

While You Can Still Decide

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Eldercare Locator

1-800-677-1116, Monday through Friday, 8 a.m. to 9 p.m. Eastern, or eldercare.acl.gov. A public service of the U.S. Administration on Aging that connects older adults and caregivers with local help anywhere in the country.

From
The Sitting Room Series

**BOOK 6 • GRIEF AND
MEMORY LOSS**

While You Can Still Decide

After a Diagnosis of Memory Loss

Stephen Deason



Alder
Creek
EDITIONS

While You Can Still Decide

After a Diagnosis of Memory Loss

Book 6 of The Sitting Room Series

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The named examples, such as Joan, Luis, and Curtis, are composites drawn from many families and written to teach, with names and details changed. They are not case histories, and real situations often resolve less cleanly. The author's accounts of his own family and work are drawn from his experience.

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Preface

This book is for the weeks and months after a doctor uses the words mild cognitive impairment, or early dementia, or Alzheimer's disease, about you. It is written to the person who heard them.

I have spent about forty years working inside health care. I began volunteering in a hospital at fifteen and was working as an orderly by sixteen, helping care for patients in hospitals and nursing homes while I worked my way through college. Later, I spent more than twenty years building and running systems for hospitals, insurers, Medicaid programs, and other health care organizations before returning to direct care through healthcare staffing, home care, and skilled nursing.

Today I run OPA Home Care, which I founded. In Georgia it is a licensed Private

Home Care Provider, or PHCP, a health care facility that delivers care in the patient's home, and I serve as an Administrator there. Our home care operations have recruited, hired, and managed caregiving staff for hundreds of families.

My own mother was found wandering the parking lot of a hospital, looking for her car. She had a urinary tract infection that urgent care and the hospital both missed, and she was sent home with severe delirium and a new diagnosis of mild cognitive impairment. It took two weeks, and a nurse practitioner and a doctor we knew who were willing to look again, before anyone found the cause. She stayed with us for two months and then moved into independent living. She has kept improving, and she is driving again.

I tell that story at the front of this book for one reason. A diagnosis given in the middle of an illness deserves a second look after the illness is over. Chapter 2 explains how to ask for one.

Many of the families who call my company have already reached the point where someone else is deciding for the person they love. A daughter is trying to find out whether her father ever signed a power of attorney. A husband cannot get the bank to talk to him. Brothers and sisters disagree about what their mother would have wanted, and nobody can ask her anymore. Many of those decisions could have been made years earlier by the person themselves, in an office visit or two.

That is what this book is for. A diagnosis of memory loss usually comes while you can still do most of what you did before, and while you can still decide. You can use the

time between now and later to say what you want, put it on paper, name who will speak for you, and keep living the life that is yours.

The facts and program rules in this book come from the sources listed at the back, each with the chapters that use it. The judgment about what to do first, what to ask, and what families discover too late comes from years of doing this work.

The first ten chapters are written to you. Part Two, at the end, is written to your care partner: the spouse, grown child, or friend who will be beside you. They are welcome to read all of it. You remain the person it is written for.

1. Who This Book Is For and How to Use It

This book is for you if a doctor has told you that you have mild cognitive impairment, early dementia, or early Alzheimer's disease. It is also for you if you have been told your memory has changed and you are waiting for tests, or if nobody has yet said what the change will become.

Some memory loss gets worse over time and some does not. You may not know yet which kind you have. This book is still for you. Where the advice differs, the chapter says so.

What this book does

It helps you understand what you were told, find out what can still be treated, and decide what you want while the decision is yours. It covers the papers to put in place, who to tell and how, work, money, and

driving, and how to keep the parts of your life that matter most to you.

It does not diagnose anything, and it does not tell you whether you can still drive or work. Those questions belong to your doctor, and some of them to your state. Each chapter that raises one of those questions names who to ask and gives you the words to ask it.

Read it in pieces

You do not have to read this book in order, or all at once. Each chapter stands on its own. Start with the one that answers the question in front of you.

Some people like to read one section at a time, or to have someone read a chapter aloud with them. Write in the margins. The pages with lines on them, and the blank pages after each chapter, are for you.

