

A decorative border with ornate floral and scrollwork designs in each corner, framing the central text.

What You Need to Know about Me

**A Notebook for Families
and Caregivers**

What You Need to Know about Me: A Notebook for Families and Caregivers

This notebook was developed in 2002 with a grant from The South Carolina Alzheimer's Resource Coordination Center (ARCC) as a joint project of The South Carolina Respite Coalition and The Center for Child and Family Studies, USC College of Social Work, Columbia, South Carolina. It was updated November 2009 and June 2014. This printing was funded by a grant from ARCC, Lt. Governor's Office on Aging.

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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 who has Alzheimer's disease or other 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 stage of the disease, your loved one may be able to help you complete it.

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 share with the respite care provider, the better that caregiving can be. It can also be used in a facility to leave at bedside so visitors and aides can know your loved one and interact better as a result.

PLEASE HELP US TO IMPROVE THE NOTEBOOK FOR OTHERS

Tear out this page and mail it to P.O. Box 493, Columbia, S.C. 29202

I am a husband/wife of someone with dementia a professional who works with family caregivers
 the daughter/son “ “ a respite provider who helps families
 a family member “ “ a family caregiver to someone who does not have dementia
 other: _____ I am female male

Please check the category that best describes your opinion √	Extremely useful	Very useful	Somewhat useful	Not useful
The Introduction (p. 4) is				
Basics section (pages 5-7) is				
My medicines section (pages 8-10) is				
My health section (pages 11-12) is				
My Day section (pages 13-15) is				
Things I may need help with (16-18) is				
Communication tips (page 19-20) are				
My story (21-23) is				
My faith page (24) is				
Photo pages (25-26) are				
Resource section (27-29) is				
OVERALL the notebook is				

The notebook is ___ very thorough ___ missing some important issues ___ covering way too much.

If I were changing it I would _____

_____ please continue on the back...

As a professional I have given copies to about ___ people. I have used it for/to _____

_____ please continue on the back...

For more information about lifespan respite OR to make a donation, contact: South Carolina Respite Coalition, P.O. Box 493, Columbia, S.C. 29202. respite@screspitecoalition or 1-803-935-5027

Enclosed is my tax deductible gift of \$ _____ Name: _____

Address _____ zip _____

Phone: _____ e-mail: _____

THE BASICS

My name: _____

How I like to be addressed: _____

The name I reply to right now: _____

Names of those who live with me:

_____ Relationship _____

_____ Relationship _____

_____ Relationship _____

_____ Relationship _____

My street address: _____

City: _____ **State** _____ **Zip** _____

Home phone #: _____

Directions to home (crossroads, landmarks) _____

EMERGENCY CONTACTS:

1) Name: _____

Relationship: _____ **Phone #s** _____

2) Name: _____

Relationship: _____ **Phone #s** _____

3) Name: _____

Relationship: _____ **Phone #s** _____

EMERGENCY INFORMATION**Doctor's name:** _____**Phone #:** _____**Hospital:** _____**Phone #:** _____**Medical Provider Payment Information****Guardianship:** _____**Social Security #:** _____**Medicaid #:** _____**Medicare #:** _____**Insurance name/#:** _____**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** _____**We have a "do not resuscitate" form (EMS DNR) for
ambulances. It is located** _____

MY HOME

This home is heated by:

- Gas . . . The turnoff valve is _____
- Electricity . . . You turn it off by _____
- Oil . . . You turn it off by _____

Water is turned off by: _____

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
(Example)	One tablet 400 mg	Three times a day after meals (with water)	Diabetes	Dizziness, headache

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MY HEALTH Medical Conditions and Allergies

Stage of Alzheimer's disease/dementia (if known):

Early _____ Middle _____ Advanced _____

Medical Condition	Current Status	Things to Watch For	What to Do

MY HEALTH
Mobility and Special Equipment

Things to know about moving or lifting: _____

Adaptive equipment and how to use it: _____

Written instructions for the equipment are located:

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.		
11:00-12:00 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 or cannot eat			
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: _____

Things I may need help with include: _____

Things that help me rest well include: _____

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

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

If I wander, here are some suggestions: _____

If I get upset, here are some suggestions: _____

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		
Going to bed		

THINGS I MAY NEED HELP WITH

Behaviors

I may try to _____

but not be able to do it. Here are some suggestions: ____

I may misplace my _____

(glasses, wallet, etc.). **It is likely to be** _____

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.")

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

When I am angry, I usually say or do: _____

and a helpful response is: _____

Other general suggestions: _____

THINGS I MAY NEED HELP WITH

Behaviors

Some things may agitate me.

