NEXT STEPS

A Guide for Families After a Dementia Diagnosis

DukeHealth

Duke Dementia Family Support Program

Duke Dementia Family Support Program

Programs and services offered free of charge, to help families live their best lives with changes in memory and thinking.

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NEXT STEPS

A Guide for Families After a Dementia Diagnosis

A diagnosis of mild cognitive impairment (MCI) or dementia can be overwhelming for many reasons. It may feel as though the future you imagined has suddenly changed, and the uncertainty can be deeply unsettling. You'll also face a range of practical decisions to navigate, from how to tell family members to choosing support resources. It's natural to feel scared.

It's okay to take some time to absorb the news. Acceptance doesn't happen all at once, and it doesn't mean you have to like what's happening. Everyone reacts differently, but when you feel ready, there are steps you can take to regain a sense of direction and support. By reading this publication, you're already taking an important first step.

This guide is here to help. The information on the following pages is drawn from over four decades of experience working with thousands of individuals and families affected by dementia. While every journey is different, we've seen time and again that certain steps can ease the path forward.

One of the first — and most helpful — things you can do is connect with support. The **Duke Dementia Family Support Program** (DDFSP) is a free resource available to anyone, whether or not they have any connection to Duke. Our team of experienced social workers is here to listen, answer your questions, and help you figure out what's next.

You can reach us by phone at **919-660-7510** or by email at **DDFSP@duke.edu**.

We hope this guide offers both practical steps and peace of mind as you navigate what's ahead, one day at a time. Above all, please know that **you are not alone**!

With warmth and care as you continue this journey,

The Duke Dementia Family Support Program Team

Please note: DDFSP does not directly endorse specific resources named in this guide. The products and services listed were recommended by family caregivers, colleagues, and vetted sources. We encourage you to use your own judgment and due diligence when deciding which products and services are right for you.

HOW TO USE THIS GUIDE

Just as a new dementia diagnosis can feel daunting, so too can the amount of information that comes with it. This guide is here to help you find your footing — not to add stress. Think of this guide as a roadmap. You do not need to read or act on everything at once.

Every family's situation and priorities are different. Use what feels right and set aside what doesn't. Some steps may feel urgent for you right now, while others may become more relevant down the road. Move through the sections at your own pace and trust your instincts. You know your loved one better than anyone, and your insight matters. Along the way, be gentle with yourself — caregiving is complex, and mistakes are part of being human.

You'll see **links (in orange**) to click on throughout the guide, leading you to articles, tools, instructions, and organizations. These are meant to support you with additional information. Follow the links when you're ready or when a topic applies to your situation.

Most caregivers find it helpful to start with one or two sections that feel immediately useful — for example, "Telling Others," "Legal Matters," or "Build Your Team" — and return to the rest later. Keep the guide handy, revisit it as questions come up, and allow it to be a resource to use over time. As always, contact DDFSP at **919-660-7510** or **DDFSP@duke.edu** with any questions.

Take Time to Breathe

It's normal to experience a mix of emotions after a dementia diagnosis — sadness, fear, anger, even relief. The impact extends beyond the individual, touching the whole family. Be patient with yourselves as you adjust. It takes time for a new reality to settle in. Give yourself space to learn, accept, grieve and breathe.

Moving Toward Acceptance

"Acceptance is a choice to be with your situation just as it is. Developing an attitude of acceptance doesn't mean you're supporting the unfairness of the situation. It simply means that you accept what you can't change."

How to embrace acceptance:

1. Realize that some things are beyond your control
2. Be a good enough care partner — you don't have to be perfect
3. Give yourself grace — you won't get everything right, and it's okay
4. Be open to whatever emotions you may feel

Excerpted and adapted from **Mayo Clinic on Alzheimer's Disease and Other Dementias, Revised and Updated**, 2025, pages 249-252

Take Time to Breathe

If you're feeling anxious or unsettled, it can help to pause and take a few moments for yourself. The exercises below are simple ways to calm your mind, ease tension, and help your body relax.

4-7-8 Breathing Exercise

Mini-Relaxation Exercises

5-4-3-2-1 Grounding

5-Minute Body Scan Meditation

For additional ideas about how to relieve stress, check out:

Cleveland Clinic on Guided Imagery

Mayo Clinic on Relaxation Techniques

> **I don't like what my mother has, but I've learned to be patient and accepting.**
> **- A son**

Educate Yourself

Gaining a clear understanding of dementia and what to expect as it progresses can make it easier to cope and communicate effectively with your health care providers. It also empowers you to make informed decisions about how you want to plan for the future.