Where to start

- If you just left the doctor's office and are not sure what you were told, start with Chapter 2.
- If the news has knocked the wind out of you, start with Chapter 4.
- If you want to get your papers in order, start with Chapter 6.
- If you are still working, start with Chapter 7.
- If someone has raised your driving, start with Chapter 8.

If you are the care partner, start with Part Two, which begins with Chapter 11, and come back here afterward.

A word about the people in this book

The named examples in this book, such as Joan, Luis, and Curtis, are composites drawn from many families. The story about my mother is mine.

Who to call first

Who to call or ask: Your own doctor, for any question about your diagnosis or your health. The Alzheimer's Association 24/7 Helpline, for questions about memory loss, any hour. The 988 Suicide and Crisis Lifeline, if you are in distress.

How to reach them: The doctor's number is on your last appointment card. The Alzheimer's Association Helpline is 1-800-272-3900, free, any hour, every day. Call or text 988, or chat at 988lifeline.org.

What you can say: I was just told I have a problem with my memory, and I want to understand what that means and what to do next.

NOTES

1. Who This Book Is For *and* How to Use It

“Lay hold of to-day’s task, and you will not need to depend so much upon to-morrow’s.”

Seneca, Moral Letters to Lucilius, Letter 1,
translated by Richard M. Gummere

2. What the Diagnosis Means

Most people leave the appointment remembering one word. It may be Alzheimer's, or dementia, or impairment. The rest of what the doctor said is a blur. That is normal, and it is the reason this chapter exists.

Mild cognitive impairment

The Alzheimer's Association describes mild cognitive impairment, often called MCI, as an early stage of memory loss or of another thinking ability, such as language or judgment, in a person who can still do most everyday activities on their own.

MCI does not always become dementia. Some people with MCI go on to develop dementia, and others do not. For some, the problem stays the same for years, and for some, thinking returns to normal. The

Alzheimer's Association estimates that 10 to 15 percent of people with MCI develop dementia each year, and it recommends that a person with MCI be checked again every six months.

Dementia

Dementia is a general term for a loss of memory, language, problem-solving, and other thinking abilities that is serious enough to get in the way of daily life. It is not one disease. Alzheimer's disease is the most common cause, and the Alzheimer's Association puts its share at 60 to 80 percent of cases. Other causes include strokes and other diseases of the brain.

In the early stage of Alzheimer's, the Alzheimer's Association says, a person may still live on their own: they may still drive, work, and take part in social activities, even as memory lapses begin, such as forgetting

familiar words or where everyday things are.

What else can look like memory loss

Many other conditions can cause memory problems or confusion. Some can be treated, and the memory problems may get better when they are. Others are a different illness from Alzheimer's disease, with their own care. In my work, I have seen many of these, if not all of them. Ask your doctor which of them have been checked and ruled out, and which have not.

Vitamins, thyroid, and fluids

- Low vitamin B12. Many older adults absorb less B12 from food, and low B12 can cause confusion and poor memory.
- An underactive thyroid, called hypothyroidism, which can cause forgetfulness and other problems with thinking.

- Dehydration, which can cause confusion. Some people lose their sense of thirst as they age, so they may not drink enough.

Medicines and alcohol

- Some medicines, or several medicines taken together, which can cause forgetfulness or confusion.
- Too much of a medicine building up in the body. Digoxin, a heart medicine, is one example, and confusion is one of the signs.
- Heavy drinking.

Infections

- Infections such as a urinary tract infection or pneumonia, which can cause delirium, sudden severe confusion, in older adults.
- Infections that reach the brain itself. Syphilis that spreads to the brain, called

neurosyphilis, can cause confusion and trouble concentrating.

Conditions in the brain

- Normal pressure hydrocephalus, a buildup of fluid in the brain that can cause trouble walking, trouble with bladder control, and trouble thinking. It is usually treated with a shunt, a thin tube that drains the extra fluid.
- A subdural hematoma, blood collecting on the surface of the brain, under the skull. In older adults it can follow a minor head injury and go unnoticed for days. It can cause confusion and memory problems.
- A series of strokes, including small ones that caused no symptoms at the time.
- A brain tumor.

