A Relationship Contract for Dementia Caregi♥ers

Navigating the Complexities & Challenges of Caring for the Memory Impaired

Debra Hallisey

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ISBN: 979-8-9852996-1-8

Printed in the United States of America

All of the persons used as examples in this book are composites of clients the authors have worked with. The names and identifying characteristics have been changed.

Published by
Debra Hallisey
Lawrenceville, NJ 08648
www.advocateformomanddad.com

Cover design: Eric Labacz, labaczdesign.com

This book is dedicated to the millions of dementia family caregivers who step into their persons reality, and in doing so, allow them to feel safe and loved. It is within this shared reality that we find the moments of joy which uplifts and sustains them and us.

What They Are Saying…

This book is a must have companion for anyone caring for a loved one or patient with Dementia. Every aspect of the extraordinary challenge of being a caregiver is so clearly explained and acknowledged, and some of the best solutions, strategies and answers are found in these pages. Deb walks us through the maze of caring for someone with Dementia, gently but firmly guiding us to being the best caregiver we can be based on her own experiences, strength and hope. There is no one better to take with us as our guide. The book helps us feel less alone, more prepared and certainly more aligned with those we love and care for.

Susanne White
Caregiver Warrior

Debra's book is an easily accessible tool for caregivers looking for an validation of their communication challenges. Examples are given in a way that provides a framework to understand new ways of communicating with our loved ones. Deb's keen observations and support of many caregivers have given her the heart and knowledge to present her unique perspective on the topic"

Annette Murphy, MSW,LSW, C-ASWCM
Aging Life Care™ Advisor
Director, Home Care &Care Management for Springpoint at Home
Co-PRESIDENT, New Jersey Chapter, Aging Life Care Association®

This book is an important contribution to our understanding of the emotional demands of being an Alzheimer's caregiver which are all-encompassing and increase over time as the disease progresses. Little acts can make a big difference. Caring for someone with Alzheimer's or another dementia is exceptionally demanding, and especially challenging. This book provides ideas to encourage people to lend a hand to a caregiver, understand the importance of effective communications, gives us permission for relationships restructuring through contacts and tools for person-centered care approaches.

How to help an Alzheimer's Caregiver is a learned responsibility. Offering caregivers a reprieve is…often a welcome gift. Even one hour can provide the caregiver with the reprieve they need to reset. It is important for family and friends to see the common signs of caregiver stress, denial, anger, social withdrawal and isolation, anxiety, depression, exhaustion, and self-health problems. This book is an important contribution to our toolbox of resources for families and ourselves and we all need the encouragement and boundaries provided to enable us to cope with the tremendous responsibility of a caregiver.

Thank you for providing an understanding of Alzheimer's caregiving and writing another real-life contribution to our everyday work and mission.

Robyn Kohn, MA, CDP, CMDCP
Caregiver, HealthCare and Dementia Educator
Director of Programs and Services, Alzheimer's Association

In her wise and comforting book, *A Relationship Contract for Dementia Caregivers*, Debra reminds us that a dementia diagnosis cannot change our most human desire to connect with and relate to each other. She shares practical tools and helpful strategies to ease our worries that a family member’s dementia diagnosis will rob us of our relationship. Instead, we can implement Deb’s ideas so that we can continue to connect in meaningful and heartfelt ways.

Denise M. Brown
Founder, The Caregiving Years Training Academy

Once again, Deb captures the most basic and deepest challenges that a caregiver may face and makes brilliant recommendations to overcome each one in a step-by-step manner. With a focus on dementia, Deb paints a colorful roadmap for a caregiver to follow. Our loved ones with dementia are not always capable of setting the boundaries in the same manner that we are. Deb breaks it down beautifully to be sure the caregiver can still help their loved one set personal boundaries within their own processing ability. She also continues to guide the caregiver to learn to set their own boundaries and practice self-care all while providing the best care for their loved one.

Sheli Monacchio, CDP, HSAC, ADLS
Senior Vice President of Business Development
Angelion Mobility

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Introduction

"But how do you set a boundary with someone who has dementia?"

I frequently hear this question and others like it from dementia family caregivers. Their questions help me to understand the unique challenges of caring for someone with dementia, in particular Alzheimer's.

For the most part, caregivers face many of the same issues, no matter what the disease or issue of the person they are caring for. How do you have the hard conversations? How do you deal with all the emotions that surface? What is the best way to deal with the expectations of other people and set needed boundaries? How do I say "yes" to help, ask for help, and get the person I am caring for to say "yes" to help? How can I build a support system that is just for me, the caregiver?