- Trusted sources of information include:
    - **Alzheimer's Association**
    - **Alzheimers.gov**
    - **Association for Frontotemporal Degeneration**
    - **Lewy Body Dementia Association**
    - **NIH: Vascular Dementia**
    - **North Carolina Caregiver Portal**

- Infographics, equally trusted, but quicker reads:
    - **Dementia Is an Umbrella Term**
    - **Know the 10 Signs**
    - **Understanding Different Types of Dementia**

- Educational podcasts:
    - **Dementia Matters**
    - **Dementia Untangled**

- If you live in the Triangle area, ask us about our DDFSP **Memory Makers: An Early-Stage Memory Loss Educational Support Group**. Memory Makers, a six-week group, is designed for the person living with memory loss and their care partner to jointly participate.
- Watch archived webinars from DDFSP's **Caregiver Connections** Educational Series
    - Suggested presentations include:
        - Dementia 101 with a Duke geriatrician: **Video Presentation** or **PowerPoint Presentation**
        - Legal Tools for the Family Caregiver with a North Carolina attorney: **Video Presentation** or **PowerPoint Presentation**
- Sign up for the **Triangle Monthly E-News**

Educate Yourself

Recommended Reading

Mayo Clinic on Alzheimer's Disease and Other Dementias, Revised and Updated: A guide for people with dementia and those who care for them, by Jonathan Graff-Radford, M.D. and Angela M. Lunde, M.A., 2025.

LIVING WELL: A Guide for Persons with Mild Cognitive Impairment (MCI) & Early Dementia, Alzheimer's Association, 2023. Each chapter includes wellness strategies to build a living well plan.

Living with Alzheimer's for People with Alzheimer's: Taking Action Workbook, Alzheimer's Association, 2017. Addresses common concerns and issues faced by people living with early-stage dementia.

Living Your Best with Early-Stage Alzheimer's: An Essential Guide, by Lisa Snyder, 2010. This book was written specifically for people living with early-stage dementia, but it is equally helpful for families. Although published in 2010 and not current on treatment or research, it remains an excellent overall resource.

For recommended reading later in the journey, click **here**.

People who are happiest are those whose expectations are best tailored to reality.
– Barry Jacobs, psychologist and author

Telling Others

Telling family and friends about the diagnosis can open the door to understanding and support, help maintain safety, and make it easier to keep daily life as normal as possible. Start with your inner circle — those closest to you, such as trusted friends and family members, and those who need to know, such as your loved one's physician and your attorney.

When, how, and with whom you share the news is a personal decision. Give yourself time to learn about the diagnosis, process your feelings, and decide what feels right for your family. When you're ready, think through your approach — whether to talk in person, by phone, or by email — and share only what feels comfortable. With acquaintances, it's fine to keep it simple, for example, "My spouse is having some memory issues."

Sharing Your Diagnosis Why disclose, who to tell, and how to share a diagnosis.

Why share the diagnosis?

- The most important reason for disclosure is that it **opens doors for more support**. The sooner you tell family and friends, the sooner they can offer the help you need.
- Keeping a diagnosis secret can be **emotionally draining**.
- Sharing the diagnosis helps **maintain engagement in activities**. Many people with memory challenges continue to enjoy their favorite activities by informing friends and allowing them to help if needed.
- Sharing the diagnosis **enhances safety**. It encourages others to notice changes and step in when your loved one needs assistance.
- Sharing the diagnosis can reduce **stigma and increase public awareness**.

Keep in mind that people's reactions can vary widely. Most will offer love, understanding, and support — but not everyone will respond as you hope. Stay focused on those who do show up for you.

It's common for family members to feel differently about when and how to share a dementia diagnosis. Often, the care partner is ready before the person living with memory loss. In this challenging situation, try to be patient but gently persistent — explain why sharing the diagnosis matters to you, and seek support through a caregiver support group or individual counseling.

No matter when and how you tell others, a key message to give is that dementia does not define your lives. You are both still the same people you were yesterday.

– Forward with Dementia Australia

Legal Matters

It’s important to get legal and financial documents in place soon after a diagnosis while the person with dementia can still make decisions. Delaying this work may create significant challenges later, including the possibility of guardianship. Core legal documents:

- For finances
    - Durable Power of Attorney for Finances
    - Standard Will
    - Living Trust (if applicable)
- For health care
    - Power of Attorney for Health Care
    - Living Will (also called an Advance Directive for a Natural Death)
    - HIPAA Authorization (to release medical information to specific people)
- Additional health care documents (to be completed with a health care provider, not with an attorney)
    - **NC MOST** (Medical Orders for Scope of Treatment
    - If desired, a **DNR** (Do Not Resuscitate) order

The following resources will help you understand these legal documents and provide guidance about difficult conversations related to important decisions.

- NIH’s **Getting Your Affairs in Order Checklist** An overview of legal documents.
- **Alzheimers.gov** explains the core legal documents to consider for health care and financial planning.
- Alzheimer’s Association’s **Legal and Financial Worksheet** To help you organize key documents and compile an inventory of assets and debts.
- **Legal Tools for the Family Caregiver** A recorded webinar presented by a North Carolina elder law attorney. (Click here for the **slides only**)
- **NC Advance Health care Directives** Download at the North Carolina Secretary of State website.
- **The Conversation Project** For care partners to understand what matters most to people living with dementia and help them have a say in their health care.

