

## CARE Partner Guide

A new pathway to <u>living with</u> dementias We exist to provide and improve access to diagnosis, education, and support for those at risk for or living with dementia.

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# Daily Living, Lifestyle, and Driving



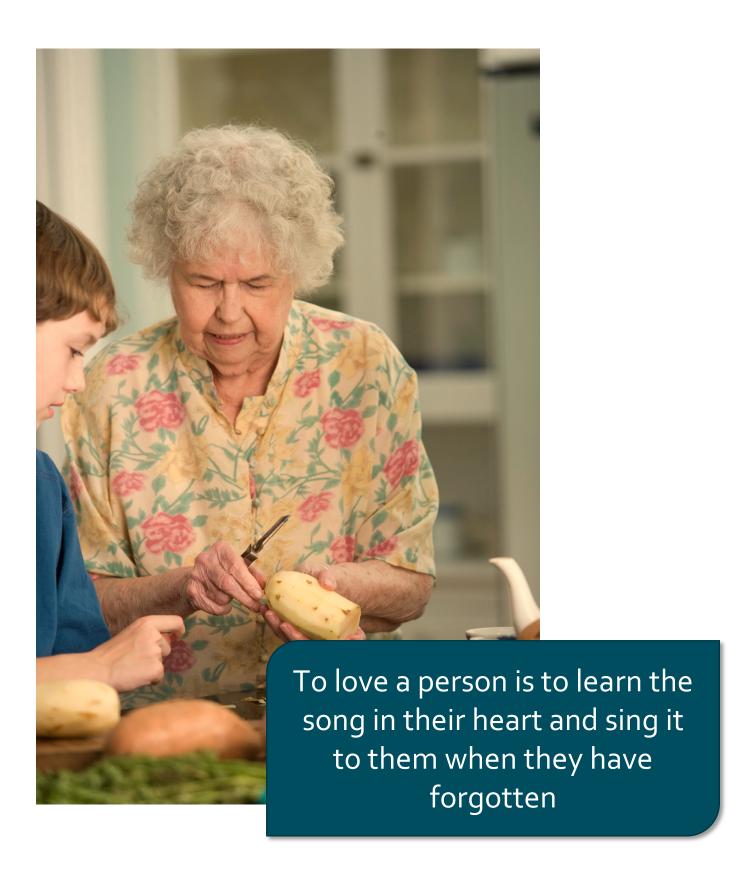
## **Our Promise**

Caring for someone with dementia can feel like taking a long walk in the woods for the first time.

Sometimes the way forward will be simple and sometimes it will be difficult and confusing. When you have a plan, you can spend more time enjoying the scenery.

This booklet was designed to help you plan and prepare for your walk with your loved one after they are diagnosed with dementia. While you cannot prepare for every situation, this guide should give you the tools you need to prepare for, and maybe even prevent, some of the harder situations.

We at the CARE Center are here to help. We wrote this guide for care partners like you because we have walked a mile or two in your shoes. We hope this guidebook helps prepare you for your walk ahead.



# Daily Activities and Planning

Daily schedules are very useful. They can help you make sure that you get things done and still have time for yourself and your loved one. They can also provide routine and structure to your loved one's day. As the disease progresses, your loved one has a harder time making decisions or knowing what is coming next and needs more structure.

Making a daily plan when your loved one has dementia isn't like making a plan for yourself. If your loved one is in the early stage of the disease, they can help create the daily routines. There are a lot of specific things to think about:

Checklist item	N/A	Started	Done	Comments
I've asked my loved one if they want to socialize with friends and family. I have also asked them which friends and family members they want to socialize with.				
If my loved one and I plan to travel, I've planned to take more time to get to our destination and back. We also plan to spend less time running around from place to place and spend more time enjoying where we're at.				
I've asked my loved one what types of activities they want to continue to do. I try to do those activities when possible.				
I make sure that my loved one and I have structured days and weeks. This can really reduce stress for both of us.				

Checklist item	N/A	Started	Done	Comments
I make time for myself, without my loved one, at least once a week.				
I make daily plans for my loved one with extra time built-in in case the unexpected happens.				
I made sure that my plans are flexible since things can change quickly.				
I've included times of day to give medication.				
I've built-in extra time to do things like laundry, prepare meals, and get ready to leave.				
I have added extra time in the schedule to rest between activities.				
I plan around the times of day that my loved one is at their best.				

**Example of a Daily Schedule:** 

Hour	Activity	Meal Plan	Person
6:ooam	Get up, let dog out, make sure		Me
	loved one takes meds		
7:00am	Make breakfast	Eggs, toast,	Me
	Get dressed	coffee	Me & loved one
	Clean up		Me
8:ooam	Go for walk with loved one		Me
9:ooam	Watch TV		Loved one
	Do laundry		Me
10:00am	Play "Life" (board game)		Me & loved one
11:00am	Play Gin Rummy		Loved one
	Prepare lunch		Me
12:00pm	Eat together	Sandwiches,	Me & loved one
	Make sure loved one takes meds	salad	Me
	Do dishes		Me
1:00pm	Take nap		Loved one
	Call friend		Me
2:00pm	Rake leaves / play with dog		Loved one
2.00000	Garden  Paka Januar / play with dag		Me
3:00pm	Rake leaves / play with dog Garden		Loved one Me
/100pm	Take Nap		Loved one
4:oopm	Rake leaves		Me
5:00pm	Prepare dinner	Fish, spinach,	Me
3.00pm	Eat	multi-grain	Me & loved one
	Make sure loved one takes meds	bread	Me
6:oopm	Wash dishes	2.000	Me
7:00pm	Shower loved one		Me & loved one
8:oopm	Watch TV		Me & loved one
9:00pm	Watch TV		Me & loved one
10:00pm	Go to bed		Me & loved one
	Make sure loved one takes meds		Me

#### Other To-Dos:

- Send thank you cards
- Call daughter
- Ask neighbor to get milk and bread next grocery visit

#### DAY:

Hourly Schedule	Activity	Meal Plan	Person Responsible
6:ooam			
7:00am			
8:ooam			
9:ooam			
10:00am			
11:00am			
12:00pm			
1:00pm			
2:00pm			
3:oopm			

