sharing stories with Grandpa while weeding the garden.

You will also need to assess whether or not your parent can stay with small children alone for short or long periods of time. The safety of your children needs to be discussed before the move.

2.2 *Talking with your spouse*

Consider your spouse's feelings. If your spouse has never gotten along with your parent, maybe moving your parent into your home isn't the best option. Statistics show that many people who take on an ailing relative later get divorced due to the additional stress added to the household.

Will your spouse understand that you won't have as much alone time together? Or that you may not be able to go on dates as often, or family vacations.

You and your spouse need to have a strong connection because there will be hard times and hurt feelings due to the needs of your parent over your spouse's needs. Note that a person with AD picks up on moods better than most people so if there is tension between you and your spouse, your parent will notice. Fighting, yelling, and tension are all much too stressful for a person with AD.

2.3 Consider your relationship with your parent

What about your relationship with your parent? If your relationship has always been rocky, please don't think that it will magically change for the better now. AD can change your parent's personality.

Even if you have always had a wonderful bond with your parent, this may change due to what your parent is going through now. You may find living with your parent brings back bad memories from childhood, which can make you less empathetic to your parent's situation now. Consider talking to a therapist to try to work through the issues so that old problems don't cause friction in your home.

2.4 Work and activity schedules

Do you and your spouse have full-time jobs? If so, consider how you will both manage the caretaking duties while working. You may need to hire someone to come into your home and look after your parent when no family members or friends are available.

In our situation, Sheila and Shawn worked full time, Monday through Friday. I worked at home editing and writing so I was able to move my work to Sheila's home during the week or I would have Mom come to my home. In the evenings I worked at a job outside my home, but my shifts don't begin until either Sheila or Shawn is home from work. We were lucky because of my work schedule, but not everyone works part time or from home.

However, working while around Mom did become stressful because some days she was so agitated I had to get her out of the house to do an activity to decrease her stress. My deadlines, including the one for this book, were long overdue. Luckily, I have some wonderfully understanding clients. Eventually we had to get Mom involved in a day program for seniors so I could stay on top of my freelance work. (See Chapter 8 for more information about adult day programs.)

Depending on how advanced the disease is, you may not be able to leave your parent alone so that means bringing him or her to all family functions, children's sports events, and other family outings. If your

family loves camping in the summer, consider how your parent will feel about being in the wilderness. You may need to reduce your camping trips, or find someone to look after your parent while you are away. (Chapter 10 discusses respite care.)

You will also need to consider your parent's activities and medical appointments. When you move your parent, you will spend countless hours setting up medical appointments, filling out insurance forms, changing his or her address on important documents, and traveling to and from appointments. Your parent may also want to be involved with clubs so driving the person to and from his or her activities will take away from you and your family's time.

If you are a part of the "sandwich generation" — supporting your parent *and* your children — you need to schedule yourself some "me" time. If not, caregiver burnout will get you sooner rather than later. (See Chapter 10 for more information about taking care of your needs.)

2.5 Increased living expenses

There may be more household costs depending on whether or not you are going to have your parent contribute to household expenses or not. It is an extra mouth to feed and increased utilities used.

In our situation the heating bills went up drastically because Mom was always cold. We all had to learn to live with a hotter home environment. Even though Mom wore more sweaters, she needed the extra heat. We bought a space heater for her bedroom so she was extra cozy at night.

If your parent insists on paying rent or for some of the food, if he or she can afford it, why not let him or her contribute? This may make the person feel some independence by being able to contribute to the family household expenses. You will need to talk to other concerned family members, such as siblings, about the financial situation. They may not feel comfortable with your parent paying you for any living expenses. Or maybe you are not asking your parent for money to help with household expenses, but you want your siblings to contribute.

Another consideration is increased gas usage in your vehicle. My vehicle's monthly gas expenses doubled due to all the appointments for Mom as well as driving across town many times a week to spend time with her at Sheila's.

Your parent may have special food restrictions due to allergies or ailments so your grocery expenses may increase, especially if you have to buy specific foods for your parent.

2.6 Renovations

Will you need to renovate your home to accommodate your parent's special needs? You may need to add grab bars to the bathtub, wheelchair ramps, or wider doorways for walkers and wheelchairs.

It is important that your parent has his or her own space, a room he or she can retreat to for privacy. In this case, you may need to convert your home office into a bedroom or move one child into another child's bedroom in order for your parent to have a room of his or her own.

If you do need to renovate to accommodate your parent, you may be able to get some tax breaks. Contact your tax authority or tax accountant for more information.