Legal Matters

The Conversation Project

Helping someone with dementia have a say in their health care through end of life is an act of kindness and caring. In fact, it may be the most meaningful way to show the person you care for that you will be there for them.

Elder law attorneys have the specialized expertise to help families affected by dementia prepare the necessary legal documents.

- **National Academy of Elder Law Attorneys** Find an elder law attorney through this site.
- **Legal Aid of North Carolina's Senior Law Project** Prepares wills and power of attorney documents free of charge. The project serves seniors of all income levels, but prioritizes clients with the greatest need.

Keep all important papers and legal documents together in a secure location, make copies, share them with family, and make sure a family member or trusted contact knows where to find them.

Discussing important legal, financial, and medical documents with someone experiencing memory impairment can be challenging for several reasons. Your loved one may have forgotten that they received a diagnosis, may be in denial about their health, or may be experiencing anosognosia. "Anosognosia is a neurological condition in which the patient is unaware of their neurological deficit or psychiatric condition." To learn more about this common symptom, read **Anosognosia & Suffering from Denial**.

> **Without legal planning and preparation, maneuvering the health care, financial, and business needs of a family member is extremely difficult.**
>
> **– Anne Kenny, author of "Making Tough Decisions About End-of-Life Care in Dementia"**

Protect Your Finances

Difficulty managing money is often one of the first signs of dementia — and may appear before noticeable memory changes. Poor financial judgement, vulnerability to scams, and money mismanagement can lead to small losses, or in some cases, wipe out savings.
The steps below can help safeguard your loved one's financial well-being, as well as your family's. Because financial abilities change as dementia progresses, plan to revisit responsibilities and safeguards regularly to balance your loved one's independence with their safety. And since technology is constantly changing, caregivers need to stay aware of new tools, platforms, and risks that may affect their loved one's finances.

Get Organized:

- Gather account numbers, bills, insurance policies, retirement details, and passwords and store in one secure place.
  - NIH **Worksheet: Important Documents and Paperwork** – short and simple checklist.
- Plan for future costs.
  - AARP **Financial Workbook for Family Caregivers** (a 44-page guide to organize and share essential information) or **FAIR Health Financial Well-Being Checklist** (a 3-page tool to review care-related costs, insurance, and legal matters).
- Create a donation list to avoid giving away too much money or duplicating donations.
- Shred old or unnecessary paperwork.

Simplify:

- Set up automatic bill payments to avoid missed due dates.
- Consolidate accounts to one or two institutions.
- Review email and unsubscribe from credit card offers, "exclusive savings" emails, and other "financial junk" emails. See **How to Safely Unsubscribe from Unwanted Emails, Texts** for steps to take.
- Sign up for the **Do Not Call Registry** or call 888-382-1222.
- Reduce unsolicited mail and e-mail at **DMAchoice**.
- Stop unwanted credit card offers with **OptOutPrescreen.com** or call 888-567-8688.
- Ask your phone carrier about blocking spam calls and texts.

Protect Your Finances

Add Oversight:

- Appoint a financial power of attorney so someone trusted can step in when needed.
- Identify a **trusted contact** such as a family member, a financial advisor or a **daily money manager**. Share the names of trusted contacts with your loved one's financial advisor, accountant and banks in case there is a concern about activity in their account.
    - Sample Trusted Contact **form**
- Learn about **Social Security Advance Designation** and **Social Security's Representative Payment Program** to manage your loved one's Social Security or Supplemental Security Income (SSI) payments.
- If your person is a veteran, look into the **VA Fiduciary Role**.

Monitor Your Finances:

- Sign up to be notified of withdrawals from bank accounts or large charges to credit cards. Go to the Security tab on your bank's website to set up alerts.
- Tools such as **EverSafe** can monitor accounts for red flags, like missing deposits, unusual withdrawals, or sudden changes in spending patterns.
- Consider parental control apps to limit risky online activity or overspending.
    - **Circle**, recommended by a DDFSP support group participant, lets caregivers monitor and manage internet access.

Limit Access Gradually:

As abilities change, work together to shift financial responsibilities gradually and sensitively.

- Provide agreed-upon spending cash.
- Lower credit card limits.
- Purchase a prepaid debit card with spending limits for the person with dementia.
- **True Link** helps families manage and monitor their loved one's spending.
- Remove online bill-pay access if it becomes confusing.

Protect Your Finances

Guard Against Identity Theft and Scams:

- **Freeze credit reports** at all three credit bureaus — **Equifax, Experian** and **TransUnion** — to reduce identity theft risk.
- Use an identity theft protection plan, such as **LifeLock** or **Identity Guard**.
- Avoid answering calls from unknown numbers. This can be difficult for someone with memory loss to remember, so consider additional safeguards, such as:
    - Blocking unwanted calls. The Federal Communications Commission provides guidance with **Call Blocking Tools and Resources**.
    - Consider a cell phone designed for seniors that allows you to limit incoming calls to contacts and approved numbers (support group participants have mentioned the **RAZ memory cell phone**).