4:00pm
5:00pm
6:oopm
7:00pm
8:oopm
9:00pm
10:00pm

#### Other To-Dos:

- •
- •
- •

### Notes about the Day:

- •
- •
- •

Love is a symbol of eternity. It wipes out all sense of time, destroying all memory of a beginning and all fear of an end



# Exercise, Nutrition, Well Being

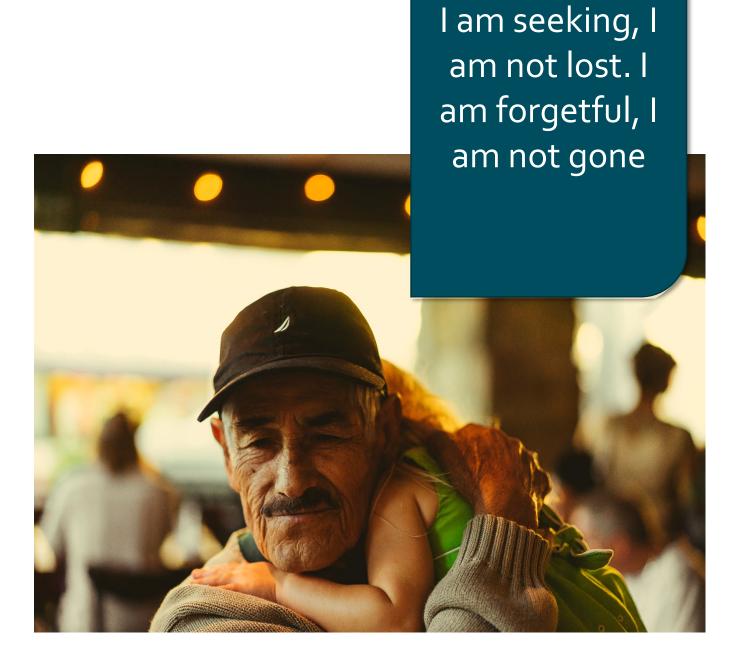
We have all heard about how important it is to stay active and eat right. Now we know that exercising, following a heart-healthy diet, socializing, and keeping your brain active can slow the progression of dementia. If you and your loved one want to stay as sharp as possible for as long as possible, make sure you check off as much as you can on the list below and keep at it!

Checklist item	N/A	Started	Done	Comments
My loved one and I eat heart-healthy foods like lots of fish, baked chicken, greens, vegetables, and fruit.				
My loved one feels full after eating.				
My loved one eats a variety of foods, including lots of fruits and vegetables.				
My loved one and I eat meals together.				
If my loved one doesn't live with me, I check – or ask their neighbor/friend to check – for expired food in their kitchen every few weeks.				
I've called Meals on Wheels to see if my loved one qualifies. If they do, I've signed them up.				
I've checked if my loved one qualifies for SNAP and Medicaid. If they do, I've signed them up.				

Checklist item	N/A	Started	Done	Comments
I exercise with or without my loved one at least three times a week.				
I've made sure it's safe for my loved one to exercise. (For example, if they need a cane, I make sure they use one when they walk.)				
At least three times a week, my loved one does some type of physical activity, such as gardening, dancing, cleaning, car washing, raking leaves, pushing a stroller, or walking up stairs.				
If my loved one is in the early stage of the disease, they get up and go to bed about the same time every night.				
If my loved one is past the early stage, the house is secured in case they wander at night.				

Checklist item	N/A	Started	Done	Comments
I make sure there is enough time every day for my loved one to nap.				
I do my best to make sure my loved one gets at least 4-5 hours of continuous sleep a night.				
If my loved one is in the early stage of the disease, I make sure my loved one does things to stay mentally active, like crossword puzzles, games, learning something new, and engaging in hobbies.				
If my loved one is in the early stage of the disease, we make plans together to keep socializing. We may need to cut back on what we do, but we socialize as much as possible.				

Checklist item	N/A	Started	Done	Comments
If my loved one is past the early stage of the disease, I make and keep plans to socialize with my friends without my loved one.				
If my loved one is past the early stage of the disease, we make plans for family and friends to visit my loved one at home from time to time.				
I continue to be as active in my religion or spirituality as I did before my loved one was diagnosed.				
My loved one gets their eyes checked once a year.				
My loved one gets their hearing checked once a year.				
My loved one sees their primary care physician once a year.				



## Driving

At some point, your loved one will need to stop driving. This can be a tough conversation to have. For most Americans, driving means independence. But for people living with dementia, driving means risking their lives and the lives of other people on the road. People living with dementia don't have the same fast reflexes they used to have and may get confused by things that didn't use to confuse them. You know your loved one best and may already know how to have this conversation, but many people don't. If that's you, we have a few ideas about how to start that conversation:

- For some, it's best to appeal to their ego ("Dad, you've worked so hard for us for so long. It's about time you had a chauffeur!").
- Others will give up their keys if they understand that they could accidentally kill someone while driving.
- A few people may need to be told by their doctor. Their doctor might consider writing a prescription to stop driving or sending a letter to the Department of Motor Vehicles so that your loved one's license gets revoked.
- If your loved one still refuses to give up driving, the last resort could be disconnecting the car battery, hiding the car keys, or always saying the car is "at the shop" so that your loved one can't drive.

Regardless of how it's done, giving up driving can be a big emotional loss. Your loved one may grieve that loss like they would the loss of a friend, and that's okay. If that sounds like your loved one, it's important to respect their grief and give them space. When they're ready to talk about it, find out

what concerns they have about being unable to drive. This may help to figure out solutions and allow your loved one to feel better about the situation.

There are ways to make this transition as smooth as possible and ensure your loved one can still get around safely. If you don't drive and need transportation, there are at least four resources out there that can help.

- 1. Check with your Medicare Advantage plan. Some plans cover transportation to doctor appointments. Rides may have to be booked in advance, so check in at least a week before your appointment to find out.
- 2. Medicaid and the Program of All-Inclusive Care for the Elderly (PACE) programs often provide transportation for routine medical care.
  - Visit the U.S. Medicaid website as well as the National PACE Association (PACE 4 You) website for more information.
- 3. The Eldercare Locator has information about resources that may help. Eldercare Locator is a free public service of the United States Administration on Aging.
  - Refer to the Resource Contact Guide for website and phone information
- 4. Dialing 211 for essential community services can connect you with a referral specialist to learn about services that support older adults, including transportation.

