

# What You Need to Know About Me:

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A Notebook for Families and Caregivers of Older Adults  
and Adults with Special Needs



South Carolina  
**Respite**  
C o a l i t i o n

Developed by South Carolina Respite Coalition,  
Alzheimer's Resource Coordination Center (ARCC),  
and The Center for Child and Family Studies, USC College of Social Work,  
Columbia, South Carolina

# Acknowledgments

This notebook was developed in June 2002 by Susan Robinson, MSW, the former Executive Director of the South Carolina Respite Coalition and Norma S. Sessions, the former Training/Development Director at the Center for Child and Family Studies at the College of Social Work (COSW) at the University of South Carolina.

It was most recently updated in December 2021, by Kathy Mayfield-Smith, Associate Director of the Institute for Families in Society, COSW, University of SC and Nicholas Julian, Executive Director, South Carolina Respite Coalition, Columbia, South Carolina.

We want to express our appreciation and acknowledge the following organizations for their immeasurable help in the original development of this work:

- S.C. Department of Health and Human Services, Community Long-Term Care
- Bureau of Senior Services, now SC Department on Aging
- Palmetto Lowcountry Hospital
- Family members of persons with Alzheimer's Disease
- Quality Time Adult Respite Care
- Family Connection of South Carolina, Inc.
- Alzheimer's Association Mid-State South Carolina Chapter
- ARCH National Respite Network and Resource Center

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For any other use, please contact the SC Respite Coalition for permission at [info@screspite.org](mailto:info@screspite.org) or call 803-935-5027.

Appropriate citation must be given.

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# Introduction

The purpose of this notebook is to provide a way for you, as a family member or other caregiver, to communicate with the people who provide respite care for the special person in your life, whether an adult with disabilities or someone who has Alzheimer's disease or dementia. We hope that this notebook helps you to describe your loved one and his/her needs so that the care can truly be individualized. Depending on the special needs or the stage of dementia, your loved one may be able to help you complete some of the information.

You can include information about all aspects of your loved one's life and update the notebook as needed. You may also want to include photographs to help the respite care provider get to know your loved one. **We suggest that you complete the notebook in PENCIL** so that you can change information as your loved one's condition changes. We also encourage you to use the Resources section at the end of the notebook, particularly for information about Advance Directives and other important documents you may need.

The more information you and your loved one gather and share with the respite care provider, the better that caregiving can be.

## Privacy Concerns and Confidentiality

Privacy and confidentiality are important to all of us. Keeping health care information confidential is critical because HIPAA, the Health Insurance and Portability and Accountability Act, is the federal law that requires this information be kept private. While it is important to share information with your respite providers so they can provide the best care possible, yours and your loved one's privacy are just as important. Because of this, you are encouraged to be careful how much information you share in different settings. For example, you may be more comfortable sharing more information with a respite provider in your home when this book stays in your home. If you use this book to share with respite providers outside your home (e.g., adult day care program, faith- or community-based Respite Breakroom), you may want to include only select information, or make sure that this booklet will be locked up and only shared with people who have a need to know. The program also should make sure that those seeing the information understand the legal requirement to keep it confidential and not to discuss or share it with anyone else.

# We Value Your Feedback

I am the primary caregiver for:

- Spouse  
  Child(ren)  
  Sibling  
  Parent  
  Other Family  
  Friend

**Please tell us how useful or not the following sections were.**

**Extremely Useful**

**Very useful**

**Somewhat useful**

**Not useful**

Introduction (p. 4)				
The Basics (p. 7)				
My Medicines (p. 10)				
My Health (p. 13)				
My Day (p. 15)				
Things I May Need Help With (p. 18)				
Communication Tips (p. 21)				
My Story (p. 23)				
My Faith p. (26)				
Photographs (p. 27)				
Resources (p. 29)				
OVERALL, the notebook is				

The notebook is:

- very thorough  
  missing important issues  
  covering way too much

If I were changing this notebook, I would:

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I am a:

- respite provider who helps families
- professional works with family caregivers
- Other: \_\_\_\_\_

**As a professional**, I have given copies to approximately \_\_\_\_\_ people.

I have used it in these ways:

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For more information about Lifespan Respite:

Visit: <https://www.screspite.org>

To make a donation, please mail your tax-deductible gift to:

**South Carolina Respite Coalition**

P.O. Box 493  
Columbia, SC 29202  
803-935-5027

You may also give securely online at: <https://www.screspite.org>

*Thank You!* The logo for the South Carolina Respite Coalition features the text "South Carolina" in a small font above the word "Respite" in a large, bold, serif font. A small red heart is positioned above the letter "i" in "Respite". Below "Respite" is the word "Coalition" in a smaller, spaced-out serif font.