Additional Resources:

- **Managing Money Problems for People with Dementia**
- **Financial Miscues Can Be an Early Warning Sign of Dementia**
- Consumer Reports offers a free **Security Planner** to help you safely back up files, reduce online tracking, avoid phishing scams and prevent identity theft.
- Read the North Carolina Attorney General's **Senior Scam Guide** for additional ways to avoid scams.
- See **8 Tech Tools for Financial Caregiving** for apps and services that can help protect your finances and those of the person with dementia.
- **My Mother's Money: A Guide to Financial Caregiving** by Beth Pinsker is a comprehensive guide for navigating end-of-life financial decisions for a loved one.

> **My parents used to go to the credit union every week to withdraw cash. My mother would give my father some spending money, but it quickly disappeared. When she discovered him giving cash to a stranger in the grocery store, those weekly trips to the credit union stopped.**
>
> **– A daughter**

Support & Self Care

Support Groups

Caring for a loved one with dementia at any stage can be challenging. From emotional stress to managing daily tasks, the demands can be overwhelming.

One way to ease some of this strain is by joining a support group. Caregiver support groups offer emotional connection, an opportunity to learn from others, and reassurance that you're not alone.

It may take trying a few different groups to find the right fit. Fortunately, there are many. And there are groups tailored to different caregiving situations. If you're reading this guide, it's not too soon to explore one.

At DDFSP, we offer a wide variety of support groups. You can find a complete list at **DDFSP support groups**.

For information about other support groups throughout North Carolina, please call the Duke Dementia Family Support Program at 919-660-7510.

Consider Individual Counseling

Individual counseling (also called "therapy") can help you manage stress, process emotions, and build healthy coping strategies as you adjust to a loved one's diagnosis. Many care partners find that counseling is a helpful complement to attending a support group, which offers peer support but is not group therapy.

Psychology Today's **Find a Therapist** tool is one way to locate a counselor who accepts your insurance.

Support & Self Care

Find Your People

Find the people who truly “get it” — your inner circle. Identify those you can trust, who will listen without judgment when you need to vent, and who can genuinely show up for you. This may be someone who has walked a similar path, such as a friend or relative who has cared for a loved one with dementia, or someone you’ve met through a support group or even in the neurologist’s waiting room.

Keep a List of Tasks

Keep a list of tasks that family and friends can help with — anything from driving your person to an appointment, to running an errand, to mowing the lawn. People often want to help but may not know how. When someone says, “Let me know if I can do anything,” be ready to say “yes” and offer a specific task.

Make and Take Time for Yourself

Caring for someone with dementia is demanding and it’s easy to put your own needs aside. But to be a strong care partner, it’s necessary to also care for yourself. Make time in your schedule to nurture your own physical, emotional, and spiritual well-being.

Taking Care of YOU: Self-Care for Family Caregivers from Family Caregiver Alliance explains the effects of caregiving on health and well-being, common barriers to self-care, and tools for self-care practice.

> **I was a hot mess when I started this group, and it has been a lifesaver. Just knowing you’re not alone.**
> **– A daughter**

Build Your Team

Caring for someone with dementia is not a one-person job. A care team is a group of people you'll lean on and work with to provide support, education, and professional care throughout the dementia journey. Having others by your side can reduce stress and help prevent you from feeling overwhelmed.

The list below includes potential care team members your family might need — but every family's situation is different, and not all will require the same team members. What every family does need, however, is a supportive village — because caregiving is not something you can do alone. What's most important is building a team that will support you through what is likely to be years of caregiving.

Your Professional Care Team

Primary care provider
Memory care specialist
Social worker
Elder law attorney
Financial advisor
Geriatric care manager
Therapist or counselor
Speech pathologist
Physical therapist
Occupational therapist
Home care provider
Adult day program (click on Provider Directory)

Your Personal Care Team

Local family and friends
Long-distance family and friends
Members of your community and/or faith group
Neighbors
Support group

Websites like **Lotsa Helping Hands** (a care-calendar tool) and **CaringBridge** (a platform for sharing updates and coordinating support) can make it easier to organize help from family and friends.

> **I was one of these A+ people and I was going to do it all by myself. Then I figured out I couldn't do this alone.**
> **– A spouse**

Balancing Safety & Autonomy

Balancing safety and autonomy is a challenge for families, especially in the early stages of memory changes. People often have a good social facade early on, so it's easy to miss potential safety risks. Many everyday activities become safety issues because of changes in judgment.

Dementia care expert and speech pathologist Adria Thompson offers practical ways to support a loved one while honoring their independence. She introduces the idea of "dignity at risk" and why early-stage care often emphasizes autonomy when the risk is small. Listen on the **Caregiver Chats Podcast**.

We encourage families to take a close look at these high-risk activities and consider working with their loved one to let go of some and allow help with others.

DRIVING

Dementia causes changes in the brain that can affect judgment and reaction time, which can make driving unsafe. If you have concerns about your person's driving, talk with their doctor. When safety is in question, consider arranging a driving evaluation.