Also, your local Area Agency on Aging (AAA) may have options for transportation around your community (see list).

Here are some things to do to make sure you've covered all the bases when it comes to your loved one and driving:

Checklist item	N/A	Started	Done	Comments
I've talked to my loved one about no longer driving.				
My loved one has agreed to stop driving our car.				
My loved one has also agreed to stop driving other vehicles like trucks, boats, tractors, riding lawnmowers				
My loved one and I have talked about how we'll get around when they stop driving. When we talked, we thought about:				
<ul> <li>The daily activities my loved one wants to continue.</li> </ul>				
<ul> <li>The type of transportation my loved one is most comfortable with (bus, taxi, friends/family).</li> </ul>				

Checklist item	N/A	Started	Done	Comments
<ul> <li>If meals, groceries, and medications can be delivered to our house (by friends, family or the store) so that we don't have to drive.</li> </ul>				
I put the car keys somewhere where my loved one can't get them.				
• I did the same thing for keys to all other vehicles they have access to (lawnmower, tractor, boat, etc.).				
I've told everyone who needs to know that my loved one has stopped driving (neighbors, doctors, church friends, their old bowling buddies, etc.).				

Georgia Area Agencies on Aging (AAA)

Regional Area Counties Contact				
Agency on Aging	Served	Info		
Atlanta Regional Commission Aging Division	Cherokee, Clayton, Cobb, DeKalb, Douglas, Fayette, Fulton, Gwinnett, Henry, Rockdale	229 Peachtree Street, NE Suite 100 Atlanta, GA30303		
Coastal Georgia Area Agency on Aging	Bryan, Bulloch, Camden, Chatham, Effingham, Glynn, Liberty, Long, McIntosh	1181 Coastal Dr., SW Darien, GA31305		
CSRA Area Agency on Aging	Burke, Columbia, Glascock, Hancock, Jefferson, Jenkins, Lincoln, McDuffie, Richmond, Screven, Taliaferro, Warren, Washington, Wilkes	3626 Walton Way Extension, Suite 300 Augusta, GA30909		
Heart of Georgia Area Agency on Aging	Appling, Bleckley, Candler, Dodge, Emanuel, Evans, Jeff Davis, Johnson, Laurens, Montgomery, Tattnall, Telfair, Toombs, Treutlen, Wayne, Wheeler, Wilcox	331 West Parker St. Baxley, GA31513		
Legacy Link Georgia Mountains Area Agency on Aging	Banks, Dawson, Forsyth, Franklin, Habersham, Hall, Hart, Lumpkin, Rabun, Stephens, Towns, Union, White	4080 Mundy Mill Rd. Oakwood, GA 30566		
Middle Georgia Area Agency on Aging	Baldwin, Bibb, Crawford, Houston, Jones, Monroe, Peach, Pulaski, Putnam, Twiggs, Wilkinson	175-C Emery Hwy. Macon, GA31217		

Regional Area Agency on Aging	Counties Served	Contact Info
Northeast Georgia Area Agency on Aging	Barrow, Clarke, Elbert, Greene, Jackson, Jasper, Madison, Morgan, Newton, Oconee, Oglethorpe, Walton	305 Research Dr. Athens, GA30610
Northwest Georgia Area Agency on Aging	Bartow, Catoosa, Chattooga, Dade, Fannin, Floyd, Gilmer, Gordon, Haralson, Murray, Paulding, Pickens, Polk, Walker, Whitfield	1 Jackson Hill Dr. Rome, GA30161
River Valley Area Agency on Aging	Chattahoochee, Clay, Crisp, Dooly, Harris, Macon, Marion, Muscogee, Quitman, Randolph, Schley, Stewart, Sumter, Talbot, Taylor, Webster	710 Front Ave., Suite A Columbus, GA 31901
Southern Georgia Area Agency on Aging	Atkinson, Bacon, Ben Hill, Berrien, Brantley, Brooks, Charlton, Clinch, Coffee, Cook, Echols, Irwin, Lanier, Lowndes, Pierce, Tift, Turner, Ware	1725 South Georgia Pkwy., West Waycross, GA 31503
Sowega Council on Aging Southwest Georgia Area Agency on Aging	Baker, Calhoun, Colquitt, Decatur, Dougherty, Early, Grady, Lee, Miller, Mitchell, Seminole, Terrell, Thomas, Worth	335 W. Society Ave. Albany, GA31701
Three Rivers Area Agency on Aging	Butts, Carroll, Coweta, Heard, Lamar, Meriwether, Pike, Spalding, Troup, Upson	13273 Hwy. 34 East Franklin, GA30217

#### **Notes**



# Healthcare Management



## Creating a Care Team

When a loved one has dementia, it can sometimes feel very lonely and isolating. Take some time now to create your own "Care Team," a group of people who may be able to help when you need it. This can include a friend who comes over to stay with your loved one while you get a haircut, a neighbor who picks up some bread and milk for you when they're at the store, or an eldercare attorney to create an Advance Directive.

Whatever you need, it's likely there is someone out there who can help you. Take some time now to write down who those people are. You'll have that list to refer to when you need it, and you'll feel much better knowing that you have a team behind you. If your loved one is in the early stage of the disease, they can help you add people they trust to this list.

Type of Person	Types of things they can help with	Names & contact information of people who can help
Family Members	<ul> <li>Emotional support</li> <li>Help with day-to-day things such as grocery shopping and staying with my loved one</li> <li>Help me find resources I need</li> </ul>	e.g., Suzy Q: (111)222- 333
Friends	<ul> <li>Emotional support</li> <li>Help with day-to-day things such as grocery shopping and staying with my loved one</li> <li>Help me find resources I need</li> </ul>	
Neighbors	<ul> <li>Help with day-to-day things such as grocery shopping and staying with my loved one</li> <li>Keep an eye out for my loved one in case they wander</li> </ul>	
Members of my community or religious group Social worker or another therapist	<ul> <li>Emotional support</li> <li>Help me find resources I need</li> <li>Emotional support and counseling</li> <li>Help me find resources I need</li> </ul>	
Geriatric care manager	<ul> <li>Help me find resources I need</li> </ul>	