Here is the thing, dementia is different. You will not be able to set boundaries in the middle to late stages of a person living with a progressive brain disease. But you will need to set boundaries with other people in your life, particularly in these later stages. And boundaries with the person that is in the early to middle stage are not only appropriate, they are necessary so you can begin to plan for this journey.

Every family is unique which makes the caregiving journey unique as well. Don't underestimate the role childhood family dynamics play in this new scenario. Frictions will resurface along with past hurts, even in families with strong ties. This makes setting boundaries a challenge. And, if your family is not intact or does not have strong ties to the community, it can complicate caregiving.

Being a caregiver takes hard work.

I don't mean the physical work of helping your loved one shower or dress. I mean the mental and emotional work it takes to be a caregiver, particularly for someone living with a progressive brain disease. Your person may look the same, may even sound the same, but they are not the same. Coming to terms with this is incredibly difficult, particularly since you know over time, things will continue to change in big and small ways.

Be prepared because your entire way of communicating is about to change in ways you cannot even imagine. It will require learning how to take your cues from your caree. That means learning how to become a master detective which is the key to a calm and peaceful life for the person living with dementia and for yourself.

Learning to live in moments is another important lesson for a caregiver of someone living with memory impairment. Living in moments is something we would all benefit from and need to practice. So is learning to treat everyone we meet as if they have dementia. The first time I heard dementia specialist Amy Matthews say this, I could not understand what she meant. Over the course of time, I've learned that it means treating everyone with compassion, dignity, and being in the moment with them.

As a Certified Caregiving Consultant™, working with dementia family caregivers has given me an insight into a world we all hope we never live in. There are many forms of dementia, but my work has been concentrated in Alzheimer's so the examples in the book are based in that form of dementia. Even within Alzheimer's, early-onset Alzheimer's has unique challenges with very little time to prepare for them.

During the last seven years I have learned lessons I want to share with you. Some are taken from being my mother's caregiver, others from dementia family caregivers.

The most important one is that becoming a caregiver changes all your relationships, your "contract," if you will. This idea of a relationship contract resounds with my clients and readers of my blog. Because it helps us to recognize there IS an unspoken contract, while inviting caregivers to do the hard-intentional work to co-create a new one.

This book is written from my point of view as an adult child who cares for an aging parent. But the worksheets and example conversation starters at the end of every chapter will help you to co-create a caregiver relationship contract with everyone in your life. This book and the tools in it are designed to help you in your caregiver role, whether you live near or far, and it will help you if your role is to support someone who is a caregiver.

One final thought: I've always looked at relationships as a dance. If one partner changes the dance, the other has no option but to adapt or stop dancing. It is an analogy that works for negotiating a new dementia caregiver relationship contract as well. In those hard conversations, in setting boundaries, in asking for help, you will change the dance you have been engaged in for years. My hope is that the ideas and tools found here keep you dancing in new, different, and better ways.

"The only way to make sense out of change is to plunge into it, move with it, and join the dance."

Alan Watts

Chapter 1

An Overview of Dementia

"If you have met one person with dementia, you have met one person with dementia."

Thomas Kitwood attribute

Let's start by dispelling the myth that age-related memory loss is normal.

It IS normal as we age for processing in the brain to take longer to store and retain things, and normal is unique to each person. Let's take my mom for example. In her late 80's I noticed that she was unable to do math in her head like she used to. Along with that change, I noticed occasionally she would ask me the same question during our conversation.

I realized that in a calm, quiet environment, these changes were less noticeable because she had the environment her brain needed to process the question or conversation. Without the calm environment, she was more easily confused. About the same time, Mom lost the rest of her eyesight and was having dangerously low blood pressure. Loss of eyesight, hearing, and low blood pressure all result in slower processing. But this is not memory loss.

This need for a calm environment and time to process was reinforced when Mom moved into an assisted living center. There were so many changes and new people in and out of the room that she could not see. Mom said more than once, "I'm afraid I am losing my mind." I asked her to give it a month and if she (and I) were still concerned we would get a diagnosis. It has been two months now and with her acclimation, she no longer worries as much about memory loss. I believe one of the primary reasons she is having less cognitive impairment is that Mom was taken off blood pressure medicine by her doctor.

All this is to say that it is important to know the memory strengths and weakness of your person. When you know what is normal and you see things changing, you will know if you have cause for concern. The key, however, is not to bury your head in the sand. You know your person and if there is concern, get tested, starting with a full physical workup. Many physical ailments can cause issues with memory.