- Parkinson's disease and Lewy body dementia, which can affect thinking and memory.

Mood and sleep

- Depression, which can cause forgetfulness, confusion, and trouble concentrating. Depression often responds to treatment.
- Stress and anxiety.
- Untreated sleep apnea, where breathing stops and starts many times during sleep. It can cause daytime sleepiness and trouble remembering and concentrating.

A diagnosis made during an illness

Sudden confusion during an illness can be delirium. MedlinePlus, the National Library of Medicine's health site, lists among its causes infections, medicines, and changes in body chemistry. A urinary tract infection

can come with confusion in an older adult, but confusion alone does not prove one.

If you were told about your memory in a hospital, in an emergency room, or during or soon after an illness, ask your doctor whether the testing should be done again once you have recovered.

In my experience, a memory diagnosis is hard to get revised, but it does happen. When a diagnosis is revised, the cause is often another problem in the body: an infection, dehydration, or trouble with blood sugar. A second look usually takes a different doctor from the one who made the first diagnosis, and a family that keeps calling and keeps asking. How long a second look takes depends on how soon you can get an appointment and how often someone follows up. My mother's diagnosis came during an infection. She kept improving after the infection was treated.

Who to ask about your diagnosis

Who to call or ask: The doctor who made the diagnosis, or your own doctor. If you want a second opinion, ask for a referral to a specialist in memory, such as a neurologist, a geriatrician, or a geriatric psychiatrist.

How to reach them: Call the office and ask for an appointment just to talk about the diagnosis. Say you are bringing someone with you.

What you can say: I would like a visit to go over my diagnosis and make a plan. What exactly do I have, how sure are you, and what have you ruled out?

A visit just for this

Medicare Part B covers a separate visit with your doctor or another health care provider to review your thinking and memory fully, confirm a diagnosis such as

dementia, and make a care plan. The visit can include an exam, a review of your medical history and your medicines, a look at who helps you at home, help with planning for future care, referrals to specialists, and information about help in your community. You may bring a spouse, a friend, or a caregiver. After the Part B deductible, you generally pay 20 percent of the Medicare-approved amount.

Ask for it by name: a cognitive assessment and care plan visit. Ordinary appointments are short, and a diagnosis like this deserves more than the last five minutes of one.

Questions to take to the doctor

Write your answers here during the visit, or ask the person with you to write them.

What exactly is my diagnosis, and how sure are you?

Is it likely to get worse, stay the same, or get better?

What have you checked and ruled out: medicines, vitamin levels, thyroid, depression, infection?

Should any test be repeated, and when?

Am I a candidate for any treatment, or for a research study?

Is it safe for me to keep driving? To keep working?

When should I come back, and who do I call in between?

Joan was told she had mild cognitive impairment at the end of a visit for her blood pressure. She drove home and did not tell her husband for three days. When she finally did, he asked what the doctor had checked, and she did not know. She called and asked for a longer visit. At that visit the doctor went over her medicines and stopped a sleeping pill she had taken for years. Her memory problem did not go away, but her mornings got clearer. Her next check is in six months.

If you want to talk it through

The Alzheimer's Association Helpline at 1-800-272-3900 is free and answers any

hour, every day. You can call to ask what a word on your paperwork means.

NOTES

2. What the Diagnosis Means

*“The heart of the prudent getteth knowledge;
and the ear of the wise seeketh knowledge.”*

Proverbs 18:15, King James Version

End of the preview

You have read the first two chapters of *While You Can Still Decide: After a Diagnosis of Memory Loss*, Book 6 of *The Sitting Room Series*. The full book has 12 chapters, in large print.

The book's page at aldercreekeditions.com has the buy links for the paperback and Kindle editions once they are on sale. The ISBN below is the paperback's.

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The worksheets from this book are free to print at aldercreekeditions.com, where the other books in the series are listed too.

You are welcome to share this preview with anyone it might help.