Type of Person	Types of things they can help with	Names & contact information of people who can help
Doctors, nurses, or other Healthcare professionals Eldercare attorney	<ul> <li>Answer my healthcare questions</li> <li>Refer me to healthcare resources I need</li> <li>Answer legal questions</li> </ul>	
Financial advisor or planner	<ul> <li>Answer financial questions</li> <li>Help me plan for the cost of my loved one's care</li> </ul>	
Home healthcare professionals	<ul> <li>Free up my time to do my errands</li> <li>Give me time to relax</li> <li>Allow me to go back to work</li> </ul>	
Adult day health centers	<ul> <li>Free up my time to do errands</li> <li>Give me time to relax</li> <li>Allow me to go back to work</li> </ul>	
Memory care centers or assisted living facilities	<ul> <li>Take care of my loved one full time when I can't</li> </ul>	



Dementia care – it's not rocket science, it's heart science

# Communicating with Doctors

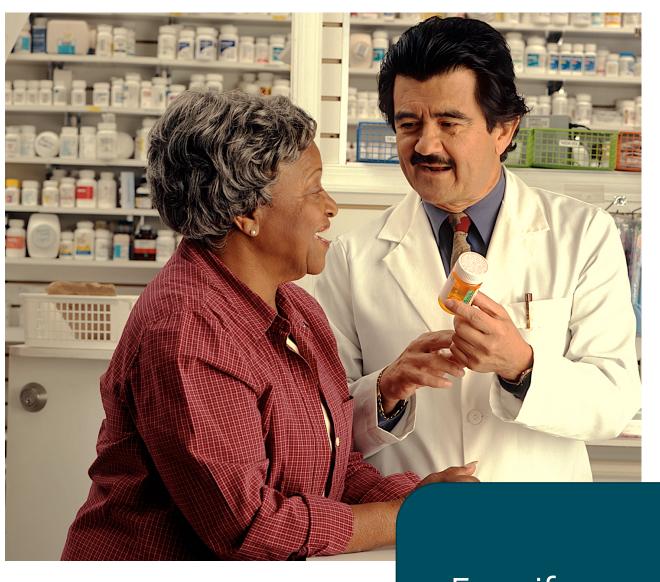
Clear communication with your doctors and nurses is so important when your loved one has dementia. It can be very frustrating when your healthcare professionals use complicated medical terms. It can also be upsetting when your doctor makes you feel like they don't care or aren't listening. It's difficult when you don't know exactly what's going on.

Luckily, there are a few things that you can do to make sure that you know what's happening with your loved one's health care.

Checklist item	N/A	Started	Done	Comments
My loved one and I try to visit the doctor's office with another person to make sure we hear everything right.				
When I go to the doctor's office with my loved one, I take notes so we can remember what they said later.				
When I go to the doctor with my loved one, we repeat back the information learned and instructions given by the doctor to ensure we understand everything discussed.				
I asked my loved one if they have any other concerns or questions for the doctor before we leave.				
My loved one signed paperwork at the doctor's office that lets the doctor discuss their treatment with other family members.				

Checklist item	N/A	Started	Done	Comments
My loved one's list of medicines includes all vitamins, supplements, and things we buy from the drugstore.				
When my loved one gets a new medication, I always ask the doctor what the side effects are.				
I made sure that all of my loved one's doctors have all my loved ones' medical records. This may involve my loved one or me giving permission for records to be sent from one doctor's office to another.				
When I go to the doctor's office with my loved one, I bring a list of their medicines, including how much they take, when they take it, and if they take it with food. (Or I bring all their medicine bottles with me.)				

Checklist item	N/A	Started	Done	Comments
My loved one or I keep a list of my loved one's symptoms every day and write down anything unusual. I bring that list with us when we go to the doctor.				
I regularly ask my doctor if my loved one needs to drink things like Ensure or Boost to make sure they're getting enough nutrition.				



Even if we can't cure, we can still care

# Managing Medication

Taking medicine is a very important part of your loved one's daily routine. Your loved one must take each medicine exactly as the doctor says they should. If they don't, they could get very sick or even end up in the hospital.

Here are some things you can do to make sure that your loved one takes their medicines correctly:

Checklist item	N/A	Started	Done	Comments
I am confident that my loved one is taking their medicines properly (as directed), including taking them at the right time of day.				
I know what each of my loved one's medicines does, as well as when and how they should be taken.				
I have a list of my loved one's medicines that I bring to every doctor's appointment. My list includes vitamins, supplements, and other things I get from the drugstore. (Or I bring all of their medicine bottles with me.)				

Checklist item	N/A	Started	Done	Comments
Whenever my loved one starts taking a new medication, I watch carefully for any side effects - such as dizziness, nausea, and agitation - and write down what happens and how often. I ask my loved one if they have any concerns about the new medication.				
If my loved one has negative side effects from a new medicine, I immediately contact their doctor.				
I regularly check that there are not an unusually high or low number of pills left at the end of the day/week/month.				

Checklist item	N/A	Started	Done	Comments
My loved one uses something that makes it easy to remember to take their medicines correctly. This can be a pillbox (with days of the week), a medicine bottle cap that counts the number of times the bottle has been opened, or something else.				
I have a simple way to make sure my loved one takes their medicines correctly. For example, if their medication must be taken at night with a full glass of water, I might set an alarm to remind me to have them take it then.				
I've written down how my loved one has to take their medications and given copies to my family in case anything happens to me. The list includes: schedule, purpose, refill information, and side effects.				

Checklist item	N/A	Started	Done	Comments
I use only one pharmacy for all medicines so that the pharmacists know what drugs my loved one takes and can spot any possible problems.				
Whenever my loved one gets on a new medication or their medications change, I ask my pharmacist to check if their medications can be taken together.				
I have notifications or automatic refills set up with my loved one's pharmacy so we never miss a refill.				

#### **Notes**


#### **Notes**



# Legal and Financial Planning



#### Finances and Insurance

Making financial plans and digging through insurance policies can be overwhelming. Still, it is very important to understand what is <u>paid for</u>.

It may also be helpful to meet with a financial advisor or planner who can walk through possible sources of funds with you. Figuring this out now helps your loved one to express their wishes and prevent possible financial complications from happening. Be sure to meet with an attorney to ensure all legal paperwork is completed correctly and follows state guidelines.