At the Crossroads: Family conversations about Alzheimer's disease, dementia & driving is the go-to guide for navigating conversations about driving – covering when to consider stopping, getting evaluations, and exploring alternatives. Don't miss page 11 for "Warning signs for drivers with dementia."

Consider asking your loved one to sign a driving agreement that gives you permission to help them stop driving when it becomes necessary. For more information about driving and dementia, see the Alzheimer's Association **Driving Information and Contract**.

We understand how hard this is. **Watch how four families deal with different issues related to dementia and driving.**

Balancing Safety & Autonomy

Driving Evaluations

A driving evaluation by an occupational therapist is considered the gold standard for assessing a person's ability to drive safely after a dementia diagnosis. The evaluation can also take the caregiver out of the decision-making role, which may help reduce stress and friction. In the very early stages, some individuals may still be able to drive — perhaps with limits and close monitoring — but eventually, everyone with dementia will need to stop driving. If you believe your loved one is no longer safe behind the wheel and they're willing to give up driving, you can spare them the stress, cost, and potential embarrassment of a formal evaluation.

Duke's Medical Fitness-to-Drive Screening Appointments: 919-684-2445
UNC Health Center for Rehabilitation Care Driving Evaluations Appointments: 984-974-9700
American Occupational Therapy Association Driving Practitioner Directory

EMERGENCY IDENTIFICATION

Look at identification bracelets in case your family member gets lost or needs help. Two of the many companies selling these products:

- **ROAD iD** offers an easy-to-wear silicone bracelet with an **Alzheimer's badge** that is a popular initial choice.
- **MedicAlert IDs and the Safe & Found Program** provide medical IDs along with protection plans that include response teams, secure personal health records, and more.

Some caregivers choose to wear an ID bracelet themselves — both as a show of solidarity with their loved one and to alert emergency responders that they are caring for someone with dementia who depends on them.

Caregivers can attach small GPS trackers, such as a **Tile** or **AirTag** to a loved one's wallet, keys and other important items.

Balancing Safety & Autonomy

In Case of Emergency (ICE)

ICE is a feature that lets first responders and hospital staff access your emergency contact information without unlocking your phone. If you haven't done so already, put ICE into the contact list on both your and your loved one's cell phones. For instructions, see **Setting Up an Emergency Contact on Your Phone**.

If You Have a Smart Phone, Set Up Medical ID

If you are injured or unresponsive, your locked phone's Medical ID contains emergency contact information and vital health information that can be accessed by a third party to provide timely assistance. This allows responders or bystanders to call your family directly from the locked screen and notify them right away.

Read setup instructions for **iPhone** or **Android**.

HOME SAFETY

Home safety for a loved one experiencing changes in memory and thinking includes many familiar concerns associated with aging — such as reducing fall risk by installing grab bars in the bathroom and removing throw rugs. When dementia is involved, however, home safety considerations expand to include issues like securing hazardous items, medication management, online safety, and recognizing when it may no longer be safe for your loved one to be home alone.

A home safety evaluation by an occupational or physical therapist can identify potential hazards in your home — such as fall risks, opportunities for wandering, or unsafe appliances and household chemicals. Beyond improving safety, this can also help your person stay as independent as possible. Ask your health care provider to order a home safety evaluation. Medicare may cover the cost.

Balancing Safety & Autonomy

Safety Resources:

Alzheimer's Association: Safety

Topics covered: Wandering, Home Safety, Driving, Medication Safety, Technology 101, Traveling, Preparing for Emergencies, and Abuse.

Alzheimer's Association Home Safety Checklist

A two-page checklist with practical suggestions to support your people with memory loss, including ideas that are useful even early on in the journey.

Medication Management

Dementia can cause people to make medication mistakes — missing doses, double-dosing, or taking the wrong medicine. Because the consequences can be serious, we encourage you to add oversight early. Creating an effective medication management regimen — such as using pill organizers, reminders, or care-partner supervision — can help ensure medications are taken safely and maintain your family member's autonomy for as long as possible.

Read about medication management at the Alzheimer's Association's **Medication Safety page**.

Family Caregiver Alliance's **Medication Management BASICS Video Series** provides instructions to help manage your family member's medications.

Online Safety

Because poor financial judgment and vulnerability to scams are common for people living with dementia, families may need to take steps to help keep their loved ones safe online. As with managing access to finances, any limits on internet use or added monitoring should be approached thoughtfully and with sensitivity to preserve dignity while prioritizing safety.

