

Visit Journal

This journal belongs to _____

Room or address _____

Journal number _____

If you need help right now

Emergency

911

988 Suicide and Crisis Lifeline

Call or text 988, any hour, or chat at 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. 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 10 · GETTING MORE HELP

Visit Journal

A Shared Record for Everyone Who Visits

Stephen Deason



Alder
Creek
EDITIONS

Visit Journal

A Shared Record for Everyone Who Visits

Book 10 of The Sitting Room Series

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The short example in Section 1 is composed to teach and is not a case history. The author's accounts of what he has seen in his work are drawn from his experience, with any detail that could identify a person left out.

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 face what this series covers, often 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 puzzle 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 series is already available somewhere. Medicare publishes Medicare's rules. The VA explains VA benefits, and each state explains its own programs. Having information spread across so many places is part of the problem. Families do not meet these questions one provider or agency at a time. The questions arrive together. I wrote this series to put many needed pieces in one place, in the order people tend to need them, with a way to record or otherwise act on each answer.

The facts and program rules in this journal come from the sources listed at the back, each with the sections 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. In this journal, that work shapes one thing most: noticing change. An older adult often changes slowly. Each day looks a lot like the day before, so a visitor who

comes every day can miss a change that is plain to someone comparing today with a month ago, or two. I see this a lot in families where one child visits every day and another comes in every few months. The call I get comes from the one who visits every few months, and it sounds like this: “What happened to Mom?” The child who visits every day had not seen it. A change can also come in a few days. A caregiver works with someone on Monday and Thursday, and the family covers the weekend. The next Monday, the caregiver finds the person confused from a urinary tract infection that began over the weekend. By then the person needs emergency care. A weekend visitor who had read the last few visits, and written down what they saw, might have caught it on Saturday. The slow changes are what the look-back pages are for: the page after every tenth visit asks you to read back over those ten visits and write down what has changed.

This journal belongs to the person you visit. You and the others who visit will do most of the writing, and most of the pages are about time spent with them.

This journal will help you see what has changed and get a worry to the right person quickly. Start with Section 1, or open to the next blank visit.

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

This journal is for everyone who visits: children and grandchildren, a husband or wife, friends, neighbors, people from church, and volunteers. Each visitor writes up the visit on the next blank page and signs it. A visit by phone or video counts. Write it up the same way, with “by phone” or “by video” under Where.

Many of the families I work with keep a shared notebook like this one, and when a family does not have one, I ask whether they would like one. These notebooks catch a great deal: a change in thinking that turned out to be a urinary tract infection, the first signs of memory loss, a fall the person never mentioned and was still hurting from two days later, a cut on an arm or a leg that is not healing. The visit page and the other fill-in pages are free to print at aldercreekeditions.com, for anyone who wants loose copies in a binder that lies flat, or more pages than this book holds.

Who writes in it

This is the person’s own journal. They can write in it any time, or ask someone to write for them, and Sections 7 and 8 are pages for them. Paid caregivers and the staff where the person lives are welcome to read it. They keep their own records, so the writing in this journal is for family and friends.

Where it lives

Keep it in the same place every time, by the chair or in the room, so the next visitor can find it. In memory care, keep it in a drawer or a family bag in the room. Write the person's name and room on the first page, so a journal that wanders can find its way back. Take a photo of Sections 2 and 3 on your phone in case the journal goes missing.

Before you go in

Read the last two or three visits. The line on each page headed "For the next visitor" is written for you.

What to write

Write what you did, what they said in their own words, and what you saw. Write every entry as if the person will read it, because they may. Write a hard change plainly and kindly: what you saw, not what you think it means. If there is more to say, call the family.

If the person tells you someone hurt them, frightened them, or took something, do not write it here. In a care community, tell the administrator or the person in charge that day; if the administrator is the one named, call the state licensing agency and the police. At home, call Adult Protective Services. Section 4 has the numbers. If the person is in danger, call 911.

Keep these out of the journal: other residents' health, care, and family business (a friend's first name is fine); account numbers, passwords, and Social Security numbers; and anything you would

not want someone else to read. The journal sits where other people can open it.

Family who live away

A son who lives three states away calls his mother every Sunday. His sister visits in person and was not sure the calls belonged in the journal. They do. After each call he texts the family a few lines, and whoever visits next copies them onto the next blank page, with “by phone” beside his name.

Some families take a photo of each visit page and send it to the rest of the family. Decide together, with the person if you can, before you start, because the photo leaves the room.

Looking back

Where I work, a nurse reads back over the past week’s notes, and the weeks before that, looking for patterns. The look-back pages let a family do the same. Watch for changes in appetite, in how awake the person is, in what they remember, and in the small stories they tell. Any change can point to something underneath, and Section 4 says who to tell.

