What You Need to Know about Me

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

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The original notebook is available at www.screspitecoalition.org. 
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Acknowledgments

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Terri Whirrett, former Training and Technical Assistance Coordinator, ARCH (National Respite Network and Resource Center)

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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

<table>
<thead>
<tr>
<th>Extremely useful</th>
<th>Very useful</th>
<th>Somewhat useful</th>
<th>Not useful</th>
</tr>
</thead>
<tbody>
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<td>The Introduction (p. 4) is</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>My Day section (pages 13-15) is</td>
<td></td>
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<td>Photo pages (25-26) are</td>
<td></td>
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<tr>
<td>Resource section (27-29) is</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.)

<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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</tbody>
</table>

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

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<th>Side Effects to Look For</th>
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</tr>
</tbody>
</table>

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### 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>
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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>
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<td></td>
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<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><strong>Usual mealtime</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What I usually eat</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Foods I don’t like or cannot eat</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Special preparations</strong> including utensils, dishes I like to use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Where I like to eat</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What I like to do after my meal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Snacks I enjoy</strong></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: _________________

____________________________________________________________________

____________________________________________________________________

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### Things I May Need Help With

<table>
<thead>
<tr>
<th>Activity</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
ELDER CARE RESOURCES (updated 11/2017)

SC Lt. Governor’s Office on Aging
Columbia: 803-734-9900 Toll free: 800-868-9095

The LGOA works with a network of regional and local organizations to develop and manage services that help seniors remain independent in their homes and in their communities. Information and services are also made available for caregivers of elders.

✓ GetCareSC.com
A website dedicated to matching seniors, and caregivers of seniors, with available resources. Seniors, caregivers, and adults with disabilities can use their zip code to search the database to find transportation, day care, meals, and in-home care in their area.

✓ Alzheimer's Resource Coordination Center
The ARCC serves as a statewide coordinator for services, information, and educational programs that assist people with Alzheimer’s disease and related disorders (ADRD) and their families.

✓ ElderCare Trust Fund
The ElderCare Trust Fund program awards grants to fund innovative programs that help seniors age in place, stay in their homes, and lead productive lives.

✓ Emergency Rental Assistance
To reduce the risk of homelessness and eviction for older adults, our emergency rental assistance program helps impoverished adults age fifty-five and older with emergency funds to pay for housing.

✓ Family Caregiver Support
Regional family caregiver advocates work one-on-one with caregivers, providing counseling, support, and help in gaining access to available community services. Family Caregiver Support Programs administer federal and state grant funds for respite care, including, but not limited to, caregivers of individuals with Alzheimer’s and other dementias.

✓ Healthy Connections Prime Ombudsman
This program helps older adults who are enrolled in Healthy Connections Prime address any concerns or conflicts that may interfere with navigating and coordinating their health coverage through Medicare and Medicaid.
✓ **Legal Assistance for Seniors**
Through partnerships with the SC Bar and the SC Bar Pro Bono Program, the Access to Justice Commission, SC Legal Services, and other agencies, the Office on Aging provides legal assistance to seniors in need.

✓ **Medicare and SHIP**
The State Health Insurance Assistance Program (SHIP) provides free, in depth, one-on-one insurance counseling and assistance to Medicare beneficiaries and their families, friends, and caregivers.

✓ **Nutrition**
Group dining and home delivered meal programs provide sustenance and human contact for frail or homebound older adults.

✓ **Long Term Care Ombudsman**
The LGOA Long Term Care Ombudsman Program advocates for residents in long term care facilities around the state.

✓ **Senior Centers**
LGOA provides funding for the creation and improvement of senior centers throughout the state.

✓ **Senior Community Service Employment Program (SCSEP)**
Senior Community Service Employment Program (SCSEP) is the only federal job training program focused exclusively on helping low-income seniors.

✓ **SC Vulnerable Adult Guardian Ad Litem**
This program provides guardians ad litem for vulnerable adults who have been abused, neglected, or exploited.

**Dementia Speaks – Presented by: Dr. Macie Smith – No Fee**

To find out about up-coming classes across South Carolina, visit [www.dtconsultant.org/dementiaspeaks](http://www.dtconsultant.org/dementiaspeaks) and click on Events and RSVP or call (803) 814-6721.

**Topics Covered/Questions Answered**
- What is Alzheimer’s Disease and/or dementia?
- What causes dementia?
- What are treatment strategies?
- How should I respond to dementia-associated behaviors?
- What are the legal implications?
- What are the available resources?
**SC Department of Health and Human Services (DHHS)**

✓ **Medicaid**  (888) 549-0820

Medicaid is South Carolina’s aid program by which the federal and state governments share the cost of providing medical care for needy persons who have low income. Medicaid and Medicare are two different programs. Medicare is a health insurance program for all people age 65 and over or who have received Social Security disability benefits for a minimum of 24 months. An individual can have both Medicare and Medicaid.

✓ **Community Long Term Care (CLTC)**  (888) 549-0820

In-home care and respite services – for people who would otherwise have to be in a nursing home. This is a Medicaid program for low-income individuals determined to be at a nursing home level of care.

**The South Carolina Respite Coalition**

www.screspitecoalition.org  803-935-5027

The SCRC is a non-profit organization formed in 1999 and incorporated in 2001 which serves all South Carolina family caregivers. They provide information, support and referrals to the primary, unpaid caregiver of a family member or friend who is disabled, chronically ill, or aging. As funds are available, SCRC issues a one-time $500 respite voucher to applying family caregivers. Family caregivers who receive a voucher can either spend up to $500 in a 90 day period to hire a private individual to provide respite care and then request reimbursement from SCRC, or they can use an agency which can bill SCRC directly. If the care receiver is 60 years of age or older, the family caregiver is referred to the Family Caregiver Support Program at their Area Agency on Aging because that program has respite funding and additional services when the care receiver is over 60.

**SC Alzheimer’s Association**

www.alz.org/sc  24 hour helpline: 800-272-3900

Anderson:  864-224-3045  Spartanburg:  864-542-9998
Midlands:  803-791-3430  Lowcountry:  843-571-2641
Greenville:  864-250-0029  Myrtle Beach:  843-213-1516

Information about Alzheimer’s disease and other dementias, support groups, choosing respite providers, nursing homes or assisted living facilities, and much more.
SC Assistive Technology Project
http://scatp.med.sc.edu  Columbia:  803-935-5263  Toll-free: 800-915-4522

The South Carolina Assistive Technology Program (SCATP) is a federally funded program concerned with getting technology into the hands of people with disabilities so that they might live, work, learn and be a more independent part of the community. SCATP provides a device loan and demonstration program, an online equipment exchange program, training, technical assistance, publications, an information listserv and work with various state committees that affect AT acquisition and IT accessibility.