2.7 Create a backup plan

If the living situation doesn't work out, you should have a backup plan in place. For example, one of your siblings will take your parent or maybe even a close friend of the family. You may not realize the extent of how advanced the AD is until the person is living with you, so long-term care may be your only option.

However, give it some time before making any rash decisions. At first, Sheila and I thought Mom was much more advanced in the disease than she was. Once we reduced her stress and she settled in, things were not as bad as they seemed in the first few weeks after she moved.

3. The "Talk" with Your Parent

When it comes time for the discussion to move your parent in with you or another family member, always remember you are changing this person's life at a time when he or she is already experiencing a lot of confusion. Your parent may not realize how much help he or she needs or even why the move is necessary. The person may be in denial or angry because of his or her loss of independence.

You need to make sure the conversation is as positive as possible. In our situation, Mom knew eventually we would come for her because she had to do that for her mother (my grandma). However, it still wasn't an easy topic for Mom to discuss.

Take a moment to imagine your life and how you would feel if someone you knew said right this moment: "You need to move out of your home (and your life) to live with us." You know as of right this moment you don't need looking after; the person with AD may also think that even though it is obvious to you that he or she does need help.

It's scary moving from a familiar situation especially for a person with AD. A person with AD copes with the disease by having routines so that it is easier to remember things. Now this person will have to learn a new routine with your family, and learning may not be so easy at this stage in his or her life.

There are so many mixed emotions to consider when you have the talk with your parent. In our situation it was hard because Mom's boyfriend didn't want to move to Alberta because his family network was in Saskatoon. He didn't want her to move because he felt he needed her there. She felt guilty leaving him, even though she knew it was for the best.

Our conversation included Mom, her boyfriend, Sheila, and I. The four of us sat in Mom's kitchen, where she was most comfortable, and we held her hands as we discussed her moving home with us. We all cried as the conversation progressed. The realization that this would change *all* of our lives was overwhelming.

I felt incredible guilt because I knew how much Mom loved her home, but the proper care wasn't available. We explained this. We also explained that she would need to be driven to and from various doctor appointments. We could help her with the medical jargon and the appropriate steps that need to be taken in the future.

We also explained that one person could no longer be a caretaker because she needed 24-hour care. She was getting lost more frequently while driving or walking to the store. This didn't mean that we had to be shackled to her side all the time. It meant having a presence in the home even if she was in a different room doing her own thing. We stressed that we were not taking away her privacy, but instead we would be there if by chance she felt lost or confused.

Explain to your loved one all the fun things you can do together. In our situation, Mom would have a chance to get to know her grandchildren better. She could go see my nephew, Kaiden, play lacrosse; and my niece, Ashleigh, graduate. Family BBQs; going to church with her son, Shawn; camping; and many other social outings would benefit her socially, which is something that is important for people with AD.

Explain to the person that his or her quality of life will improve. That should be the main reason why you move your elderly parent into your home. Your goal should be to make sure your parent is comfortable and is treated with dignity and respect while he or she is going through this difficult disease.

Tips for your conversation:

- Keep the conversation positive.
- Do not yell or argue because this causes your parent to have stress and with AD, you need to reduce stress.
- Discuss the benefits of moving into your family's home.
- Only make promises you are positive that you can keep. You need to build trust with your parent.
- Include your parent in the planning of the move, but if you notice your parent becoming agitated or stressed during this conversation, break the planning into small tasks so he or she is not overwhelmed.
- If your parent has a house pet, try to accommodate by bringing the animal into your home. Pets are a great comfort (see Chapter 8 for more information about pets).
- Ask for your parent's opinion and incorporate what he or she wants into the planning.
- Reassure the person that you are always going to be there for him or her.
- Do not focus on negative issues or past conflicts. This is about the here and now.
- Focus on the current issues.
- Never talk down to your parent.

Your parent may feel he or she will be a burden to you and your siblings so you need to reassure him or her that he or she will be included as a valued member of your family. You are doing this because you want to help him or her, and to enjoy the time you will have together.

If the conversation isn't going well with your parent, enlist help from others such as doctors or therapists.

3.1 *Enlist a doctor's help*

Before the move you should talk to your parent's doctor. He or she may be able to help with the discussion about moving in with the family.

We were lucky that Mom's doctor insisted she move home with us. Mom trusted her doctor's opinion so she was more willing to listen to the doctor's advice than to us.

When you are booking an appointment, make sure the medical clerk knows that it is a consult with the family and your parent. The medical clerk may need to book extra time. In our situation, the medical clerk didn't book for extra time (even though I explained the situation), which upset the doctor because it pushed back all of her other patient appointments. In fact, the doctor had us come back during her lunch hour to finish the discussion.