What the staff can tell you

Federal privacy law allows a nurse or a doctor to tell you what bears on your part in the person’s care, unless the person objects. It allows this but does not require it, and when the person cannot decide, the staff use their judgment. The law covers health care providers such as doctors, hospitals, and nursing homes; some

assisted living and independent living communities are not covered and follow their own policies. If you hold a power of attorney for health care, or another legal role, ask the nurse or the social worker what they need from you.

Writing a concern in this journal does not report it to anyone. If something worries you, Section 4 says who to tell and how soon.

2. About the Person

Routine matters more than most families expect, and it matters most when someone is living with memory loss. I watched a caregiver notice that a man who always started his morning with coffee was drinking tea and was short with everyone. The coffee machine downstairs in his building had broken. She found a way to make coffee in his room, and the rest of his day went well. Write the small things on these pages so every visitor knows them.

Fill these pages in with the person, and change them when things change.

What they like to be called

The people in their life, and how each is related

What they like to talk about

What they would rather not talk about

What helps on a hard day

Their routine: meals, rest, and the best time of day to visit

The small things that make a day go right

Things to bring, and things not to bring

Faith, music, programs, and pastimes that matter to them

Glasses, hearing aids, dentures, and other things that go missing: where they belong

Clothes and laundry: how things are labeled, and who does the wash

What every visitor should know: a walker or cane, a special diet, help with eating or walking

How they are now, so later visitors can compare: walking, talking, eating, sleep, memory, and mood. Date it.

3. The Visitors

Write down everyone who visits, how to reach them, and the day they usually come.

Name	How related	Phone	Usual day

Where the person lives or gets care

Name of the place or the provider

Main number

After-hours number

Charge nurse or nurse on duty

Director of nursing

Administrator

Social worker

Grievance official (in a nursing home)

Their doctors and other help

Main doctor

Doctor's number

Other doctors or nurses

Pharmacy

Home care, home health, or hospice office

Health care agent or power of attorney

Case manager (Medicaid, the VA, or insurance)

Dentist

Eye doctor and hearing aid office

Faith leader

Neighbor or friend to call

Numbers for a worry

Hospice 24-hour number

Long-term care ombudsman

Adult Protective Services

State licensing complaint line

State survey agency (nursing homes)

BFCC-QIO (Medicare quality and appeals)

Where the do-not-resuscitate order or POLST is kept

3. The Visitors, continued

Who is coming

Plan the visits a week at a time, so no stretch of days goes without one.

Week of	Who is coming, and which days

3. The Visitors, continued

Week of	Who is coming, and which days

4. If Something Worries You

This section is for the visitors, so you know who to call if something goes wrong. Most visits will never need it. The state numbers here are Georgia's, as examples; write your own state's numbers in Section 3.

Someone has to notice a concern and say it. If you see something, tell the staff, and keep telling people until someone acts, wherever the person lives: at home, in independent living, assisted living, memory care, a nursing home, or a hospital. The people who work in senior care are busy all day, moving from one hard situation straight into the next. You may have to say the same thing several times before someone gives it full attention.

For a concern about health or safety, if you have no answer within a few hours, go to the next person named below for that setting.

How soon

- Right now: anything that looks like an emergency, such as trouble breathing, chest pain, heavy bleeding, or a person you cannot wake. Call 911, and if there is staff on duty, get them at the same time.
- Right now: sudden new confusion, over minutes or hours, that is not their usual; trouble speaking; trouble seeing; trouble walking or keeping balance; a sudden severe headache; or numbness or weakness in the face, an arm, or a leg, especially

on one side. These can be signs of a stroke. Call 911, and note the time the signs started.

- Right now, after a fall with a blow to the head: a headache that gets worse, weakness or numbness, a seizure, vomiting more than once, slurred speech, one pupil larger than the other, confusion or agitation, passing out even briefly, unusual drowsiness, or a person you cannot wake. Call 911 or go to an emergency room.
- Right now, if the person has taken the wrong medicine or too much of one: call Poison Help at 1-800-222-1222, any hour. If they stop breathing, collapse, or have a seizure, call 911 first.
- As soon as you notice it: confusion that builds over a day or two, compared with their usual. It can come from an infection, such as a urinary tract infection, or from a new medicine. Call the person's doctor or nurse, and if they cannot see the person that day, go to an emergency room.
- As soon as you notice it: any fall. Make sure the person is checked by a doctor or nurse; in a care community, ask the nurse what the check after the fall found. If they take a blood thinner, including aspirin, and hit their head, they need to be seen right away, even if they seem fine, because blood thinners raise the risk of bleeding in the brain. If their doctor cannot see them right away, go to an emergency room.
- The same day: a new injury or bruise, a cut that is not healing, a change in eating or sleep, or a medicine that seems wrong. Tell the nurse or the person's doctor.

