

When More Help Is Needed

# **If you need help right now**

## **Emergency**

911

## **988 Suicide and Crisis Lifeline**

Call or text 988, any hour, or chat at [988lifeline.org](https://988lifeline.org). For anyone in distress, or worried about someone who is.

## **Eldercare Locator**

1-800-677-1116, Monday through Friday, 8 a.m. to 9 p.m. Eastern, or [eldercare.acl.gov](https://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**

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**BOOK 1 · GETTING MORE  
HELP**

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# When More Help Is Needed

*A Guide for You and Your Family*

Stephen Deason



Alder  
Creek  
EDITIONS

# **When More Help Is Needed**

*A Guide for You and Your Family*

Book 1 of The Sitting Room Series

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## About This Book

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The named examples, such as Evelyn, Walt, and Margaret, 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.

To the fullest extent the law allows, the author and publisher are not liable for any loss, injury, or damage arising from the use of this book. In an emergency, call 911. In a crisis, call or text 988.

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# Preface

This book is personal for multiple reasons. 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 am an Administrator of a licensed health care facility that delivers care in patients' homes.

That facility is OPA Home Care, which I founded and run. In Georgia it is a licensed Private Home Care Provider, or PHCP. My healthcare staffing company employed

nurses and aides across hundreds of health care facilities around the country, including through the COVID years, and our home care operations have recruited, hired, and managed caregiving staff for hundreds of families. I have watched older adults and their families make the decisions in this book, usually in a hurry and usually at a difficult time.

What I kept seeing was this. Families meet the information in pieces, after they already need it, from people who each answer a different piece. The hospital owns the discharge. The insurer owns the benefit. The home care provider owns its services. Each of them may do that job well. The family still has to put the pieces together.

It happened to my own family. My 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. The infection was ordinary. The months that followed were the cost of catching it late.

Much of the information in this book is already available somewhere. Medicare publishes Medicare's rules. The federal government publishes home safety guidance. The VA explains VA benefits, and each state explains its own programs. That is part of the problem. A family deciding whether more help is needed does not meet those questions one agency at a time.

The questions arrive together. I wrote this book to put them in one place, in the order people tend to need them, with a way to act on each answer.

The book is written to you, the person whose life is changing, because the decisions are about your life. Your family has its own chapters at the end and its own boxes along the way. They are welcome to read all of it. You remain the person it is written for.

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 which facts matter, how they fit together, what families often discover too late, and what questions to ask comes from years of doing this work. Chapter 12, on hiring a helper yourself, draws on that work most. Before I started OPA Home Care, covering for a worker

who called out was the work my staffing company did every day. When my own family needed care at home, we found that many private caregivers and private-pay agencies could not reliably do it. I have watched the same thing happen to hundreds of families since, and Chapter 12 says plainly what it costs.

This book will help you notice what has changed, decide what you want to keep, talk with your family, find the help that fits, and know who to call. Start with Chapter 1, or with whatever brought you here.

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

This book is for you if daily life has started to take more out of you than it used to.

You may be wondering whether it is time for some help. It is also for you if someone in your family has already said so, and you are not sure what you think about that.

It is written to you, the person whose life it is. The decisions in it are yours to make, unless you choose to hand one to someone else. Chapter 11 explains which questions need a doctor or a lawyer first. Your family has its own boxes in Chapters 5 and 10, and its own part at the end of the book. If you are reading this because you are worried about someone else, you can start with Part Two, For Your Family, which begins with Chapter 14, and come back here afterward.

## **What this book does**

It helps you look at what has changed, decide what matters most to you, talk about it with the people around you, and learn what kinds of help exist. Then it helps you take one first step.

It does not tell you what you need. Nobody can know that from a book. The people who can help you work it out are named in the chapters where they come up. Each names who to call, how to reach them, and the words you can use.

## **Use what you need**

You can read the book from the beginning, or start with the chapter that answers the question in front of you. Write in it, skip what does not apply, and come back when the question changes. You do not need to finish the book before you do something useful.