# The Basics

My name: \_\_\_\_\_

The name I prefer to be called: \_\_\_\_\_

Names of those who live with me:

\_\_\_\_\_ Relationship: \_\_\_\_\_

\_\_\_\_\_ Relationship: \_\_\_\_\_

\_\_\_\_\_ Relationship: \_\_\_\_\_

\_\_\_\_\_ Relationship: \_\_\_\_\_

My street address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Home phone #: \_\_\_\_\_



# Emergency Contacts

1. Name: \_\_\_\_\_

Relationship: \_\_\_\_\_ Phone #s: \_\_\_\_\_

2. Name: \_\_\_\_\_

Relationship: \_\_\_\_\_ Phone #s: \_\_\_\_\_

3. Name: \_\_\_\_\_

Relationship: \_\_\_\_\_ Phone #s: \_\_\_\_\_



# Medical Provider Information

Primary Doctor's name: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

## OTHER PHYSICIANS/HEALTH CARE PROVIDERS

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Specialty: \_\_\_\_\_ Address: \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Specialty: \_\_\_\_\_ Address: \_\_\_\_\_

Hospital Preference: \_\_\_\_\_

Phone: \_\_\_\_\_



# Other Emergency Information

Police Department: \_\_\_\_\_

Fire Department: \_\_\_\_\_

Poison Control: \_\_\_\_\_

Fire Extinguisher is located: \_\_\_\_\_

First Aid Kit is located: \_\_\_\_\_

My Advance Directives (living will, health care power of attorney, durable power of attorney) are located:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_





# My Home

UTILITY COMPANY PHONE NUMBERS:

Electricity: \_\_\_\_\_

Gas: \_\_\_\_\_

Oil Company: \_\_\_\_\_

Water: \_\_\_\_\_

Rooms I prefer to be in:

\_\_\_\_\_  
\_\_\_\_\_

Rooms that are “off limits”:

\_\_\_\_\_  
\_\_\_\_\_

Other information about my home:

\_\_\_\_\_  
\_\_\_\_\_



# My Medicines

(Prescription, Over-the-Counter, Herbal, etc.)

Name of my medicine	How much I take	When and how I take it	What I take it for	Side effects to look for
<i>(Example)</i>	<i>One tablet 400 mg</i>	<i>Three times a day after meals (with water)</i>	<i>Diabetes</i>	<i>Dizziness, headache</i>



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# My Health

## Medical Conditions and Allergies

Medical Condition	Current Status	Things to watch for	What to do



# My Health

## Mobility and Special Equipment

Things to know about moving or lifting:

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Adaptive equipment and how to use it:

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Other important information:

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# My Day

Usually, this is how my day is spent:

	WEEKDAY	WEEKEND
6:00–7:00 A.M.		
7:00–8:00 A.M.		
8:00–9:00 A.M.		
9:00–10:00 A.M.		
10:00–11:00 A.M.		
11:00 A.M.–Noon		
Noon–1:00 P.M.		
1:00–2:00 P.M.		
2:00–3:00 P.M.		
3:00–4:00 P.M.		
4:00–5:00 P.M.		
5:00–6:00 P.M.		
6:00–7:00 P.M.		
7:00–8:00 P.M.		
8:00–9:00 P.M.		
9:00–10:00 P.M.		
10:00–11:00 P.M.		
11:00 P.M.–Midnight		



# My Day

## Meals

	BREAKFAST	LUNCH	SUPPER
Usual mealtime			
What I usually eat			
Foods I don't like, cannot eat, or am ALLERGIC to			
Special preparations including utensils, dishes I like to use			
Where I like to eat			
What I like to do after my meal			
Snacks I enjoy			

