



Pennsylvania  
Department of Aging

# The First 5 Steps

A Get-Started Guide for Spousal Caregivers

**PA CareKit**

## Jen and Rob's Story

Jen and Rob have been married for 40 years and retired nearly 10 years ago. They enjoy staying active, meeting friends, traveling, and spending time with their grandchildren.

A few years ago, Jen noticed Rob's memory was slipping. At first, he forgot names and addresses. Then one day, he couldn't find his way home from the grocery store. The doctor diagnosed Rob with dementia. Now, he needs care all the time.

Jen was a librarian before she retired, and she likes to be organized. She manages Rob's medical needs but struggles with the physical strain of caring for him. Rob is much bigger than Jen, making tasks like bathing him difficult. One of their daughters lives a few hours away, but Jen feels guilty asking for help.

Last month, Jen hurt her back helping Rob out of the shower. She now struggles to sleep and hasn't seen a doctor because she can't leave Rob alone. Stuck at home, she rarely sees friends. She is often feels like crying, especially when Rob, who was once her best friend, feels like a stranger.

The PA CareKit can help Jen and Rob in many different ways. Training videos could teach Jen how to safely lift and transfer Rob, making him more comfortable and reducing her risk of injury. Jen can find a local respite provider or Adult Day Center where Rob can socialize under supervision and give her time to see her doctor and care for her own needs.

The CareKit offers more information on dementia so Jen and Rob can feel more prepared for the journey ahead. Jen could join a virtual support group and find comfort in sharing her experiences



with others who understand. Caregiving is hard, but the PA CareKit offers resources and support to make it a little easier.





## Step 1 Understanding your Role

Before you begin, take time to reflect on your role as a caregiver.

- **What kind of support does the person you are caring for need?** Physical, emotional, financial, or a combination? Make a list.
- **What type of support are you already providing?** Write down tasks you're handling now.
- **What responsibilities will evolve over time?** Be prepared for your role to grow as needs change.
- **What emotions do you feel about this role?** Acknowledge and process both positive and negative feelings.
- **What motivated you to take on this responsibility?** Reflect on this commitment and acknowledge the importance of your role.
- **How has caregiving changed your relationship?** Take time to think about the changes and how they make you feel. Consider sharing them with the person you are caring for when appropriate.
- **What areas of caregiving feel most challenging or overwhelming for you?** Identify difficult activities, like lifting, giving medical care, or dealing with relationship changes. Then, prioritize tasks, seek help, or delegate responsibilities to others.
- **What aspects of caregiving feel rewarding to you?** Identify positive moments that bring meaning to your caregiving journey.
- **How does caregiving affect your personal goals?** Reflect on how your responsibilities impact your education, career plans, or family and social life.

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## **Step 2** Gather Information

Being informed will empower you to make decisions with confidence.

- **What does the person you are caring for value the most in this stage of their life?** Have a candid conversation about their priorities and wishes to learn what truly matters to them.
- **How can you best support their emotional and physical well-being?** Identify specific ways to meet their needs, such as encouraging hobbies, maintaining social connections, or addressing health and mobility challenges.
- **Are you communicating openly with the person you are caring for?** Practice active listening and share your own thoughts and concerns to maintain a strong relationship.
- **What information do you need to improve care?** Gather details about their condition, treatment options, or local resources.
- **What type of health conditions is the person you are caring for living with?** Speak to your healthcare provider and research these conditions to understand symptoms and treatments.
- **What medications does the person you are caring for take?** Keep a list, including schedules for dosages and refills.
- **What benefits or financial aid are available?** Learn about their coverage details for Medicare, Medicaid, or private health coverage. Research public benefits that offer financial assistance.

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## Step 3 Strengthen the Support System

Caregiving is not a solo journey. Build a team to help.

- **Who can offer help?** List family, friends, neighbors, or others.
- **What kind of help can they offer?** Transportation, meal preparation, or companionship? Make a list.
- **When can they help?** Coordinate their availability.
- **Who can offer emotional support?** Identify friends, neighbors, or online support groups where you can share your experiences and feelings.
- **What information do you need from health providers?** Prepare a list of questions.
- **Are you communicating openly with your support system?** Hold regular family meetings to discuss challenges, share updates, and plan for the future.
- **What community or professional resources are available?** Research agencies that offer transportation, meal delivery, housekeeping, or companionship.
- **Do you know where to seek additional help?**



Contact the PA Link for Aging and Disability Resources by calling 800-753-8827 or email [carelink@pa.gov](mailto:carelink@pa.gov). Learn more about the PA Link at [pa.gov/PALink](http://pa.gov/PALink).