- The day you suspect it: abuse, neglect, or someone taking the person's money. Report it using the routes below. If someone is in danger, call 911.

If the person is on hospice, ask at the first visit what to do in an emergency, whether the person has a valid out-of-hospital do-not-resuscitate order or POLST form, and where it is kept. Write the hospice's 24-hour number and where the form is kept in Section 3. For symptoms the hospice has told you to expect, call the hospice first. If the person stops breathing and there is no valid out-of-hospital order saying not to attempt resuscitation, call 911. If the person is choking, call 911. If you cannot reach the hospice right away and are unsure what to do in another emergency, call 911.

At home

If a licensed home care provider or a home health agency sends caregivers, call its office first. Call the person's doctor about a change in health. If a case manager is assigned through Medicaid or the VA, tell the case manager too. A Medicare home health agency must tell the person about the state's home health hotline, which takes complaints and questions about home health agencies. If a licensed home care provider does not settle a problem, call the state licensing agency, if your state licenses home care. If a worker sent by an agency may have abused the person, report it to Adult Protective Services and the licensing agency the same day. In Georgia, that is the Department of Community Health, Healthcare Facility Regulation, at

1-800-878-6442, weekdays from 8 a.m. to 5 p.m. If a home health agency gives notice that Medicare will stop paying for its care, the notice explains how to ask the BFCC-QIO for a fast appeal (see In a hospital). Follow the deadline printed on it, usually noon the day before services end.

Abuse, neglect, or exploitation at home

Who to call or ask: Adult Protective Services in the person's state.

How to reach them: Call the Eldercare Locator at 1-800-677-1116 and ask for Adult Protective Services, or find the state office at napsa-now.org. In Georgia, call 1-866-552-4464, choose your language, then option 3, Monday through Friday, 8 a.m. to 7 p.m. Eastern (check the hours at aging.georgia.gov/adult-protective-services), or use the online form linked at georgia.gov/report-elder-abuse. If someone is in danger, call 911.

What you can say: I am calling about my father, who lives at home. I am worried that he is being neglected. Here is what I saw, and when.

In independent living

Start with the community's manager. The long-term care ombudsman serves nursing homes, assisted living, and similar care homes, so for someone in independent living, use the routes under At home, including Adult Protective Services for abuse, neglect, or exploitation.

In a nursing home

Start with the charge nurse. If that does not settle it, go to the director of nursing or the administrator. Every nursing home that takes Medicare or Medicaid must name a grievance official. You can raise a concern with that person out loud or in writing. The resident has the right to a written decision, which must include the date the grievance was received and the steps taken to investigate it. Ask for one. If the home gives notice that Medicare will stop paying for skilled care, the notice explains how to ask the BFCC-QIO for a fast appeal. Follow the deadline printed on it, usually noon the day before services end.

You do not have to go through the home first. At any time, you can call the state survey agency, which inspects nursing homes, or the long-term care ombudsman. The home must post their names and numbers. If you suspect abuse, call the state licensing agency and the police. In Georgia, the licensing agency is the Department of Community Health; report it to Healthcare Facility Regulation at 1-800-878-6442, weekdays from 8 a.m. to 5 p.m., or online at any hour through dch.georgia.gov. If someone is in danger, or you think a crime happened, call 911 or the police now. Tell the administrator and the ombudsman too, unless the administrator is the one you suspect.

A nursing home resident may have visitors of the resident's choosing, at times of the resident's choosing. Immediate family and other relatives must be given immediate access unless the resident says no, within any clinical or safety limits in the home's

written visiting policy. Other visitors need the resident's consent and may be limited for reasonable clinical or safety reasons. These rules are for nursing homes; assisted living rules vary by state. If visits are being cut back, call the ombudsman.

In assisted living, memory care, or a personal care home

Start with the administrator or the person in charge that day. If that does not settle it, call the long-term care ombudsman or the state licensing agency. For abuse or neglect, call the state licensing agency and the police. In Georgia, report it to Healthcare Facility Regulation at 1-800-878-6442, weekdays from 8 a.m. to 5 p.m., or online at any hour through dch.georgia.gov. If someone is in danger, or you think a crime happened, call 911 or the police now. Tell the ombudsman too. Outside Georgia, ask the ombudsman or the Eldercare Locator, at 1-800-677-1116, for the licensing agency's number. In some states, Adult Protective Services also takes these reports.

The long-term care ombudsman

Who to call or ask: The ombudsman program in the person's state, which serves people in nursing homes, assisted living, personal care homes, and similar residences.

How to reach them: Look for the number posted in the building, find the state program at theconsumervoice.org/get_help, or call the Eldercare Locator at 1-800-677-1116. In Georgia, call 1-866-552-4464 and choose option 5.