Balancing Safety & Autonomy

General Online Considerations:

- Pause before responding to messages that feel urgent. Scammers are trying to confuse or appeal to one's emotions to get what they want.
- Never share passwords, PINs, or verification codes. No company or banking institution will contact you asking for passwords.
- Beware of emails asking you to "click this link" to sign into online accounts or banks.
- Beware of pop-up messages with a phone number to call technical support.
- Never allow access to your computer by someone who claims to be offering technical support.
- To simplify iPhone use, see the **Assistive Access User Guide for iPhone.**

Online Safety Tips:

- Make computer time something you do together.
- Consider parental control apps to limit risky online activity.
    - **Qustodio**, mentioned in this 2025 **AARP article**, allows monitoring and managing family member's activity on all devices.
- Reduce unsolicited mail and e-mail at **DMAchoice**.
- Get rid of any electronic devices not used regularly.
- Make sure devices are up to date with security and have current antivirus software installed.
- Use a password manager, such as **1Password** (monthly fee) and **Bitwarden** (free plan available) — and be sure you know your loved one's master password.
- Set up **multifactor authentication** to add an extra layer of security.
- Backup everything in case something is accidentally deleted.

Balancing Safety & Autonomy

Social Media Safety:

- Set accounts to private. Facebook does not make this easy – click here for **instructions**. In addition, disable location tagging.
- Review list of friends together and remove unfamiliar contacts.
- Limit the use of online communication platforms — such as Facebook Messenger, WhatsApp, etc. — which create more opportunities for criminals to make contact.
- Never send money, gift cards, or personal information to online contacts.
- Be cautious of:
  - Requests for help or money.
  - Romantic messages from strangers.
  - Impersonation of family or friends.

See Consumer Reports' **Security Planner**, a free guide to staying safe online.

Alicia Fernandez Hogan, IT Analyst, Duke OASIS (Office of Academic Solutions and Information Systems Technology Support) contributed to the Online Safety section. Naveed Moeed, an IT consultant based in Durham, reviewed this section.

Staying Alone

Realizing you can no longer leave a loved one with dementia alone is a major caregiving milestone — one that calls for careful observation and trusting your instincts to adjust your care plan.

Additional Reading on Staying Alone:

Alzheimer's San Diego, **When is it Unsafe to Leave Someone Living with Dementia Alone?**

When Is My Relative with Dementia No Longer Safe Staying Alone?

Balancing Safety & Autonomy

Owning Guns

For a person living with dementia, the greatest firearm-related risk is suicide. Firearms can also pose a danger to family members, caregivers, and visitors, as dementia may cause confusion, delusions, or difficulty recognizing people.

We strongly encourage families to remove firearms from the home when a loved one is diagnosed with dementia. However, we recognize that not all families are ready to take this step right away. If firearms remain in the home, take these precautions:

- Keep all guns unloaded.
- Store guns locked.
- Keep keys or lock combinations hidden.
- Store ammunition separately.

For families who choose to keep firearms in the home, using a written firearm safety agreement can help clarify expectations and responsibilities. For an example of a firearm safety directive, go to the firearm section in **SAFETY in dementia**.

Additional Reading on Firearm Safety:

- Alzheimer's Association **Firearm Safety**
- The Alzheimer's Foundation of America **Firearm Injury Prevention**

> **The time to think about safety issues is before there's a problem.**
> **– Dr. Kris Herfkens, neuropsychologist**

Have a Backup Plan

Art was caring for his wife Nanette, who had dementia. One hot afternoon, Art fainted while waiting in line to buy a movie ticket. When he woke up in the ambulance, his first thought was, "Who is going to pick Nanette up from her day program." That frightening moment was Art's wake-up call – he realized he needed a backup plan.

Who will care for your loved one if something happens to you? This is one of the most common and deeply felt worries caregivers share. Even if you've completed all the important legal documents needed, none provide a substitute care partner.

What to Do

Identify your backup caregiver. Find someone who can step in temporarily if you're suddenly unavailable. This might be a family member, friend, neighbor, or a hired geriatric care manager who can help identify temporary caregivers. Instead of relying on just one person, a good approach would be to find several people – ideally a mix of friends, family, and professional support.

Create an emergency how-to guide. The Family Caregiver Alliance article, **What if Something Happens to Me?** suggests using a brightly-colored binder and lists the information to include in your guide.

If you haven't already created a free account with the North Carolina Caregiver Portal, consider doing so now to access the Trualta 2024 **Emergency Planning Workbook**. This workbook includes worksheets and checklists to help you organize important information. Completing it (or organizing the information in your own notebook) ensures that if you ever become unavailable, others will have the details they need to provide care in your absence. MemoryCare in Asheville offers a shorter guide to help you think through this important issue: **What's Your Plan B?**

Think beyond the logistics. What makes your person feel happy and safe? A backup caregiver won't necessarily know. One support group participant recommends: "Something important to do is to include a list of activities that your loved one enjoys doing that specifies TV shows or movies, walks (where), crafts/puzzles, and musical likes. This will change over time but it's helpful to list what the person enjoys doing, seeing, hearing."

> **I sleep so much better knowing I have a backup plan.**
> **– A spouse**

Understanding Long-Term Care Options

You may see the words "long-term care" and be tempted to skip this section, thinking your loved one was just diagnosed and residential care is years away. But long-term care is a continuum that includes much more than residential care. Companion care and adult day programs are part of that continuum — and many families find these services helpful in the early stage.

