

The Caregiver's Journey®

Finally! Practical Tips and Candid Conversations
for Alzheimer's and Dementia Family Caregivers

Supporting Your Loved One With Dementia:

In the Beginning

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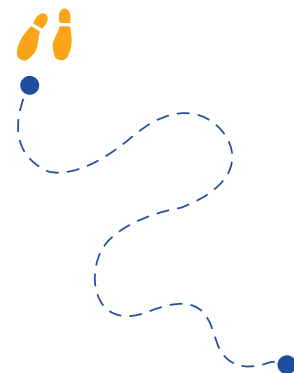
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This guide brings our years of experience in a variety of family caregiving roles. We are sharing our personal experiences, not medical advice, to help prepare you to navigate your caregiving journey.

Introduction



Caring for someone with dementia is both a meaningful and challenging journey. Each day brings new obstacles and opportunities as you work to help your loved one maintain independence and dignity while adjusting to their changing needs.

This guide is designed to provide practical strategies for caregivers in the early stages of dementia care—what we call “the beginning.” In this stage, you’re primarily helping your care receiver continue to function independently, often working discreetly behind the scenes.

We are Sue Ryan and Nancy Treaster. We’ve each navigated multiple dementia caregiving journeys with loved ones. This guide is developed from conversations on our podcast, where we share candid insights and practical tips that offer you a roadmap to help make your caregiving experience more manageable.

The guide is divided into two main sections:

- **Part 1: Understanding and Adapting to Memory Loss**
- **Part 2: Effective Communication Strategies**

This guide is created serve as a companion on your caregiving journey, reminding you that you are not alone, and that with the right tools and support, you can successfully navigate this journey.

Part 1: Understanding and Adapting to Memory Loss

Watch *The Caregiver's Journey Podcast Episode 2: Memory Loss*



SCAN TO WATCH



The Emotional Reality of Early Memory Loss

When someone you love begins to lose their memory, it can feel like a series of daily heartbreaks. One day, you realize they don’t remember their birthday. The next day, they’ve forgotten their address or phone number. Perhaps they can no longer recall your birthday or their ATM code.

This creates an emotional roller coaster for both of you. While you’re processing your own feelings, you’re simultaneously trying to help your loved one navigate their day-to-day life. What makes this stage particularly difficult is that your care receiver is often still aware they’re forgetting things, adding another layer of complexity to this early chapter of your caregiving journey.

“Because they are still in the phase where they know they’re forgetting things, they’re going through their own series of emotions.” — Sue Ryan

Both you and your loved one may be experiencing a range of emotions:

- Anxiety
- Fear
- Frustration
- Grief.

It's important to acknowledge what Sue Ryan calls “drip grief”—the small but significant losses that accumulate day by day. Each forgotten skill or memory triggers something you may grieve, and recognizing these emotions is an essential part of the caregiving process.

Stages of Dementia Care

When thinking about the progression of dementia, we conceptualize it in three main stages:

- **The Beginning** – You're primarily helping your loved one maintain independence, often working behind the scenes.
- **The Messy Middle** – You're starting to assert more control.
- **Later On** – You're directing almost everything.

This guide focuses on the first stage—the beginning—when your role is primarily supportive rather than directive.



Tip 1: Identify What They Can No Longer Recall

The first step in helping your loved one is to carefully observe what they can no longer recall or do independently. Common examples include:

- **Personal information:** Birthdays, addresses, phone numbers
- **Financial information:** ATM codes, passwords, account information
- **Technology usage:** Computers, smartphones, tablets
- **Medication management:** Prescribed medications, over-the-counter drugs, vitamins, herbals and other supplements
- **Appointments:** Recurring (e.g.: hair), important (e.g.: doctor), recorded on digital devices, written on paper lists.

Real-Life Example: Nancy describes realizing her husband could no longer use an ATM when he claimed his card wasn't working. After observing him at the machine, she discovered he had forgotten both his PIN and how to operate the ATM. Rather than correcting him or drawing attention to the issue, she found a workaround—whenever they went out, she would ask if he needed cash, stop at an ATM, and handle the transaction while he maintained his dignity.

Practical Application:

- Start a caregiving journal to track changes and document patterns
- Observe carefully what tasks are becoming difficult
- Look for ways to provide support while preserving dignity
- Get added to important accounts (e.g.: financial, deeds) while your loved one can still consent
- Collect passwords and access information for online accounts
- Secure copies of important documents and ID cards.

Wallet Management Strategy: Create a system to prevent loss or misuse of important cards:

1. Place your contact information in your loved one's wallet
2. Replace important cards with less meaningful cards of the same color. Nancy replaced her husband's American Express with a metro card that was the same color.
3. Make copies of important cards with slightly altered numbers (so they can't be misused if lost). Laminate these copies for your loved one to carry. Sue did this and her husband was none the wiser.
4. Keep the real cards secure with you.