Checklist item	N/A	Started	Done	Comments
If my loved one is a veteran, I've spoken with Veterans Affairs (VA) about the benefits my loved one can receive.				
I've checked with my loved one's health insurance (private, Medicare, Medicaid, etc.) to see what is and is not covered.				
I've researched other types of insurance to see if there's more money available for my loved one's care. This could include:				
<ul> <li>Supplemental Security Income (SSI)</li> </ul>				
<ul> <li>Social Security         Disability         Insurance (SSDI)     </li> </ul>				
<ul> <li>Life Insurance</li> </ul>				
<ul><li>Disability</li><li>Insurance</li></ul>				
<ul> <li>Long-term Care Insurance</li> </ul>				

Checklist item	N/A	Started	Done	Comments
My loved one and I have chosen reliable people who can take care of finances with me or in my place. Those people have agreed to do this if they need to.				
My loved one and I have made sure that I or someone else we trust has financial power of attorney for my loved one.				
My loved one and I have made sure that I or someone else we trust has healthcare power of attorney for my loved one.				
I have a list of my loved one's passwords, including their:				
<ul> <li>Computer passwords</li> </ul>				
<ul> <li>Phone passcode</li> </ul>				
<ul> <li>Online banking passwords</li> </ul>				

Checklist item	N/A	Started	Done	Comments
<ul> <li>Online bill paying passwords (for utilities, credit cards, etc.)</li> </ul>				
<ul> <li>Code to any safe they have</li> </ul>				
<ul> <li>Access to their 401k or any other retirement accounts</li> </ul>				
<ul> <li>Social media and email account passwords</li> </ul>				
I've had a financial advisor, financial planner, or someone with a strong financial background look at my loved one's financial situation.				
I plan to include – or have included – a financial advisor or planner on my care team if possible (See <i>Creating a Care Team</i> ).				



In the end, you tried and you cared and that is enough

# **End-of-Life Planning**

It can be tough to talk about end-of-life matters, but it's necessary for both you and your loved one. It's important to ask your loved one what their wishes are as early as possible. Having the right documents in place ensures your loved one gets the care they want as the disease progresses and gives you peace of mind that you're doing the right thing.

Having an Advance Directive for Healthcare reduces the number of hospitalizations you or your loved one is likely to have and reduces the amount you'd have to pay. It lets your loved one pass the way they want. An Advance Directive for Healthcare spells out the treatments your loved one would want to receive if:

- They are facing a medical crisis.
- They have been diagnosed with a terminal illness.
- They are unable to speak for themselves.

There are a lot of things to think about and talk about with your loved one. Go to the Conversation Project website for a guide to how to talk about end-of-life issues with your loved one (called "Your Conversation Starter Guide").

Here are some important documents and other terms to know:

- Living Will This is a legal document that tells others what your loved one's personal choices are about end-of-life medical treatment. In Georgia, the Living Will has been replaced by the Advance Directive for Healthcare. Make sure to check for your state's end-of-life treatment plans.
- Advance Directive for Healthcare This states what medical treatment your loved one does or does not want if they lose the ability to make decisions themselves. In Georgia, it replaces the Living Will. Your loved one must complete this form, which you can find on the Department of Human Services website, on the Division of Aging Services page.
- Healthcare Agent, also known as Durable Power of Attorney for Healthcare (DPA-HC) – When someone is made your loved one's power of attorney for healthcare, that person can make healthcare decisions for them. The Healthcare Agent is stated in the Advance Directive for Healthcare.
- **Five Wishes document** This document can replace a living will or advanced directive in Georgia. Advance directives are often overwhelming. The Five Wishes document helps outline your loved one's goals and wishes in a simple document. You can find the Five Wishes document on the Five Wishes organization website.
- **POLST (Physician Orders for Life-Sustaining Treatment)** This form *does not replace* other forms. However, it allows you to describe:
  - What treatments <u>not</u> to use in case of medical emergencies
  - Under what conditions certain treatments can be used
  - How long treatments may be used
  - When treatments should be stopped.
     A POLST also indicates what advance directives your loved one
    has and who serves as their healthcare agent. Many people do
    not have a POLST. Your loved one must complete this form,
    which you can find at the Georgia POLST Collaborative website.

- **Do-not-resuscitate order (DNR)** This is a legal document from a doctor that says no steps will be taken to restart a patient's heart or restore their breathing in the event of cardiac or respiratory arrest (a heart attack). Your loved one must complete this form, which you can find on the Department of Human Services website, on the Division of Aging Services page.
- Financial Power of Attorney When someone is made your loved one's financial power of attorney, that person controls your loved one's finances if they cannot (for example, if they are in a coma).
   Check with an attorney to see your state's legal guidelines and required forms on how to officially designate a financial power of attorney.
- **Hospice** Hospice care is comfort care for your loved one once the doctor has estimated they have six months or less to live. Medicare usually pays for hospice.
- **Will** This is different from a living will. A will is a document that describes what is to be done with a person's belongings after they have died.

This is not a complete list of important documents to know, and is not legal advice. It's best to check with an attorney to determine exactly what documents are needed to ensure your loved one's wishes are able to carried out.

Here are things you can do now to prepare yourself and your loved one:

Checklist item	N/A	Started	Done	Comments
My loved one has an up-to-date will that can be accessed when needed. I know where it is and have checked state laws or gotten legal advice from an attorney to make sure it is legally valid.				
My loved one has an Advance Directive for Healthcare and/or a Do-Not-Resuscitate order (DNR). I know where they are and can get them quickly.				
The person that my loved one chose to be their Healthcare Agent has agreed to do it and has a copy of their Advance Directive.				

Checklist item	N/A	Started	Done	Comments
My loved one's power of attorney and all of my loved one's healthcare providers have a copy of my loved one's Advance Directive. The nearest hospital also has copies on file.				
My loved one has a POLST (Physician Orders for Life-Sustaining Treatment). I know where it is and can get it pretty quickly.				
My loved one has completed the necessary paperwork which gives financial power of attorney to someone. I know where it is and can get to it quickly.				
The person that my loved one chose to be their Financial Power of Attorney has agreed to do it and has a copy of their legal form.				

Checklist item	N/A	Started	Done	Comments
I've checked with all of my loved one's banks and credit unions to see if other forms need to be filled out for the Financial Power of Attorney.				
Our emergency contacts know who my loved one's Healthcare Agent and Financial Power of Attorney are and have their contact information.				
My loved one has a wallet-sized card that they carry which states that they have an Advance Directive and where it can be found.				
All of my loved one's forms are easy to get to in case of emergency.				

