

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

# **What You Need to Know about Me**

**A Notebook for Families  
and Caregivers**

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

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a grant from

The South Carolina Alzheimer's Resource Coordination Center  
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

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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.



## 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.)

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

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## MY HEALTH

### Medical Conditions and Allergies

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

**Early**\_\_\_\_\_ **Middle** \_\_\_\_\_ **Advanced**\_\_\_\_\_

<b>Medical Condition</b>	<b>Current Status</b>	<b>Things to Watch For</b>	<b>What to Do</b>

**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:*

	<b>Weekday</b>	<b>Weekend</b>
<b>6:00-7:00 A.M.</b>		
<b>7:00-8:00 A.M.</b>		
<b>8:00-9:00 A.M.</b>		
<b>9:00-10:00 A.M.</b>		
<b>10:00-11:00 A.M.</b>		
<b>11:00-12:00 noon</b>		
<b>Noon-1:00 P.M.</b>		
<b>1:00-2:00 P.M.</b>		
<b>2:00-3:00 P.M.</b>		
<b>3:00-4:00 P.M.</b>		
<b>4:00-5:00 P.M.</b>		
<b>5:00-6:00 P.M.</b>		
<b>6:00-7:00 P.M.</b>		
<b>7:00-8:00 P.M.</b>		
<b>8:00-9:00 P.M.</b>		
<b>9:00-10:00 P.M.</b>		
<b>10:00-11:00 P.M.</b>		
<b>11:00 P.M.-Midnight</b>		

**MY DAY**  
***Meals***

	<b>BREAKFAST</b>	<b>LUNCH</b>	<b>SUPPER</b>
<b>Usual mealtime</b>			
<b>What I usually eat</b>			
<b>Foods I don't like or cannot eat</b>			
<b>Special preparations including utensils, dishes I like to use</b>			
<b>Where I like to eat</b>			
<b>What I like to do after my meal</b>			
<b>Snacks I enjoy</b>			

**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

	<b>Yes/No</b>	<b>What kind of help? Suggestions. . . .</b>
<b>Dressing</b>		
<b>Bathing</b>		
<b>Shaving</b>		
<b>Eating</b>		
<b>Toileting</b>		
<b>Taking my medications</b>		
<b>Care of my teeth</b>		
<b>Care of my hair</b>		
<b>Going to bed</b>		

## 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):** \_\_\_\_\_

---

---

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---

---

---

**Things I usually say to get my needs met:**

<b>When I need to go to the toilet</b>	
<b>When I want something to eat</b>	
<b>When I'm tired</b>	
<b>When I'm angry</b>	

## **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/](http://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](http://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](http://www.screstitecoalition.org)

[screstitecoalition@yahoo.com](mailto: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](http://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](http://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](http://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](http://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](http://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.*