Tip 2: Help with Tasks They Can No Longer Do

As memory loss progresses, your loved one will gradually lose the ability to perform various tasks. These might include:

- Using telephones
- Operating remote controls
- Using household appliances (microwave, coffee maker)
- Following multi-step processes.

Practical Strategies:

- Rather than introducing new devices, simplify existing ones (remove apps from smartphones, streamline interfaces). They will likely struggle more with learning a new device than adapting to a change in an existing one.
- Unplug potentially dangerous appliances when not in use.
- Adapt your approach to provide just enough help while encouraging independence.
- Prepare in advance for tasks that require multiple steps.

Real-Life Example: Nancy noticed her husband was struggling with the TV remote, inadvertently purchasing shows repeatedly. She implemented parental controls requiring a PIN for purchases and would check in during breaks from work calls to ensure he was watching what he wanted to watch.

Tip 3: Get Others Involved (As Appropriate)

Deciding when and how to tell others about your loved one's diagnosis can be challenging. Some individuals may not want anyone to know, while others are comfortable sharing widely. Your journey as a caregiver, and your loved one's journey, will both be much easier if you share openly so others can lean in to support each and both of you.

If your loved one resists sharing:

- Have a specific conversation to understand their concerns
- Address the root causes of their reluctance
- Try again later if initially unsuccessful
- Be aware that 80% of people with dementia will at some point forget they have dementia
- Your need for support is also important.

If your loved one is open to sharing:

- Embrace the opportunity for broader support
- Support friends and family adapting their interactions appropriately
- Accept offers of help!

Real-Life Example: Sue's husband was comfortable with people knowing about his diagnosis. This openness allowed others to support him more effectively—like the fellow church member who offered to drive him home after Mass.

Tip 4: Be Alert for UTIs

Urinary tract infections (UTIs) can significantly impact cognitive function and may be mistaken for dementia progression.

Key points about UTIs:

- They're often caused by dehydration, which can happen when someone doesn't drink enough fluids
- Older adults may not experience the typical painful symptoms of UTIs
- Symptoms can mimic stroke, increased memory problems, and/or cause behavioral changes
- UTIs can become severe before they're detected.

Prevention strategies:

- Monitor fluid intake daily
- Provide regular prompts to drink
- Track hydration (using marked containers or counting glasses).

Warning sign: Any sudden change in cognition or behavior should prompt consideration of a UTI.

The Importance of Self-Care

Watch *The Caregiver's Journey Podcast Episode 27: The Realities of Caregiver Self-Care*



While focusing on your loved one's needs, don't neglect your own well-being. You are a caregiver for two people - your loved one and you! It's important to be just as diligent about caring for you as it is to be caring for your loved one.

The beginning stages of caregiving are the perfect time to establish self-care habits:

- Build a support network
- Join a caregiver support group
- Take time for your physical and mental health.
- Create a list of what brings you joy and prioritize it.
- Self-care isn't selfish, it's essential.

SCAN TO WATCH



"I encourage you in the very beginning to focus on yourself. You've got all these other things going on. Don't give up on yourself." — Sue Ryan

Part 2: Effective Communication Strategies

Watch *The Caregiver's Journey Podcast Episode 3: Communication – In the Beginning*



SCAN TO WATCH



The Evolution of Communication

Communication with someone experiencing memory loss requires constant adjustment. As a caregiver, you'll need to:

- Observe what they can and cannot understand
- Adjust your communication style accordingly
- Continuously adapt as their abilities change.

This process is about helping your loved one maintain their independence and dignity for as long as possible.

Tip 1: Help Plan Their Day

Creating structure helps your loved one feel secure and accomplished. This involves:

1. Understanding what they can realistically accomplish
2. Creating appropriate and manageable to-do lists
3. Providing prompts throughout the day to help them complete tasks.

The Difference Between Reminding and Prompting:

- Reminding assumes they can recall information once mentioned—this won't work for someone with memory loss.
- Prompting involves actively placing the information in front of them when needed.

“In your mind you’re thinking you’re reminding them, but you’re not. The sooner you can let go of the concept of reminding and accept the concept of prompting, the sooner you’ll find your attitude is so much better.” — Nancy Treaster

“Please consider removing the word ‘remember’ from your vocabulary when you’re speaking with your loved one. You want them to remember, so it’s reasonable you use this word. They are struggling to remember, so not using this word helps reduce their anxiety.” - Sue Ryan

Practical Prompting Strategies:

- Use sticky notes in relevant locations
- Create written daily schedules
- Use visual cues when written prompts no longer work (like a drawing of a stick figure running to show you’ve gone for a run)
- Maintain familiar routines with subtle supportive prompts.

Real-Life Example: Sue’s husband was a “list guy,” so she created daily lists they would review together each morning. Throughout the day, she would reference the list and sometimes ask him what was next, maintaining his engagement with the planning process.

Tip 2: Simplify and Minimize

As cognitive abilities decline, instructions and environments need to become increasingly streamlined.