Dementia is Not a Disease

It is a Category of Symptoms

There are two causes of dementia, neurodegenerative diseases and other conditions that can cause dementia like symptoms.

Let’s be clear, dementia and Alzheimer’s are not the same. It’s confusing because the terms get used interchangeably. Dementia is the category of symptoms that illustrates a decline in cognitive ability. When the decline is severe enough to interfere with activities of daily living there is cause for concern.

Activities of Daily Living (ADLs)

ADLs are one of two standards used by the healthcare industry. The other is Instrumental Activities of Daily Living (IADLs). Together they help to define what it takes to live independently at home. ADLs are the normal daily activities that a person does for themselves throughout the day. We will take a deep dive into these standards in chapter 3 “Life Changes for Everyone.” But it is important to understand how they play into causes for concern.

- ♥ Can the person go to the bathroom, dress, and brush their teeth without help?
- ♥ Can the person get in and out of the bath?
- ♥ Does the person walk with a steady gate?
- ♥ Can the person go upstairs without help?
- ♥ Can the person feed themselves?
- ♥ Can the person dress without help?

There are four core mental abilities that are cause for concern: recent memory, language, visuospatial function, and executive function. If your person is having problems with two or more, they can be showing signs that may qualify as dementia. For example, not remembering if they ate or if they can’t find the bathroom, these can be signs of a loss of recent memory and visuospatial function.

Notice I use the term “may qualify” because the diagnostic process looks for these changes. Changes to these four core mental abilities can be caused by things other than a neurodegenerative disease. Hearing loss or a urinary tract infection (UTI) are just two causes.

Remember when I said Mom started showing signs of cognitive decline? Not only was her blood pressure dangerously low, but she had an undiagnosed UTI, both of which sent her to the hospital for a week.

It was only through my pushing the doctors that she went from 60 mg of blood pressure medicine down to 10, and then off completely. Despite asking questions, no one had reduced the BP medicine to match her new, lower weight.

Like Mom, there are typically multiple causes when a person shows a cognitive decline, which is why a diagnosis is so important. The diagnosis is a rule out one based on several evaluations. Through this process, doctors can be ninety to ninety-five percent accurate in determining the cause of the symptoms of dementia.

Neurodegenerative Diseases That Cause the Symptoms of Dementia

Below are the four most common diseases that cause the symptoms of dementia. There are more than four diseases but, I have listed them from the most to least common. The causes of, and behaviors, are different for each. Alzheimer's is most common among the elderly and age is the greatest risk factor.

- ♥ Alzheimer's is most commonly described as progressing in three stages: early, middle, and late. Each stage correlates to increased brain damage. In the early stage, the most notable symptom is no short-term memory. It is a slow and progressive loss in ability and memory. It is deceiving because they will look and sound the same, but they have a brain disease. In this stage, families will often chalk it up to getting older. Often it is not until a family notices the loss of executive function like safety awareness that causes them to realize this is not just memory loss due to getting older. Because each person is unique, the way Alzheimer's affects the individual will also be unique. Be aware that this disease will magnify their personality, good or bad.
- ♥ Vascular dementia is caused by a series of small strokes (TIAs) The result is the short-term memory comes and goes. Where the TIAs strike in the brain affects behavior as well. One thing to note is that there is also mixed dementia of which the most common is a combination of Alzheimer's and Vascular.
- ♥ Dementia with Lewy bodies (DLB) looks like a combination of Parkinson's disease and Alzheimer's with physical affects and progressive loss in memory and ability. About 50% of individuals with this disease also suffer from sleep disorders.

♥ Frontotemporal dementia (FTD) is the least common and tends to hit younger people with an average age of 40-60. Frontotemporal dementia progresses more rapidly than these other neurodegenerative diseases. Behavior becomes unpredictable and can change without warning. Individuals living with this type of progressive brain damage must be watched carefully. One moment they can be okay and the next they are enraged.

Other Conditions That Cause the Symptoms of Dementia:

These conditions also cause the symptoms of dementia, but they can be managed and cured.

♥ Depression

♥ Medication: The older the body, the longer the drug stays in the body and, the older the body the more differently the drug reacts making periodic medication reviews important. These changes continue as we age.

♥ Metabolic imbalances: Kidney, thyroid, liver

♥ Vitamin Deficiency: Lack of B vitamins: niacin, thiamin, B12

♥ Infection (e.g. UTI)

♥ Dehydration

♥ Malnutrition

How Do You Know the Difference?

