



**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.screpitecoalition.org](http://www.screpitecoalition.org).

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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.



## 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>
(Example)	One tablet 400 mg	Three times a day after meals (with water)	Diabetes	Dizziness, headache

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**MY HEALTH**  
**Medical Conditions and Allergies**

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

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

<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:*

	Weekday	Weekend
<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</b> including utensils, dishes I like to use			
<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>Dressing</b>	<b>Yes/No</b>	<b>What kind of help? Suggestions. . . .</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):** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### **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**

## **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 (ARD) 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.screstitecoalition.org](http://www.screstitecoalition.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](http://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 on-line equipment exchange program, training, technical assistance, publications, an information listserv and work with various state committees that affect AT acquisition and IT accessibility.