What you can say: My mother lives in a nursing home. I raised a concern with the staff this morning and have not had an answer. Can you help?

The ombudsman works for the resident, and acts with the resident's consent, or with a representative's consent when the resident cannot give it. Anyone can call. In most cases the ombudsman needs that consent before reporting abuse, so report abuse to the licensing agency and the police yourself.

In a hospital

Start with the charge nurse, and ask whether the hospital has a patient relations or patient advocate office. A hospital that takes Medicare must have a grievance process. It must tell patients whom to contact, set time frames for a response, and give a written decision. You can also take a complaint about the quality of care to the state survey agency. If the person has Medicare, you can also go to the Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO). Two companies

serve as BFCC-QIOs for Medicare, each covering certain states. In Georgia it is Acentra Health, at 1-888-317-0751. Complaints about any provider licensed through Georgia's Healthcare Facility Regulation go to 1-800-878-6442.

If the person was admitted as an inpatient and you think the hospital is discharging them too soon, read the Important Message from Medicare the hospital gave them. It explains how to reach the BFCC-QIO to ask for a fast appeal. Call no later than the day of discharge. If you ask later, the BFCC-QIO can still review the case, but you might have to pay for the extra days in the hospital. Some people who were admitted as inpatients and then changed to observation status can also ask for a fast appeal before they leave the hospital. Ask the BFCC-QIO whether the person qualifies.

With hospice

Ask for the hospice's after-hours number at the first visit, and write it in Section 3. Medicare requires hospice nursing services to be routinely available 24 hours a day, 7 days a week. If a concern about care is not settled, call the state licensing agency (in Georgia, 1-800-878-6442, for a provider licensed through Healthcare Facility Regulation) or the BFCC-QIO, which takes complaints about the quality of Medicare-covered care. If the hospice gives notice that Medicare will stop paying for its services, the notice explains how to ask the BFCC-QIO for a fast appeal. Follow the deadline printed on the notice, which is usually noon the day before services end.

5. Questions and Follow-Up

Keep each question or concern on this log, with the date you raised it and the answer you got.

Use one row for each concern. Write the date, what you raised, who you raised it with (their role is enough), the answer, and when to follow up. When it is settled, write how it ended.

A new bruise or injury goes on the visit page as what you saw, and to the nurse or doctor that day. A suspicion of abuse does not go in this journal, where anyone may read it. Report it, and keep your notes somewhere else.

Date	What we raised, and with whom	The answer, and how it ended	Next check

5. Questions and Follow-Up, continued

Date	What we raised, and with whom	The answer, and how it ended	Next check

5. Questions and Follow-Up, continued

Date	What we raised, and with whom	The answer, and how it ended	Next check

5. Questions and Follow-Up, continued

Date	What we raised, and with whom	The answer, and how it ended	Next check

6. Care Meetings

In a nursing home, the resident and the resident's representative take part in the care plan where they can, and the plan is reviewed after every assessment, including the quarterly ones. Other settings keep their own plans. Ask when the next review is, and ask to be there.

Date _____ **Next meeting** _____

Who was there _____

What changed

What to watch for

What we asked, and the answer

6. Care Meetings, continued

Date _____ **Next meeting** _____

Who was there _____

What changed

What to watch for

What we asked, and the answer

6. Care Meetings, continued

Date _____ **Next meeting** _____

Who was there _____

What changed

What to watch for

What we asked, and the answer

7. In My Own Words

These pages are yours.

Write here yourself, or ask someone to write down what you say.

What I want my visitors to know

What I like us to do together

What I would rather we did not do

7. In My Own Words, continued

Things I would like to do or see again

Anything else, in my own words

8. Notes to Each Other

These pages are for writing to each other: the person you visit to the family, and the family to the person. Read them aloud together if you like.

What I enjoy most about your visits

[illegible]

8. Notes to Each Other, continued

A few lines from each of us to you

[illegible]

[illegible]

The Visits

One visit to a page. Start at the next blank page and sign your name. A short visit can have a short entry. After every tenth visit there is a look-back page.

Visit 1

Date _____ **Where** _____

Who visited (sign) _____

What we did

What they said

How the day went: mood, pain, eating, sleep, memory, falls

For the next visitor, and anything you told the staff

Anything they asked us to write down

Visit 2

Date _____ **Where** _____

Who visited (sign) _____

What we did

What they said

How the day went: mood, pain, eating, sleep, memory, falls

For the next visitor, and anything you told the staff

Anything they asked us to write down

End of the preview

You have seen the opening pages of Visit Journal: A Shared Record for Everyone Who Visits, Book 10 of The Sitting Room Series, and the first two of its 100 visit pages, in large print.

The book's page at aldercreekeditions.com has the buy links once the paperback is on sale.

ISBN 979-8-952410-22-0

Refill copies of the journal's fill-in pages 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.

