

A decorative border with ornate floral and scrollwork patterns 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

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and

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USC College of Social Work

Columbia, South Carolina

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Respite Coalition for permission: screspitecoalition@yahoo.com or 803-935-
5027. Appropriate citation must be given. The notebook is available in electronic
form with appropriate credit included.

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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 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.

PLEASE TELL US WHAT YOU THOUGHT OF THE NOTEBOOK...

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

1. The notebook is ___ exactly what I needed ___ somewhat what I needed
 ___ only a little of what I needed or ___ not what I needed.
2. The notebook is ___ very thorough ___ missing a few of the important issues
 ___ missing most of the important issues ___ covering way too much.
3. The Introduction (p. 4) is ___ very useful ___ somewhat useful ___ not useful.
4. Basics section (pages 5-7) is ___ very useful ___ somewhat useful ___ not useful.
5. My medicines section (8-10) is ___ very useful ___ somewhat useful ___ not useful.
6. My health section (11-12) is ___ very useful ___ somewhat useful ___ not useful.
7. My Day section (13-15) is ___ very useful ___ somewhat useful ___ not useful.
8. Things I may need help with (16-18) is ___ very useful ___ somewhat useful ___ not useful.
9. Communication tips (19-20) are ___ very useful ___ somewhat useful ___ not useful.
10. My story (21-23) is ___ very useful ___ somewhat useful ___ not useful.
11. My faith page (24) is ___ very useful ___ somewhat useful ___ not useful.
12. Photo pages (25-26) are..... ___ very useful ___ somewhat useful ___ not useful.
13. Resource section (27-28) is ___ very useful ___ somewhat useful ___ not useful.

If I were changing this notebook I would _____
 _____ please continue on the back...

As a professional I have given copies out to appx. _____ people. I have used it _____
 _____ please continue on the back...

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

Enclosed is my tax deductible gift of \$_____ or charge it to my VISA/Master Card Acct. #_____

Expiration date _____ Signature: _____
--

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

Alzheimer's Association - S.C. Chapter www.alz.org/sc/

Contact the main office in Anderson for Respite Information

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

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.

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, Area Agency on Aging** sponsor of **Family Caregiver Support Program**), or Community Long Term Care (CLTC) office. They can send you a printed directory of Aging Resources, state and nationwide. Also, call to reach the S.C. Ombudsman's office to request a packet on **Advance Directives** (living will, health care power of attorney, durable power of attorney).*

Community Long Term Care (CLTC) (get local # from # above)

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) 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.

The South Carolina Respite Coalition www.screstitecoalition.org

screstitecoalition@yahoo.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 "The Benefits of a Break" or "Faith Community and Respite: next best thing to kin."

Eldercare locator:

www.eldercare.gov or

800-677-1116

Family Caregiver Alliance**(800) 445-8106.**For the full list, see: www.caregiver.org/caregiver/jsp/publications.jsp?nodeid=345**FCA Fact Sheets** are available free online. Printed versions are \$1.00 each—

FCA Publications, 180 Montgomery St., Suite 1100, San Francisco, CA 94104.

Dementia, Caregiving and Controlling FrustrationTaking Care of YOU: Self-Care for Family CaregiversHiring In-Home HelpCommunity Care OptionsPractical Skills Training for Family Caregivers, Mary A. Corcoran, 2003**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 modification fact sheet #D-16065

Home modification: key to independent living #D-18524

Lighting the Way: a key to independence #D-17460

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

Home Equity Conversion kit also available for \$1.00

D-15601

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:*

- **Your local Council on Aging**
- **The S.C. Longterm 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**

They charge for a directory, but you can find the list free on the Internet at www.naela.org & put in your zip code for those near to you. Staff at your local library will look it up for you if you don't use the Internet.