Checklist item	N/A	Started	Done	Comments
I also have an up-to- date will, Advance Directive, and financial and healthcare power attorney paperwork. My loved one is not my Healthcare Agent or my Financial Power of Attorney.				
My loved one and I have discussed hospice care. We've researched local hospice providers and have a hospice plan for when the time comes.				
My loved one and I have discussed funeral plans. I know if my loved one has any specific requests and wants to be buried or cremated.				
My loved one and I have discussed donating their brain to Alzheimer's and dementia research after their death.				



### Other Care Options

Taking care of your loved one is a full-time job, and you'll need "vacation time" every so often. There may also come a time when it's safest for your loved one to live in a long-term care facility. Finding a good facility can take time, so it's best to start looking early. If your loved one is in the early stage of their disease, they may want to look with you so that they feel comfortable with the decision.

It's also important to recognize when you need some time off and have a plan for someone to take care of your loved one. If your loved one is in the early stages of the disease, you can work with them to find care options they are comfortable with whenever you're away.

Here are some definitions of available care options:

- Adult Daycare Center A place where people with dementia, and sometimes adults with other disabilities, go during the day so that their families can do other things during the day. Often the VA or Medicare will pay a portion of the costs.
- Certified Nurse Assistant (CNA) A healthcare professional who
  helps patients and people living with dementia do things like shower,
  brush their teeth, eat, and get dressed. CNAs work at adult daycare
  centers, hospitals, long-term care and memory care facilities, and
  home healthcare agencies.

- Home Healthcare (HHC) A home healthcare agency is a company that sends care partners, often CNAs, to people's homes to take care of sick people or people living with dementia. HHC is cheaper than using a facility but more expensive than adult daycare centers.
   Medicare and the VA sometimes pay for HHC services.
- **Memory Care** A facility similar to an assisted living facility but solely for people living with dementia. Usually, people living in the middle or last stages of dementia stay at memory care facilities.
- **Respite Care** This is planned time off for care partners. Usually, either a friend or family member stays with the person living with dementia, or the person living with dementia goes to a memory care facility for a few days to a week so that the care partner can have some time off.

Checklist item	N/A	Started	Done	Comments
I have a plan in place for when I need a break. This could include:				
<ul> <li>Contacting 211         to find out what         care options are         available.</li> </ul>				
<ul> <li>Respite care at a memory care facility.</li> </ul>				
<ul> <li>Getting home healthcare for my loved one such as hiring a Certified Nurse Assistant (CNA).</li> </ul>				
<ul> <li>Using a local senior day center to give me a break during the day.</li> </ul>				
<ul> <li>Family or friends that my loved one is comfortable staying with for a week or a long weekend.</li> </ul>				

Checklist item	N/A	Started	Done	Comments
I've looked into long- term care options in case my loved one needs more care than I can provide. This can include contacting Medicaid to learn about long-term care options in Georgia.				

#### **Notes**




### Safety Considerations



Release in your mind who your loved one used to be, and accept who they are today

### Home Safety

Most people living with dementia will continue to live at home. A house that used to be easy for your loved one to get around in may start to become tricky. Every person is different. Your loved one may be able to continue to do things like cook and clean for a long time – or they may have to stop sooner than they would like. It's important to pay attention to how they're doing so they can be safe.

The best thing to do is to make changes now to avoid problems rather than waiting for problems to happen before making a change. If you make small modifications to the house, they can live at home as long as possible. Making these changes as soon as possible also allows you to include your loved one in the decisions.

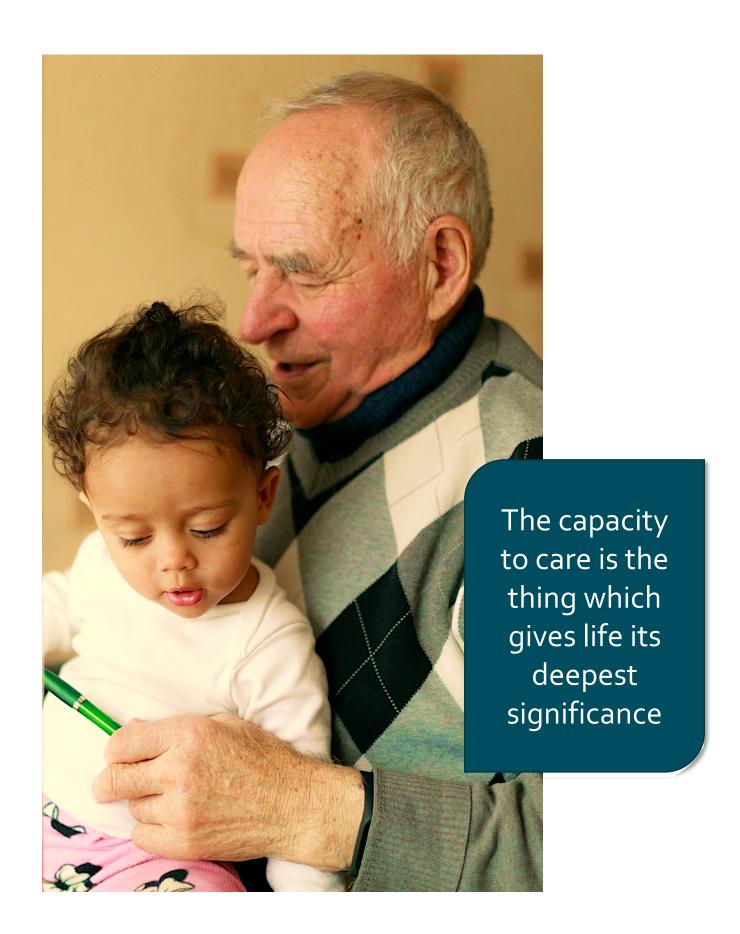
When you make changes, think about...

- ✓ All rooms of the house, the garage, and any outbuildings that may need changes.
- √ Where your loved one likes to spend the most time.
- ✓ The hobbies and activities your loved one would like to safely continue (gardening, fishing, working out, cooking or baking, etc.).
- ✓ Who your loved one can stay with if you're not at home.
- ✓ Talking to your loved one about locking up medications, cleaning supplies, detergent, kitchen knives, tools, and other potentially dangerous items.