I am allowed to have alcohol (beer, wine, liquor): \_\_\_\_\_ yes \_\_\_\_\_ no

If yes, how much? \_\_\_\_\_





# My Day

## Bedtime

The time I usually go to bed: \_\_\_\_\_

What I normally do before I go to bed:

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Things I may need help with include:

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Things that help me rest well include:

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If I get up in the middle of the night, here are some suggestions:

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If I have trouble going back to sleep, you might try:

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If I wander, here are some suggestions:

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If I get upset, here are some suggestions:

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# Things I May Need Help With

	Yes/No	What kind of help?/Suggestions...
Dressing		
Bathing		
Shaving		
Eating		
Toileting		
Taking my medications		
Care of my teeth		
Care of my hair		
Getting into or out of a bed or a chair		



# Things I May Need Help With Behaviors

I may try to \_\_\_\_\_ but not be able to do it. I may become frustrated. Here are some suggestions how to handle this:

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I may misplace my: \_\_\_\_\_ (glasses, wallet, etc.). You will likely find it/them:

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If it is not there and we can't find it, a helpful thing to say is: *(For example, "We'll look for it tomorrow.")*

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If I start to argue with you, a helpful response is:

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When I am angry, I usually say or do:

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A helpful response is:

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Other general suggestions:

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# Things I May Need Help With

Behaviors *(continued)*

**Some things may agitate me.**

Television (Yes or no? Suggestions):

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Stereo/Music:

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Computer:

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Other people in the house:

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Other things which are upsetting to me:

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Suggestions:

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# Communication Tips

The best way to communicate with me (to make sure I understand you):

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Things I usually say or do to communicate my feelings or needs:

When I need to go to the toilet	
When I want something to eat	
When I'm tired	
When I'm angry	



# Communication Tips

Other Communication Tips That May be Especially Helpful for Caregivers of Loved Ones with Cognitive Impairment

*(Check those that apply.)*

- Please accept what I say and use distraction rather than trying to make me understand or remember.
- Listen to me, even if you cannot understand my words or gestures. I will be happier if you are at least paying attention to me.
- DO NOT ARGUE.
- DO NOT SAY *“Oh, you remember, we did that yesterday...”*  
I probably don't remember.
- Don't take things personally. What may seem like stubborn or manipulative behavior is more likely to be a result of my confusion.
- Unless an item is dangerous, do not try to remove it from my hands. I may just want to hold your pocketbook and go for a walk. I'll put it down soon enough.

I especially like:

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If I can't sit still, just walk and pace with me. You are keeping ME company.

Other tips:

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# My Story

I was born (when): \_\_\_\_\_ (where): \_\_\_\_\_

My parent's names and what I call(ed) them:  
\_\_\_\_\_  
\_\_\_\_\_

Brothers' and sisters' names and what I call(ed) them:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I grew up (where): \_\_\_\_\_

After I finished school, I:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

The kind of work I did:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

My spouse's name: \_\_\_\_\_

We've been married for (how long?): \_\_\_\_\_

My child's/childrens' names:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



Other important people in my life (friends, other relatives):

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My pets:

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My social/civic activities:

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My hobbies:

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Places I have traveled:

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Things I am most proud of:

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# My Faith

My faith is:

\_\_\_ the most important thing in my life      \_\_\_ very important

\_\_\_ somewhat important      \_\_\_ not of interest to me

I was raised in the \_\_\_\_\_ faith.

I converted to the \_\_\_\_\_ faith.

Church names I might mention

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

My favorite religious song(s):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I like to hear you read from: (e.g., The Bible, devotional literature, etc.)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I pray before my meals: \_\_\_ yes \_\_\_ no

Praying with me is \_\_\_ welcome \_\_\_ OK \_\_\_ not welcome

The way I pray/words I use:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

# Photographs



# Photographs





# Resources

## **GetCareSC [www.GetCareSC.com](http://www.GetCareSC.com)**

Toll Free: 800-868-9095

Provides a search tool for seniors, caregivers, and adults with disabilities to find providers and available services, like respite care, assisted living, transportation, and insurance -- and if you need help and you don't know where to start. The GetCareSC website is maintained by the South Carolina Department on Aging, helping connect you to local resources and find help in your community.

