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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The South Carolina Alzheimer’s Resource Coordination Center  
as a joint project of  
The South Carolina Respite Coalition  
and  
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USC College of Social Work  
Columbia, South Carolina

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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...**

<table>
<thead>
<tr>
<th>I am</th>
<th>a husband/wife of someone with dementia</th>
<th>a professional who works with family caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ the daughter/son</td>
<td>□ a respite provider who helps families</td>
</tr>
<tr>
<td></td>
<td>□ a family member</td>
<td>□ a family caregiver to someone who does not have dementia</td>
</tr>
<tr>
<td></td>
<td>□ other: _____________________________</td>
<td>I am □ female □ male</td>
</tr>
</tbody>
</table>

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. 1-803-935-5027 or 1-866-345-6786 toll free.

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.)

<table>
<thead>
<tr>
<th>Name of My Medicine</th>
<th>How Much I Take</th>
<th>When and How I Take It</th>
<th>What I Take It For</th>
<th>Side Effects to Look For</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Example)</td>
<td>One tablet 400 mg</td>
<td>Three times a day after meals (with water)</td>
<td>Diabetes</td>
<td>Dizziness, headache</td>
</tr>
</tbody>
</table>

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# MY MEDICINES
( Prescription, Over-the-Counter, Herbal, etc.)

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<td>Dizziness, headache</td>
</tr>
</tbody>
</table>
## MY MEDICINES
*(Prescription, Over-the-Counter, Herbal, etc.)*

<table>
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<tr>
<th>Name of My Medicine</th>
<th>How Much I Take</th>
<th>When and How I Take It</th>
<th>What I Take It For</th>
<th>Side Effects to Look For</th>
</tr>
</thead>
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<td>Three times a day after meals (with water)</td>
<td>Diabetes</td>
<td>Dizziness, headache</td>
<td></td>
</tr>
</tbody>
</table>
MY HEALTH
Medical Conditions and Allergies

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

Early_____ Middle _____ Advanced______

<table>
<thead>
<tr>
<th>Medical Condition</th>
<th>Current Status</th>
<th>Things to Watch For</th>
<th>What to Do</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>
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:*

<table>
<thead>
<tr>
<th>Time</th>
<th>Weekday</th>
<th>Weekend</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:00-7:00 A.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:00-8:00 A.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8:00-9:00 A.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9:00-10:00 A.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:00-11:00 A.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:00-12:00 noon</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Noon-1:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1:00-2:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2:00-3:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3:00-4:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4:00-5:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5:00-6:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6:00-7:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7:00-8:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8:00-9:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9:00-10:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:00-11:00 P.M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:00 P.M.-Midnight</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## MY DAY

### Meals

<table>
<thead>
<tr>
<th></th>
<th>BREAKFAST</th>
<th>LUNCH</th>
<th>SUPPER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usual mealtime</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What I usually eat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foods I don’t like or cannot eat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special preparations including utensils, dishes I like to use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Where I like to eat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What I like to do after my meal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Snacks I enjoy</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I am allowed to have alcohol (beer, wine, liquor): [ ] yes [ ] no

If yes, how much? ____________________________________________

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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

<table>
<thead>
<tr>
<th></th>
<th>Yes/No</th>
<th>What kind of help? Suggestions. . . .</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shaving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Toileting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking my medications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care of my teeth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care of my hair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going to bed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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:

<table>
<thead>
<tr>
<th>When I need to go to the toilet</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>When I want something to eat</td>
<td></td>
</tr>
<tr>
<td>When I’m tired</td>
<td></td>
</tr>
<tr>
<td>When I’m angry</td>
<td></td>
</tr>
</tbody>
</table>
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
RESOURCES

The South Carolina Respite Coalition 803-935-5027
Toll free 1-866-345-6786
Call for information on respite in your community and to become a volunteer advocate for respite; to receive information, newsletters, and updates; for more copies of this notebook and other resources; and to schedule a speaker on “The Benefits of a Break” for care receivers and caregivers or “Faith Community and Respite: next best thing to kin.”

Alzheimer’s Association Offices
Palmetto Chapter (Columbia offc) 803-722-3346; 1-800-636-3346
Charleston: 800-860-1444, Surfside: 866-8004460, Pee Dee: 866-334-1108
Upstate Chapter (Anderson offc) 864-224-3045; 1-800-273-2555
Greenville: 866-844-0995, Greenwood: 866-844-0992,
Rock Hill: 866-844-0993, Spartanburg: 800-908-9690
Call for information about Alzheimer’s disease and other dementias, support groups, choosing respite providers, choosing a nursing home or assisted living facility, ID bracelet for your loved one and much more.

Lt. Governor’s Office on Aging
Columbia 803-734-9900
Toll free 1-800-868-9095
Call for phone numbers for your local Council on Aging, Area Agency on Aging (which sponsors the 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). Jon Cook or Dale Watson can answer your questions about these documents.

Community Long Term Care (CLTC) (get local # from # above)
Call for home care and respite services – for people who would have to be in a nursing home if you couldn’t provide care. Your loved one may be eligible now or later on. Get on the waiting list if you can.

S.C. Department of Health and Environmental Control (DHEC) 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.
County Health Department  Look in the blue pages under County Government

Contact to learn about health and family support services. Also, ask about these booklets:

- Blueprint for a Safe Home  #ML-007047
- Caregiving - A Path with Heart  #ML-007061
- Making Life Easier-DHEC Home Health Services  #CR-003090
- Your Right to Make Decisions About Your Health Care  #ML-007017

American Association of Retired Persons (AARP)  1-800-424-3410

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:

- Do-able, Renewable Home  #D-12470
- How Well Does Your Home Meet Your Needs  #D-16270
- Tools and Gadgets for Independent Living  #D-17035
- Decisions about Help at Home for Alzheimer’s Caregivers  #D-17623
- Lighting the Way  #D-17460 (402)

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 (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. 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. Staff at your local library will look it up for you if you don’t use the Internet.