Communication Simplification:

- Break down complex tasks into single steps
- Give one instruction at a time
- Allow extra time for task completion
- Gradually increase your involvement as needed.

Environmental Simplification:

- Minimize distractions during important activities
- Prepare everything in advance for meals or other activities
- Avoid interruptions that can derail a process.

Real-Life Example: Nancy found that when preparing meals at home, she needed to mute the TV and have everything on the table before calling her husband to eat. If she had to get up during the meal to retrieve something, he would stand up too and wander away, making it difficult to resume the meal.

Adapting to Changing Abilities:

- What works today may not work tomorrow
- Continually observe and adjust your approach
- Journal changes to track patterns.

Social Situation Strategy: When dining out, simplify menu decisions by:

1. Reviewing the menu online beforehand
2. Pre-selecting potential options
3. Offering limited choices (e.g., “They have filet mignon and grilled chicken. Which would you prefer?”).

Tip 3: Use Positive Reinforcement and Body Language

The way you communicate—verbally and non-verbally—significantly impacts your loved one’s response and emotional state.

Positive Reinforcement:

- Provide genuine praise for completing tasks
- Use encouraging language (“Great job!” “Thank you for doing that.”)
- Celebrate small accomplishments
- Focus on what they can do rather than what they can’t.

Body Language Awareness:

- Your body language affects their emotional response
- Get on their level when speaking
- Make eye contact
- Use a warm, encouraging tone
- Watch their body language for signs of confusion or distress.

The Impact of Negativity: Avoid critical language or frustrated tones such as:

- “Why aren’t you using the soap?”
- “Why aren’t you brushing your teeth?”
- “Why are you brushing your teeth like that?”

These approaches create anxiety and damage dignity without helping the situation.

Real-Life Example: Nancy changed her approach after seeing how positively her husband responded when a new part time caregiver came on board and was using encouraging words about almost everything. Nancy discovered that positive reinforcement improved both her and her husband’s experiences.



Tip 4: Share “The Truth They Need to Hear”

When communicating with someone who has memory loss, the concept of “truth” requires flexibility. The goal is to provide information that reduces anxiety and maintains dignity rather than insisting on literal truth in all situations.

The Compassionate Approach:

- Focus on what is helpful for them to know in the moment
- Avoid unnecessary details that might cause confusion or anxiety
- Stay aligned with what brings comfort and security.

Real-Life Examples:

- For a complex outing with multiple destinations, simply say, “We’re going out for a little while.” or share one place you’re going to. “We’re going to the grocery store.”
- For handling car keys or explaining why a car won’t start, provide a simple explanation that preserves dignity.

“The real takeaway from this is, it is less about what the actual truth is, it’s how do we stay in integrity that we’re telling the ‘truth’ that we’re in alignment with. What is the ‘truth’ that’s most helpful for our care receiver? This is the ‘truth’ they need to hear. — Sue Ryan

This approach isn’t about deception—it’s about compassionate communication that reduces anxiety and frustration while maintaining your loved one’s sense of self-worth.

Conclusion

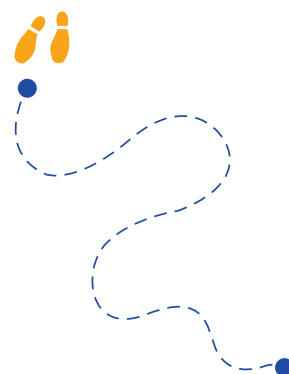
Caring for someone with dementia is a dynamic journey that requires patience, creativity, and constant adaptation. Throughout the beginning stages, consider these key principles:

1. **Observe and adapt** continuously as abilities change
2. **Support independence** whenever possible
3. **Preserve dignity** in all interactions
4. **Practice self-care** to sustain your health throughout your caregiving role.

The challenges you face in the early stages of memory care may seem overwhelming, but they are temporary. As you develop strategies and confidence, you’ll find ways to manage each new situation effectively.

You are not alone on this journey. With compassion, patience, and the practical strategies outlined in this guide and other resources, you too can provide meaningful support to your loved one while preserving your own well-being.

As Sue and Nancy always say: *“We’re all on this journey together.”*



Quick Reference Guide

Memory Loss Tips

1. **Identify struggles:** Observe what they can no longer recall and create workarounds
2. **Help with difficult tasks:** Adapt environments and provide subtle assistance
3. **Involve others:** Create a support network while respecting privacy preferences
4. **Watch for UTIs:** Monitor hydration and be alert for sudden cognitive changes.

Communication Tips

1. **Plan the day:** Create structure with prompts, not reminders
2. **Simplify everything:** Break down tasks and minimize distractions
3. **Use positive reinforcement:** Encourage and observe body language
4. **Tell “the truth they need to hear”:** Focus on reducing anxiety rather than literal accuracy.

Self-Care Reminders

- Establish self-care habits early
- Acknowledge your grief (“drip grief”)
- Connect with support groups
- Accept help from others
- Care for yourself; it enables you to care for others

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