## **How the book is laid out**

- Chapters 2 and 3 are about noticing the change, whether you noticed first or someone else did.
- Chapter 4 helps you write down what you want to keep. Everything after it is measured against that page.
- Chapter 5 is the first conversation with your family, with words you can use.
- Chapter 6 is a map of every kind of help, from a neighbor who checks in to a nursing home.
- Chapter 7 is about money. It gives you the questions to ask, and tells you who can answer each one, many of them for free.
- Chapter 8 is about the times when it is not safe to wait, including leaving the hospital.
- Chapter 9 walks you through your home, room by room, to make it safer.

- Chapter 10 is about driving, and about other ways to get around.
- Chapter 11 is about deciding together, and the papers to sign while you can.
- Chapter 12 is about what you are paying for when help comes into your home, and the first weeks of having a helper there.
- Chapter 13 is a plan for your first month.
- Chapters 14 and 15 are for your family, and for anyone who helps you.

The chapters follow the order these decisions usually come in. You do not have to settle everything at once. Most of the time, you need to understand the next decision well enough to make it.

## **Two ways to use each chapter**

Some people work things out by talking them over. Some people would rather have a list and get on with it. Most chapters end

with a short section for each. Use whichever one fits you, or both.

## **The pages for writing**

There are pages in this book for you to write on. You will change your mind about some of what you write. If you want fresh copies, the worksheets are free to print at [aldercreekeditions.com](http://aldercreekeditions.com).

## **Why the writing is plain**

You may be reading this tired, worried, interrupted, or in a hurry. The writing is plain on purpose. Important ideas sometimes appear more than once, and the same kinds of questions and sections come back from chapter to chapter. You should be able to put the book down, come back later, and understand what matters without starting over.

## **The examples in this book**

The named examples in this book are composites drawn from many families, with names and details changed so that each one shows a particular problem clearly. Real families are messier, and some of the examples end without a fix. They are here to help you recognize a situation and see one way through it.

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### **If you need help right now**

In an emergency, call 911.

If you are in crisis, or worried about someone who is, call or text 988.

To find help for an older adult anywhere in the United States, call the Eldercare Locator at 1-800-677-1116.

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## **Where the rest of the series picks up**

The other books, listed at the back, cover help at home, choosing a place to live, moving, papers, memory loss, and grief.

NOTES

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

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*“I had three chairs in my house; one for solitude, two for friendship, three for society.”*

Henry David Thoreau, *Walden* (1854),  
“Visitors”

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## 2. Noticing It Yourself

You may notice the change before anyone else does. It can show up in small ways, each one easy to explain away.

A woman who has gardened for forty years finds she is doing the front beds and leaving the back ones for another day, and then another. A man who always paid his bills the day they came finds two of them under a magazine, a month late. Neither of them would say anything had changed. Both of them knew it had.

### **Some changes you may notice**

None of the changes below, alone or together, says what is happening to you or what you should do about it.

- The stairs take longer, or you have started living mostly on one floor.

- Meals have gotten simpler, or you skip them more often than you used to.
- The mail piles up. Bills get paid late, or twice.
- You are less sure you are taking your medicines the way they were prescribed.
- You drive less, or only in daylight, or only on roads you know.
- You have fallen, or nearly fallen, and did not tell anyone.
- You go out less, and see fewer people than you did a year ago.
- Housework or yard work you used to finish in a morning now takes the week.
- Bathing, dressing, or getting in and out of a chair takes more effort and more care.

If some of these sound familiar, the rest of this book is about what you can do next.

## **Why it is easy to explain away**

Each change has a reason. The bills were late because the statement came on a busy week. The back garden can wait. You have not been out because it rained. Each explanation may be true. Taken one at a time, the changes are easy to set aside until something forces the question.

Over the years I have watched families explain these changes away for months. A father gets lost driving home on a road he has taken for thirty years, and it was dark, or there was construction. He catches himself on the kitchen counter three or four times in two weeks, and the floor was wet, or he stood up too fast. Then he falls and breaks a hip, and the question becomes where he will go when he leaves the hospital. In my experience the explaining usually lasts three to six months before an event like that ends it. With the

confusion a urinary tract infection can cause, it is often two or three weeks. With balance, it can be weeks to months. With memory loss, it can be a year or more.