## **South Carolina Respite Coalition**

[www.screspite.org](http://www.screspite.org)

[info@screspite.com](mailto:info@screspite.com)

**803-935-5027 or 1-866-345-6786**

Call for information on respite in your community and to become a volunteer advocate for respite; to receive information and updates; for more copies of this notebook and other resources; and to schedule a speaker on “Respite,” “The Benefits of a Break” or for technical assistance in starting a Respite Breakroom or other respite program in your faith-based or community-based organization.

## **SC Chapter, Alzheimers Association <https://alz.org/SC>**

Information about Alzheimer’s disease and other dementias, support groups, choosing respite providers, nursing homes or assisted living facilities, the national registry Safe Return program for wanderers and much more.

<b>Office Location</b>	<b>Local Number</b>	<b>Toll-Free Number</b>
Anderson (Main Office)	864-224-3045	1-800-273-2555
Columbia	803-791-3430	1-800-636-3346
Greenville	864-250-0029	1-866-844-0995
Spartanburg	864-542-9998	1-800-908-9690
Charleston	843-571-2641	1-800-860-1444

## **Community Long Term Care (CLTC) (888) 971-1637 SC Department of Health and Human Services (Medicaid)**

In-home care and respite services – for people who would otherwise have to be in a nursing home. Your loved one may be eligible for a Home and Community Based Waiver. Get on the waiting list.

## S.C. Department of Health and Environmental Control (DHEC)

[www.scdhec.gov](http://www.scdhec.gov)

803-545-4370

Call to learn of citations (investigated complaints that were found true) of nursing homes and assisted living facilities. DHEC will explain how to write a letter under the “freedom of information act” requesting the information. Say that you are considering placing your loved one there for respite or long term care. The information will be mailed to you in about two weeks, free of charge.

**DHEC (at 803-545-4204)** can also send a **“do not resuscitate” form (EMS DNR form)** to your doctor. Anyone who does not want to be resuscitated (have his/her heart started or breathing tube put in) in an ambulance must use this. Advance Directive forms are not enough.

ARCH National Respite Network has downloadable factsheets on a variety of respite topics including respite for a wide variety of special populations:

<https://archrespite.org/>

**Family Caregiver Alliance Fact Sheets** are available online at no cost.

Many of the topics they cover can be found at [www.caregiver.org/caregiver-resources/](http://www.caregiver.org/caregiver-resources/). Sample topics include:

- *Dementia, Caregiving and Controlling Frustration*
- *Taking Care of YOU: Self-Care for Family Caregivers*
- *Hiring In-Home Help*
- *Community Care Options*
- *Practical Skills Training for Family Caregivers, Mary A. Corcoran, 2003*

Within each of these main topics are related pages that can be printed directly from their web site. If you would instead like for FCA to print copies of any of the information on their web site and mail them to you, the cost for each is \$3.00, which includes shipping. Mail your request for copies of information printed from their web site to:

Attn: Lana Sheridan  
Family Caregiver Alliance  
101 Montgomery Street, Suite 2150  
San Francisco, CA 94104

**American Association of Retired Persons (AARP)**  
1-866-389-5655 or 803-765-7381  
<https://states.aarp.org/south-carolina/>  
<https://aarp.org>

*Call for brochures on changes to your house for someone with a disability. You do not have to be a member.*

Also, your local **Council on Aging** or **Vocational Rehabilitation Office** can give you information about building a safe wheelchair ramp for your home.

**National Association of Professional Geriatric Care Managers**  
[www.caremanager.org](http://www.caremanager.org)  
**1-520-881-8008**

Contact to find a social worker or medical person to set up the services you need. Insurance may cover these, but usually you have to pay a fee.

**Information about Advance Directives (living will, health care power of attorney, durable power of attorney):**

There are a number of places to get information about obtaining and completing these forms, including:

- Your local Council on Aging
- The S.C. Long Term Care Ombudsman's office: 1-800-868-9095
- The Carolinas Center: 1-800-662-8859

You can complete these forms yourself, but they must be notarized. Check with your local Council on Aging or bank for a notary.

**If you need a lawyer:**

S.C. Bar Association Lawyer Referral Service	1-800-868-2284
Legal Services Corporation (free services)	1-803-799-9668
National Academy of Elder Law Attorneys	1-520-881-4005