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## **Step 4** Make a Plan

Planning reduces stress and ensures no detail is overlooked, especially in an emergency.

- **What does a typical day look like for you and the person you are caring for?** Document daily activities like meals, hygiene, medications, and appointments.
- **How can you make daily activities more efficient?** Group similar tasks like meal prep. Try to multitask and automate things when you can. Plan ahead to cut down on stress and save time.
- **What are their long-term care needs?** Consider housing, mobility, and financial planning.
- **When are the next medical appointments?** Keep a calendar and attend with questions ready.
- **How do you prevent accidents in their living space?** Remove hazards, add grab bars, improve lighting, and use safety tools like alarms or locks to reduce risks.
- **How will the person you are caring for be supported in an emergency or if you are unavailable?** Create an emergency plan with contacts, medications, and procedures.
- **What are their wishes for their care in the future?** Document their preferences about medical care and end-of-life decisions.

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## Step 5 | Take Care of Yourself

Caregiving is hard work and your health and well-being matters.

- **How do you manage stress?** Explore breathing exercises, hobbies, journaling or talking to a friend.
- **Are you eating healthy and exercising?** Simple changes like balanced meals and walks can make a difference.
- **Are you sleeping well?** Sleep is crucial for your mental and physical health.
- **Are you taking time for yourself?** Arrange for respite care or ask family members to step in so you can schedule time for hobbies and other activities that help you recharge.
- **What support do you need to feel balanced?** Explore counseling, support groups, or talking with a trusted friend to share your experiences.
- **Do you know where to seek additional help?** Connect with caregiver support groups, counseling services, or local respite care providers if you feel overwhelmed. Look into the Caregiver Support Program for additional help.
- **Are you celebrating your successes?** Recognize and reward yourself for the hard work you do, balancing caregiving with personal growth.

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## Resources for Caregivers

**Local Area Agencies on Aging:** Your local Area Agency on Aging (AAA) is the front door for aging services in your community. Your AAA is staffed with skilled workers who can provide information about services and also help in getting access to those services. Find your local AAA at [pa.gov/aging/AAA](http://pa.gov/aging/AAA).

**Adult Day Centers:** Adult Day Centers (ADC) provide a safe and supervised place for older adults and those with conditions like dementia or Parkinson's Disease. They offer personal care, nursing, social services, activities, meals, and emergency care. Some centers also provide physical therapy, occupational therapy, speech therapy, and other medical services. These centers help support caregivers by offering an alternative to living in a care facility. Find a local ADC at [pa.gov/aging/ADC](http://pa.gov/aging/ADC).

**Senior Community Centers:** Senior Community Centers (SCC) are located throughout the state. In addition to providing a nutritious meal, Centers offer social activities, a range of informative programs, creative arts, exercise, volunteer opportunities, community services, and other special events which are unique to individual centers. Find a SCC in your area at [pa.gov/aging/SCC](http://pa.gov/aging/SCC).

**The PA Link to Aging and Disability Resources:** The PA Link helps people living with disabilities and older adults find information to connect them to supports and services in their community. Call the PA Link at 800-753-8827 or by email at [carelink@pa.gov](mailto:carelink@pa.gov). Learn about the PA Link at [pa.gov/PALink](http://pa.gov/PALink).

**Caregiver Support Program:** Pennsylvania's Caregiver Support Program (CSP) offers resources and assistance to support caregivers and help them maintain a healthy, ongoing relationship with the person they are caring for. Apply for CSP by contacting your local Area Agency on Aging (AAA). Learn more at [pa.gov/aging/caregiver](http://pa.gov/aging/caregiver).

## Helpful Printables

Worksheets and checklists can help to keep you and the person you care for organized. Find the following printables at [pa.gov/CareKit](http://pa.gov/CareKit).

- Budget Worksheet
- Care Needs Worksheet
- Caregiver Coordination Worksheet
- Caregiver Decisions Worksheet
- Emergency Preparedness Worksheet
- End-of-Life Planning Worksheet
- Funeral Planning Worksheet
- Home Health Hiring Worksheet
- Home Safety Worksheet
- Important Documents Worksheet
- In-person Visit Worksheet
- Long-term Care Facility Worksheet
- Managing Medications and Supplements Worksheet
- Medical Appointment Worksheet
- Older Adult Housing Needs Worksheet





This booklet is a product of Aging Our Way, PA – Pennsylvania’s 10-year strategic plan to transform the infrastructure and supports for older adults as we age.

Paid for with Pennsylvania Taxpayer Dollars.

**For more caregiving information and resources,  
find the PA CareKit at [pa.gov/CareKit](https://pa.gov/CareKit).**