If you feel your parent should no longer drive, talk to the doctor about that as well. Because Mom was moving to a new province, I discussed the situation with my doctor first and he suggested that we have her current doctor remove her license. This prevented her from being mad at her new doctor for taking away a piece of her independence.

Note that many doctors don't like to be involved in the decision about removing a driver's license so you may need to talk to a driver's licensing bureau, which may insist your parent take another driving test to determine whether or not he or she can still drive. (See Chapter 5 for more information about driving.)

Talking with your parent's doctor while your parent is there is a good way to find out about the medical issues that are going on with your loved one. There may be medical issues your parent doesn't understand or has completely forgotten about. You can also get a list of the proper medications and dosages for your parent, which is important.

If your parent has many doctors, then you should take the time to talk with all of them to find out why there are so many doctors treating your parent.

Unfortunately, in many areas, doctors are not taking on new patients so you will need to find a doctor in your area that is willing to have your parent as a patient. I have a wonderful doctor who normally doesn't take on new patients but because I talked to him in advance and said I would like to have the same doctor as Mom, he agreed to have her as a patient. It is beneficial for doctors to treat all the same family members in case there are chronic health problems in the family. It gives the doctor an opportunity to know the family history better and to be able to treat problems within the family.

After you have acquired a doctor in your area for your parent, you will need to contact all the doctors your parent has dealt with in his or her former area. You will need to get all the medical files transferred to the new doctor before your parent even meets the doctor. Depending on how many doctors your parent was seeing, this can be an expensive but necessary endeavor. The cost for file transfers is up to the clinic you are dealing with. As far as I know, there are no regulations or set costs for

file transfers. I paid \$30 at one clinic because they had to scan all the files into the computer and then transfer them, and it had to be paid by check or cash not debit or credit card. Another clinic didn't charge me at all because it was an electronic-file transfer.

You will need to keep on top of the file transfers because, as in our situation, the scanning of the files was a big task that the medical clerks kept putting off. I had to keep calling to remind them to get it done. I believe it took about three weeks before the files were finally sent. I'm sure they would have never have arrived if I hadn't kept calling.

3.2 Contact a therapist or counselor

If your parent is willing, it may be beneficial to have him or her talk to a therapist or counselor before the move. Your loved one may be going through anxiety, depression, and anger because of the move and from the realization that he or she is losing some independence. A therapist or counselor may be able to help smooth the transition for your parent.

Your parent may want one-on-one time with the therapist or he or she may want to discuss some issues with you there. The therapist may be able to provide some techniques for both you and your parent to deal with the many family issues that can be caused by this major change in lifestyle for all of you.

3.3 Contact the Alzheimer Society

Your local Alzheimer Society or Alzheimer's Association will be able to help you by providing information, brochures, videos, and other helpful tools so contact them as soon as you can. They are the experts and they know the disease having dealt with many people with AD. Tap into that resource because it is free and there for families like yours.

I am so grateful to our local branch because they have been a wealth of information and support for our family.

4. Power of Attorney and Health-Care Directives

As your parent progresses through the disease you will need to take on more responsibility for his or her finances and health care. You will constantly be asked if you have the proper documentation and if it has been "enacted" in order to discuss your parent's situation. Government agencies, medical facilities, credit card companies, insurance agents, and many others will ask for copies of these documents before they will talk to you in regards to your parent.

I discovered using the Power of Attorney and Health Care Directive Mom had certified in Saskatchewan were accepted in some situations, but the wording was different in my province, so many institutions didn't understand exactly what the documents meant. When Mom had signed the documents, they were automatically enacted because that is how they were worded and it was what Mom wanted.

If your parent already has documents in place, but it was certified in a different state or province than the one he or she is moving to, your parent will need to talk to a lawyer in your area. If your parent is too far along in the disease, he or she may not be able to legally sign documents so you will need to talk to a doctor about getting a "doctor declaration" so you can move forward in being your parent's guardian or trustee. You will also need to apply to the local courts so you can be declared as your parent's guardian and/or trustee.

The names for these documents vary depending on your jurisdiction. The financial document is usually called something along the lines of power of attorney, springing power of attorney, or power of attorney for property. The health-care instructions fall under personal directives, medical consents, and health-care directives.

Because there are so many variations in the rules and wording of these types of documents (and I'm not a lawyer), I can't go into the details without writing a whole other book about it. Each area is different so talk to an attorney in your area and find out what steps need to be taken. There are also many good books you can buy or borrow to find out more about this.

The important thing to know is you will need this paperwork in place as soon as possible. You will also need to carry a copy of the documents to appointments, so talk to an attorney right away.