Television: (Yes or no? Suggestions...) _____

Stereo: _____

Computer: _____

Other people in the house: _____

Other things which are upsetting to me: _____

Suggestions: _____

THINGS I MAY NEED HELP WITH

Communication Tips

How best to communicate with me (to make sure I understand you): _____

Things I usually say to get my needs met:

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

Other Communication Tips:

(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 touching or holding _____**

- If I can’t sit still, walk and pace with me. You are keeping ME company.**
- Other tips: _____**

MY STORY

I was born
(when): _____ **(where):** _____

My parent's names and what I called them: _____

Brothers' and sisters' names and what I called 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 children's names: _____

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

My pets: _____

My social/civic activities: _____

My hobbies: _____

Places I have traveled: _____

Things I am most proud of: _____

Things I cherish: _____

Things I enjoy remembering and talking about: _____

Things I'd rather not talk about: _____

Other important things about me: _____

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 (updated 6/2014)

Alzheimer's Association - S.C. Chapter www.alz.org/sc/
24 hour helpline: 800-272-3900

Anderson (Main Office) 864-224-3045 **toll free 1-800-272-3900**
Midlands 803-791-3430 **Greenville 864-250-0029**
Spartanburg 864-542-9998 **Lowcountry 843-571-2641**
Myrtle Beach 843-213-1516 **(same toll free # for all offices)**

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.

→ *Contact the Anderson office for Respite funds to attend support groups and educational programs on dementia care and care giving.*

NOTE: Voucher funds for Alzheimer's respite are now handled by the Family Caregiver Support Programs statewide. See next entry

Lt. Governor's Office on Aging www.scaccesshelp.org
Columbia 803-734-9900 **Toll free 1-800-868-9095**

Call for phone numbers for

- *your local **Council on Aging** (home delivered and senior center meals and activities, transportation, home-maker services, information.)*
- ***Family Caregiver Support Program** (assessment of care giving needs, advice, support groups and respite funding),*
- ***Area Agency on Aging/Disability Resource Center.** (aging and other resource information & referrals, health insurance information.)*
- ***Community Long Term Care (CLTC) office,***
- *a **printed directory of Aging Resources**, state and nationwide.*
- *Also, the S.C. Ombudsman's office has packets on **Advance Directives** (living will, health care and durable powers of attorney).*

The South Carolina Respite Coalition www.screspitecoalition.org
respite@screspitecoalition.org **803-935-5027 or 1-866-345-6786**

Information on respite for ALL family caregivers of ALL ages and how to become an advocate for respite; for more copies of this notebook and other resources on finding providers and developing a "circle of support." Call to schedule a speaker on "The Benefits of a Break" or "Faith Community and Respite: next best thing to kin" or current respite trends and issues.

The Respite Coalition sometimes has funding for respite care.

Community Long Term Care (CLTC) (888) 549-0820
www.scdhhs.gov/historic/insideDHHS/Bureaus/BureauofLongTermCareServices/How%20Do%20I%20Apply.html

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

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

They 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.

Eldercare locator: www.eldercare.gov or 800-677-1116
Family Caregiver Alliance (FCA) (800) 445-8106.

***FCA Fact Sheets** are available free online. Printed versions are \$2.00 each— FCA Publications, 180 Montgomery St., Suite 1100, San Francisco, CA 94104. Topics: caregiver issues & strategies, legal issues, health conditions. For the full list, see: <https://caregiver.org/fca-publication-order-form>*

American Association of Retired Persons (AARP) 1-800-424-3410
www.aarp.org

Call for brochures on changes to your house for someone with a disability. You do not have to be a member. Give the name and stock number:

Home Fit Guide	#D-18959
Making your house a home for a lifetime through design	#D-19058
Universal design: creating a comfortable, safe& easy to use home for lifelong living	#D-19072

Also, your local **Council on Aging** or
South Carolina Vocational Rehabilitation office www.scvrd.net
800-832-7526 (Toll free) 803-896-6553 (TTY)

can give you information about building a safe wheelchair ramp for your home. The rule is 1 foot of ramp for every 1 inch of rise (height of your stairs).

S.C. Assistive Technology Project 803-935-5263 or 800-915-4522
<http://www.sc.edu/scatp/scatpexchange.htm>

Information on low or high tech devices for independent living; also has exchange to sell, buy or trade such devices (wheelchairs, ramps, adapted vehicles). Each year the latest equipment is displayed at their annual Assistive Technology Expo – well worth attending.

Dementia Dialogues: www.sph.sc.edu/osa/programs_dementia.html
Phone: (803) 777-5337 Email: osainformation@sc.edu

MUST HAVE TRAINING COURSE for families and professionals who care for a person with dementia. Developed by the Office for the Study of Aging, USC, these are power point slides for self-paced study, plus a contact list of volunteers across the state trained offer live sessions. Contact one near you for a schedule.

National Association of Professional Geriatric Care Managers
www.caremanager.org (Internet) 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: **www.scaccesshelp.org**

- **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**
<http://www.sbar.org/lrs> 1-800-868-2284
- **Legal Services Corporation (free services)** **1-803-799-9668**
<http://www.sclegal.org/> 888-346-5592
- **National Academy of Elder Law Attorneys** **1-520-881-4005**
www.naela.org

They charge for a directory, but you can find the list free on the Internet. Put in your zip code for those near to you. Staff at your local library will look it and the other items up for you if you do not use the Internet.