Dementia-like symptoms caused by the conditions listed above will typically be marked by sudden change in mood, memory, or a change in personality and behavior. At the same time Mom was having the “off and on” dementia-like symptoms, she would also have what I called her “spells.” She would act as if she was sleeping sitting up. She would answer questions, but if I asked her to do something she would normally do, she was not able to follow the command. Sometimes she would pick at her clothes. Her doctor always went to a drop in her sugar because of the diabetes. Later I realized it was after she took her morning medicine which has the first of two blood pressure medicines in the mix. It wasn’t until she was hospitalized with dehydration, low blood pressure, and a UTI that I was able to force the issue of lowering the blood pressure medicine because we had an accurate weight for her. Her inability to complete a task wasn’t executive function issue, it was a mix of health issues.

Since there are multiple causes of the symptoms of dementia, it is important to get an accurate diagnosis. Getting a diagnosis typically starts with the primary care physician (PCP). The PCP is looking at the whole person which is necessary to rule out other conditions as the cause of the symptoms and behaviors you recount.

However, a primary care physician is not necessarily an expert in geriatrics. It is important that you ask the PCP what percent of their patient population are elderly and has memory problems.

Before you make an appointment with a neurologist which is often our first inclination, ask for a referral for a comprehensive geriatric assessment. Many hospitals have geriatric departments or specialists. You can Google geriatric assessment centers and a list of hospital systems and doctors can also get you started.

The geriatric assessment should be a comprehensive medical, physical, psychological, and cognitive exam that includes blood work and scans like an MRI, PET and CAT. A full assessment includes social and medical history. It is only after a full assessment that you can rule out physical causes and more specifically hone in on which disease it may be. Remember, dementia is an umbrella term for symptoms, it is not the disease. You want to know the disease so you can take appropriate action and care.

I cannot say it enough**.** ***It is important to know normal patterns of behavior and get an accurate diagnosis.*** If someone gets confused during the day but wake up clear, this is his/her normal pattern of confusion. The day they wake up confused is your clue that something is going on.

Exercise 1.1

Getting Ready for Your Doctor Visit

A strong healthcare team is support not just for the person with memory impairment, but for you the caregiver as well. Being organized for a visit to the multiple doctors on your healthcare team is key.

To get ready for a visit:

♥ Plan ahead by writing down concerns and questions and then bring the list to the appointment! Don’t be afraid to call after the visit with follow-up questions.

♥ Keep notes on specific changes in behaviors, routines, or eating. Specific includes: when does it happen, how often, did you notice a trigger.

- ♥ Bring medications to each appointment, including over-the-counter medications. It is important to include any vitamins or herbal supplements as well. If you bring a list, be sure to include dosage being taken for ALL medications.
- ♥ Ask questions until you understand what the healthcare person is telling you. If they use jargon, stop them and ask for an explanation.
- ♥ Talk about treatment goals and understand all the options.
- ♥ Keep good records. Records should include test results, changes to medications or care plans. Without this, doctors can not coordinate care, but remember you are still the first and last line of defense.
- ♥ Review the care plan before you leave and note follow-up steps.

Exercise 1.2

When to Revisit the Treatment Plan

Your treatment goals and plan need to evolve as your dementia journey continues. The available options, the risks, and benefits should consider your person living with this progressive brain damage and YOURSELF as their caregiver. It is important to work closely with the doctor and other members of the health care team as often as needed during this journey.

To ensure an optimal treatment plan, a review should be done at the very least when you hit these milestones:

- ♥ As age increases and overall health changes.
- ♥ When current treatment goals don’t seem to be working anymore.
- ♥ When the severity of symptoms and their impact on your life changes.
- ♥ If the living situation or availability of family members and caregiver’s change.

Exercise 1.3

Alzheimer’s Treatment Questions to Ask the Doctor

- ♥ What treatment options are available?
- ♥ Which symptoms are being targeted by each medication?
- ♥ How will the effectiveness of each treatment be measured?
- ♥ How much time will pass before you will be able to assess the treatment’s effectiveness?

- ♥ How will you monitor for possible drug side effects?
- ♥ What side effects should we watch for at home?
- ♥ When should we call you?
- ♥ Is one treatment option more likely than another to interfere with medications for other conditions?
- ♥ What are the concerns with stopping one drug treatment and beginning another?
- ♥ At what stage of the disease would you consider it appropriate to stop using the drug?

*Taken and adapted from the Alzheimer's Association website.