Checklist item	N/A	Started	Done	Comments
We have a fire extinguisher that we keep in the kitchen specifically made for our type of stove (gas or electric). We also have a fire extinguisher next to the fireplace.				
I check my home's smoke detectors at least twice a year and check our fire extinguishers at least once a year.  If I can't reach the smoke detectors, I've had a friend, family member, or my local fire department check them for me.				
I have (or the local fire department has) checked that there are enough smoke detectors in our home, including my loved one's bedroom.				

Checklist item	N/A	Started	Done	Comments
If my loved one or I have any firearms (in our house, garage, attic, car, shed, etc.), we've given them away, sold them, or locked them up. I've made sure my loved one doesn't have access to the keys.				
If my loved one or I have any ammunition (in our house, garage, attic, car, shed, etc.), we've given it away, sold it, or locked it up separately from the firearms. I've made sure my loved one doesn't have access to the keys.				

Checklist item	N/A	Started	Done	Comments
I've made sure that any hunting or fishing items (fishing or hunting knives, bow and arrow, etc.) have been given away, sold, or safely locked away. I've made sure my loved one doesn't have access to the keys.				
If necessary, I have removed the knobs on our stove or oven so that my loved one doesn't accidentally turn the stove or oven on.				
If there are candles, lighters, or firecrackers on our property, I've made sure they're safely stored where my loved one can't access				
them. I have keys to all my loved one's properties.				



Beer, J. M., Renzi-Hammond, L. M., Washington, T., Kim, D., Call, K. M., Akpolo, E. M, Council, S. C., & Leathers, T. A. (2022). CARE Partner Guide. Version 1.0. Technical Report. Athens, GA. University of Georgia, Cognitive Aging Research and Education Center.

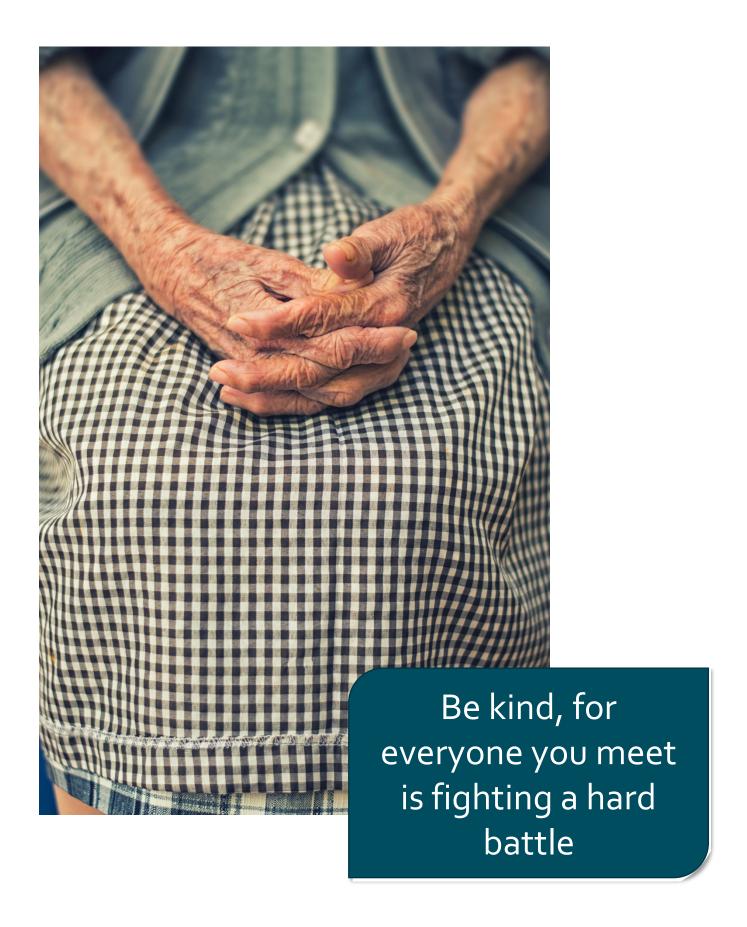
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### Preventing Falls

People living with dementia are more likely to fall than people without dementia. Places where your loved one is used to walking may become harder for them to get around. Their sense of balance may get worse as the disease progresses. And if they don't exercise, their muscles will get weak, and they may fall more often. There are still things you can do to take control of the situation and minimize the chances that your loved one suffers a fall.

Checklist item	N/A	Started	Done	Comments
I've made a plan to keep my loved one's muscles strong with regular exercise.				
My loved one always wears shoes or slippers with good support and heels with good grip.				
All the stairs in our house (inside and outside) have secure handrails.				
At later stages of the disease, my loved one has a help bracelet or necklace that they can use to call for help if they fall.				
We have put flashlights around the house in case the electricity goes out.				
We've gotten rid of our rugs or taped them down because they're easy to trip over. If our carpet sticks up a bit, we've taped it down or replaced it.				

Checklist item	N/A	Started	Done	Comments
If we get new chairs or couches, we try to get ones with armrests, so they're easier to get into and out of.				
We've made sure that there are no cords to trip over (from the TV, lamps, stereo, etc.).				
We always make sure our shoes are somewhere they can't be tripped over (like on a shoe rack).				
There are no lamps or small tables sticking out that would be easy to trip over or run into.				
Our halls and rooms are well lit and have nightlights so that it's easier to see at night.				
We've made the bathroom easier to get into and out of. We've added grab bars in the shower and next to the toilet, put a textured mat on the shower floor, or made the shower/tub easier to walk-in.				



## Wandering and Getting Lost

Wandering is common for people with dementia. When it happens, it can be very scary. It's best to be prepared if your loved one goes missing. Having a plan will help you get your loved one home as quickly as possible.

One way to minimize the chances that your loved one will wander is to have a regular routine that provides structure to their day. If your loved one is in the early stages of the disease, work with them to set up schedules that work for both of you. If your loved one is in a later stage of the disease, make sure that the routine causes minimal disruption to your loved one's day. When a person with dementia has a regular schedule, they are less likely to wander because they understand that they will be doing something soon.