Evelyn, who is 81, started a record like the one in this chapter mostly to prove her son wrong. On the third day she wrote that she had skipped lunch because the can opener hurt her hands. On the sixth day she wrote the same thing. On the ninth she wrote that she had missed choir practice because she did not want to drive home after dark. When she read the two weeks through, the lunches surprised her. She had written the same line twice and had not noticed it was the same line. She took the page to her next appointment. Her doctor sent her to an occupational therapist, who brought a different can opener and some ideas for her hands. Choir she sorted out herself, with a ride from a woman in the alto section.

Writing the changes down for two weeks lets you see them side by side. You may find there is less going on than you feared. You may find there is more. Either way, you will have something concrete to show your doctor or your family if you decide to.

### **Keeping a two-week record**

Use the record on the next pages. Each day, write one or two things that were harder than you expected, and what you did about it. Leave a day blank if nothing comes to mind. At the end of two weeks, read it through once and circle anything that came up more than once.

| Day | What was harder today | What I did about it |
|-----|-----------------------|---------------------|
| 1   |                       |                     |
| 2   |                       |                     |
| 3   |                       |                     |
| 4   |                       |                     |
| 5   |                       |                     |
| 6   |                       |                     |
| 7   |                       |                     |

| Day | What was harder today | What I did about it |
|-----|-----------------------|---------------------|
| 8   |                       |                     |
| 9   |                       |                     |
| 10  |                       |                     |
| 11  |                       |                     |
| 12  |                       |                     |
| 13  |                       |                     |
| 14  |                       |                     |

**What came up more than once:**

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## **When a change belongs with your doctor**

Some changes are worth a call to your doctor's office without waiting for the two weeks to end. A fall is one, even a fall that did not hurt. So is a noticeable change in memory or thinking, or a medicine that seems to be causing problems. Your doctor decides what these changes mean. Your job is to tell them.

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## **Who to call about a fall or a sudden change**

**Who to call or ask:** Your own doctor, or the doctor's nurse line. For questions about medicines, your pharmacist.

**How to reach them:** The number on your last appointment card, your insurance card, or your prescription label. If you cannot reach anyone and the change is sudden or serious, call 911.

**What you can say:** I am calling because something has changed. Last week I fell in the kitchen. I did not hit my head, but I want to tell the doctor and ask whether I should come in.

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## **Getting the most from the appointment**

Appointments are short. It is easy to leave without asking the one question you came with. Bring these with you:

- Your two-week record.
- A list of every medicine you take, including vitamins, supplements, and anything you buy without a prescription. Or put them all in a bag and bring the bag.
- Your questions, written down, with the most important one first.

Some questions people find useful:

- Could any of my medicines be part of this?
- Is there someone, such as a physical therapist or an occupational therapist, who could help me with this?
- What should I watch for, and when should I call you?
- Is there anything I should stop doing, or start doing?

If you would like someone with you, bring them. A second person can take notes

while you talk. Tell the doctor at the start that you want them there.

### **If you want to talk it through**

Pick one person you trust and tell them you have started keeping a record. You do not have to show it to them. Saying it out loud to one person makes the next conversation easier.

### **If you want something to do**

1. Write today's line in the two-week record.
2. Put your doctor's number and your pharmacy's number on the My Own Numbers page at the back of this book.
3. If you have fallen in the last few months and not told your doctor, call this week.

**NOTES**

2. Noticing It Yourself

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*“The years teach much which the days never know.”*

Ralph Waldo Emerson, “Experience,”  
Essays: Second Series (1844)

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# End of the preview

You have read the first two chapters of When More Help Is Needed: A Guide for You and Your Family, Book 1 of The Sitting Room Series. The full book has 15 chapters, in large print.

The book's page at [aldercreekeditions.com](http://aldercreekeditions.com) has the buy links for the paperback and Kindle editions once they are on sale. The ISBN below is the paperback's.

**ISBN 979-8-952410-12-1**

The worksheets from this book are free to print at [aldercreekeditions.com](http://aldercreekeditions.com), where the other books in the series are listed too.

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