It's important to have conversations about future care preferences early, while your loved one can clearly express their wishes. So, explore long-term care resources sooner rather than later — don't wait until you need them because you don't want to make decisions in a crisis. Keep in mind that finding care options takes time and involves more than a single phone call.

TYPES OF LONG-TERM CARE

In-Home and Community-Based Care

This category of long-term care is generally the first choice for families affected by dementia.

- **Home care**
  - Companion and personal care is common for people with dementia. Companion care provides support, supervision, and social connection. Personal care offers help with daily activities like bathing and dressing. These services, which can be found through a home care agency or privately (including through **Care.com**), are usually not covered by insurance. Some agencies have certified nursing assistants, in addition to personal care assistants, who can also help with toileting and mobility challenges.
  - Home health provides temporary services to people with medical needs that require a registered nurse or other skilled services, such as physical therapy, occupational therapy or speech therapy. Personal care is not included as part of home health care services, but some home health care agencies employ personal care assistants or nursing assistants who can be hired.
    - Home Health Agencies can be found at Medicare's **Home Health Compare**
  - If you're considering in-home help, these resources can guide you:
    - **Hiring In-Home Help** from the Family Caregiver Alliance
    - Home Care Services List on Wake County's Resources for Seniors' **In-Home Care Services** page

Understanding Long-Term Care Options

- **Adult day services** are supervised community settings that provide social engagement, companionship, nutritious meals and snacks, and a range of meaningful activities. Adult day services are a rare “win-win”: they offer the care partner a much-needed break while giving the person with memory loss social engagement and structured activities.
  - **NCDHHS Adult Day Services** explains adult day services and describes the important difference between Adult Day Care and Adult Day Health Care. You can also use their link to the Adult Day Care Provider Directory to find a certified program near you.
  - **Questions to Ask When Visiting an Adult Day Center** from the National Adult Day Services Association.

Residential Care

- **Adult Care** (commonly referred to as assisted living)
  - **Assisted living facilities** are for people who need help with daily care and the facility provides 24-hour supervision. These facilities are licensed in North Carolina for 7 or more residents.
  - **Family care homes** provide assisted living level of care in a residential home licensed in North Carolina for 6 or fewer residents.
  - **Memory care** (also known as special care units or dementia care units) provides a higher level of assistance with activities of daily living as well as specialized supports and protections, including locked entrances, for people with dementia. Memory care is often housed within an assisted living facility but may be free-standing or part of a nursing home.
  - The North Carolina Department of Health and Human Services posts **updated lists** of the memory care facilities it licenses or registers.
- **Nursing homes**, also called skilled nursing facilities, provide around-the-clock nursing care for individuals whose health needs cannot be met in assisted living or memory care communities.
  - Medicare’s **Nursing Home Compare** can locate nursing homes near you, compare nursing homes on topics you consider most important, and give you a “snapshot” of the quality of each nursing home.
- **Continuing care retirement communities** (CCRCs) offer several levels of care (from independent living through nursing home care) in one location so that residents may move to a higher level of care if needed. CCRCs typically charge a large entry fee plus monthly fees and often have waitlists.
  - North Carolina Department of Insurance offers a **Portal** (see Access CCRC Data Portal) with information about each CCRC in North Carolina.

Understanding Long-Term Care Options

To Learn More about Long-Term Care:

- **Choosing a Residential Care Community** from the Alzheimer's Association includes a list of questions to ask when looking at care communities.
- **Cost of Care Survey tool** from Genworth and CareScout, helps families calculate the costs of long-term care by type of care and location.
- **Long-Term Care Basics** from **Friends of Residents in Long-Term Care**, a North Carolina nonprofit organization.
- **LongTermCare.gov**, a government website to help families plan for long-term care needs.
- "Understanding Residential Care Options for People with Dementia" (a webinar) – **Video Presentation** and **PowerPoint Presentation**

For Support and Guidance on Long-Term Care Options

Aging Life Care Association - An aging life care specialist (also known as a geriatric care manager) can help you navigate the complexities of long-term care and find the most appropriate services — whether in your home, in the community, or in a residential setting. Geriatric care managers typically charge by the hour.

North Carolina Long-Term Care Ombudsmen - A long-term care ombudsman can help you understand your options when choosing a residential community and share certain information about specific facilities. To find the ombudsman who serves your community, contact your regional **Area Agency on Aging**. Speaking with an ombudsman is free of charge.

Placement Services - Senior living advisors help families determine the type of care a loved one needs and identify appropriate in-home or residential care options. Many agencies offer these services to families free of charge. To find help in your area, reach out to local organizations such as senior living specialists, senior placement companies, or senior centers. You can contact DDFSP at 919-660-7510 and we can share names of placement services that other families have found helpful.

> **Hire home care earlier than you "think" you need it. You probably do need that break.**
> **– A spouse**

Consider a Research Study

Researchers are working to improve how dementia is diagnosed, treated, and prevented, as well as to find better ways to support people living with dementia and their caregivers. Participating in a study can help advance this work — potentially benefiting you and your loved one, your community, and future generations.