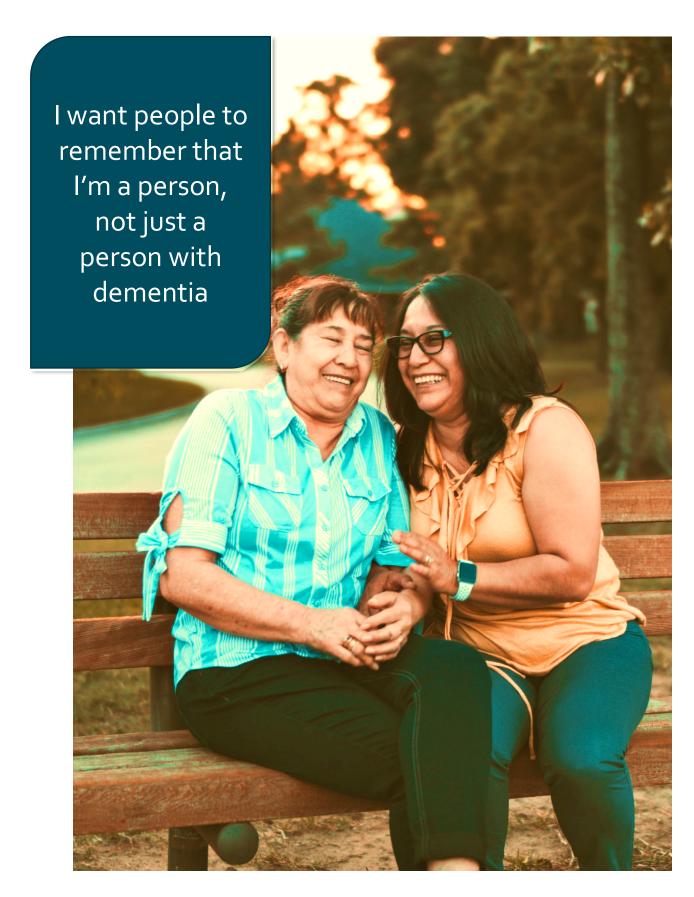
Keep in mind that wandering can happen with *any* care partner. If this happens, don't be hard on yourself. There's a lot to learn from a wandering event that can help you if there is a next time. For example, if your loved one wanders right before dinner, you can plan activities for them to do at that time each day.

Checklist item	N/A	Started	Done	Comments
My loved one and I have made plans in case something happens if they're alone in the early stage of the disease.				
If my loved one is in a later stage of the disease, I've made plans to make sure they're not left alone. This may mean my loved one stays with me, family, friends, or paid assistance				
If my loved one is in the early stage of the disease, we've created a plan to use if they go missing when the disease progresses. The plan includes things like:				
<ul> <li>Creating a list of people that should be called for help.</li> <li>My loved one has a wallet-sized card that they carry with this information.</li> </ul>				

Checklist item	N/A	Started	Done	Comments
<ul> <li>Notifying         neighbors, family,         and friends about         the possibility of         wandering and         making sure they         have a list of people         to contact and what         to do if they see my         loved one         wandering.</li> </ul>				
<ul> <li>Discussing places that they are likely to visit if they do wander, such as previous workplaces, restaurants, friends' homes, etc.</li> </ul>				
A friend or neighbor has a spare key in case my loved one wanders off, or there is a key safely hidden near our home that my friend or neighbor knows about.				
I have a recent photo of my loved one on hand in case they get lost.				

Checklist item	N/A	Started	Done	Comments
I have a list of my loved one's key physical characteristics (height, weight, eye color, hair color), medical insurance, and medical issues (allergies, medicines, medical conditions, etc.).				
My loved one has a medical bracelet or necklace engraved with emergency contact information.				
My loved one has a wallet-sized card that they carry with emergency contact and medical information (insurance information, allergies, medicines, medical conditions, etc.) on it.				
If my loved one tends to wander, I've checked into getting home camera monitoring.				

Checklist item	N/A	Started	Done	Comments
If my loved one tends to wander, I've checked into installing extra locks or alarms that go off when outside doors are opened. The alarm could be something as simple as a bell that rings when the door is opened.				
My loved one has a cell phone with ICE (In Case of Emergency) phone numbers as contacts.				
If my loved one has a cell phone, I have downloaded apps onto their phone to track their phone location (such as "Find My Phone" or "Life 360").				



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# **Emergency Contacts**

Life happens. Your loved one may wander off, you may get in a car accident, or you may suddenly need to visit a sick relative in the hospital and need to leave your loved one with a friend. Take a few minutes to plan now for emergencies so that when life happens, you'll have one less thing to worry about.

Checklist item	N/A	Started	Done	Comments
I have ICE (In Case of Emergency) phone numbers on my phone.				
My loved one has a cell phone with ICE (In Case of Emergency) phone numbers as contacts.				
There's a list of my loved one's health care providers' contact information and health insurance in an easy-to-find place in case of emergency (like in my wallet, on the refrigerator, etc.).				
I keep the list of my loved one's medicines in my wallet or on the refrigerator. The list of medicines includes how often they are taken, what they are for, and what side effects my loved one has. This list is kept up-to-date.				

Checklist item	N/A	Started	Done	Comments
My list of emergency contacts includes health care providers who have prescribed medications. I can contact them if my loved one starts having negative side effects from their medications.				
I have a wallet-sized card that I carry with my loved one's name and medical information on it in case something happens to me.				
My loved one has a wallet-sized card that they carry with emergency contact and medical information on it.				

# **Notes**

# To our grandmothers



Grandma June



Grandma Evelyn

We see dementia differently. That is why we built the Cognitive Aging Research and Education (CARE) Center – a clinical, research, and outreach space where we deliver education on dementia risk reduction, provide screening and diagnosis, conduct cutting-edge research, and provide support for persons with dementia and their care partners.

We are a team of interdisciplinary researchers, dedicated educators and students, and authentic health communicators. Our team believes that we can create a new pathway to dementia education and diagnosis; a pathway built upon scientific evidence, passion, collaboration, and sincerity.

To our grandmothers, we love you, we miss you, and this work is a promise kept.

Dr. Jenay Beer & Dr. Lisa Renzi-Hammond

Co-Directors of the CARE Center

Jany M. Bear

With special thanks to our Bulloch County partner, the R.O.A.D. Foundation: <a href="https://rockinoutalzheimers.org/">https://rockinoutalzheimers.org/</a>

