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.

Authors

Susan Robinson, Executive Director, South Carolina Respite Coalition
Norma S. Sessions, Former Training/Development Director
Center for Child and Family Studies, University of South Carolina

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Frances L. Brannon, former Alzheimer’s Program Specialist,
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W. C. Hoecke, Respite Coordinator, Family Connection of South Carolina, Inc.
Paul H. Jeter IV, former Executive Director, Alzheimer’s Association,
Mid-State South Carolina Chapter
Terri Whirrett, former Training and Technical Assistance Coordinator,
ARCH (National Respite Network and Resource Center)

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*Tear this page out, complete it and mail it to S.C.R.C.*

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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: ____________________________  □ female □ male

---

**Please check the category that best describes your opinion**

<table>
<thead>
<tr>
<th>Category</th>
<th>Extremely useful</th>
<th>Very useful</th>
<th>Somewhat useful</th>
<th>Not useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Introduction (p. 4) is</td>
<td>✓</td>
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<tr>
<td>Basics section (pages 5-7) is</td>
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<tr>
<td>My medicines section (pages 8-10) is</td>
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<tr>
<td>My health section (pages 11-12) is</td>
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<tr>
<td>My Day section (pages 13-15) is</td>
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<tr>
<td>Things I may need help with (16-18) is</td>
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<tr>
<td>Communication tips (page 19-20) are</td>
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<tr>
<td>My story (21-23) is</td>
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<tr>
<td>My faith page (24) is</td>
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<tr>
<td>Photo pages (25-26) are</td>
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<tr>
<td>Resource section (27-29) is</td>
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<tr>
<td>OVERALL the notebook is</td>
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</tbody>
</table>

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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>
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<td>Dizziness, headache</td>
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( Prescription, Over-the-Counter, Herbal, etc. )

<table>
<thead>
<tr>
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<th>When and How I Take It</th>
<th>What I Take It For</th>
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<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 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:
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

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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>
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<tr>
<td>7:00-8:00 A.M.</td>
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<tr>
<td>8:00-9:00 A.M.</td>
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<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>
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<tr>
<td>3:00-4:00 P.M.</td>
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<tr>
<td>4:00-5:00 P.M.</td>
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<tr>
<td>5:00-6:00 P.M.</td>
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<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? _____________________________________________
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>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: ________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

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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
Greenville  864-250-0029
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.

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

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.

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