There are many different types of research studies, ranging from trials that are testing experimental treatments to studies that are designed to gather stakeholder perspectives through interviews and focus groups. Some studies require frequent visits or testing, whereas other studies can be completed entirely by telephone. Research participation is always voluntary. If you are interested in contributing to research, there are many resources to help you find study protocols that fit your interest and availability.

Connecting with Research Opportunities

- **Alzheimer's Association TrialMatch**,(800) 272-3900, TrialMatch@alz.org
- **Alzheimers.gov**, (800) 438-4380, adear@nia.nih.gov
- **The Association for Frontotemporal Degeneration**, (866) 507-7222, info@theaftd.org
- **ClinicalTrials.gov**
- **Duke & UNC Alzheimer's Disease Research Center (ADRC)**, 919-660-2340, adrc@duke.edu
- **Lewy Body Dementia Association**, (800) 539-9767, support@lbda.org
- **NC Registry for Brain Health**, (919) 613-8633, ncbrainhealth@duke.edu

Learn More

Why Participate in a Clinical Trial?

What Are Clinical Trials?

> **Participating in a research study for caregivers has been invaluable to me. I've learned so much about my husband's specific diagnosis, how to deal with a wide range of symptoms, and how to make each day as easy as possible for both of us.**
>
> **– A spouse**

Additional Resources

North Carolina Organizations

Alzheimer's Association, Eastern NC Chapter	800-272-3900
Alzheimer’s Association, Western NC Chapter	800-272-3900
Dementia Alliance of NC	919-832-3732
Duke Dementia Family Support Program	919-660-7510
Friends of Residents in Long-Term Care	919-782-1530
My Music NC	919-832-3732
NC Caregiver Portal	
NCDHHS: Area Agencies on Aging	
NCDHHS: Division of Aging	919-855-3400
NCDHHS: Long-Term Care Ombudsman	800-662-7030
Project C.A.R.E.	(Caregiver Alternatives to Running on Empty)

Additional Resources

National & International Organizations

Aging Life Care Association 520-881-8008

AARP – Family Caregiving

Alzheimer's Association 800-272-3900

Alzheimers.gov 800-438-4380

Alzheimer's Foundation of America 866-232-8484

The Association of Frontotemporal Degeneration 866-507-7222

At the Crossroads: Family conversations about Alzheimer's disease, dementia & driving

The Conversation Project Starter Guide for Caregivers of People with Alzheimer's or Other Forms of Dementia

Family Caregiver Alliance 800-445-8106

Lewy Body Dementia Association 800-539-9767

Lewy Body Dementia Resource Center 516-218-2026

LongTermCare.gov

Medicare.gov Find & Compare Tool

SAGE (National Resource Center on LGBTQ+ Aging)

Social Security **Compassionate Allowances**

Young Onset Dementia

VA Caregiver Support Program 855-260-3274

Glossary

Alzheimer’s disease

Alzheimer’s disease is a brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks. People with Alzheimer’s also experience changes in behavior and personality.

Dementia

Dementia is an umbrella term used to describe a range of neurological conditions affecting the brain that worsen over time. It is the loss of the ability to think, remember, and reason to levels that affect daily life and activities. Some people with dementia cannot control their emotions and other behaviors, and their personality may change.

Frontotemporal dementia (FTD)

Frontotemporal dementia is caused by a group of disorders that gradually damage the brain’s frontal and temporal lobes. These damages cause changes in thinking and behaviors. Symptoms can include unusual behaviors, emotional problems, trouble communicating, challenges with work, and difficulty with walking.

Lewy body dementia (LBD)

Lewy body dementia (LBD) is a brain disorder that can lead to problems with thinking, movement, behavior, and mood. Visual hallucinations, or seeing things that are not there, are a common symptom, and tend to happen early on.

Mild cognitive impairment (MCI)

Mild cognitive impairment (MCI) is a condition in which people have more memory or thinking problems than other people their age. The symptoms of MCI are not as severe as those of Alzheimer’s disease or a related dementia. People with MCI can usually take care of themselves and carry out their normal daily activities.

Vascular dementia

Vascular dementia is caused by conditions such as stroke that disrupt blood flow to the brain and lead to problems with memory, thinking, and behavior. Vascular dementia is the second most common dementia diagnosis, after Alzheimer’s disease, and can occur alone or alongside another form of dementia.

Definitions from **Alzheimers.gov**.

Acknowledgements

Written by: Barbara “Bobbi” Matchar, MSW, MHA
Edited by: Natalie Leary, MSW, LCSW, Janeli McNeal, LCSW-A
and Cornelia Poer, MSW, LCSW
Layout by: Rebecca Bratsch, MSW

Special thanks to Sonda Oppewal, PhD and Heather E. Whitson, MD, MHS, Director, Duke Aging Center and Co-Director, Duke/UNC Alzheimer’s Disease Research Center who reviewed this guide and provided invaluable feedback.