



Pennsylvania
Department of Aging

The First 5 Steps

A Get-Started Guide for Working Caregivers

PA CareKit

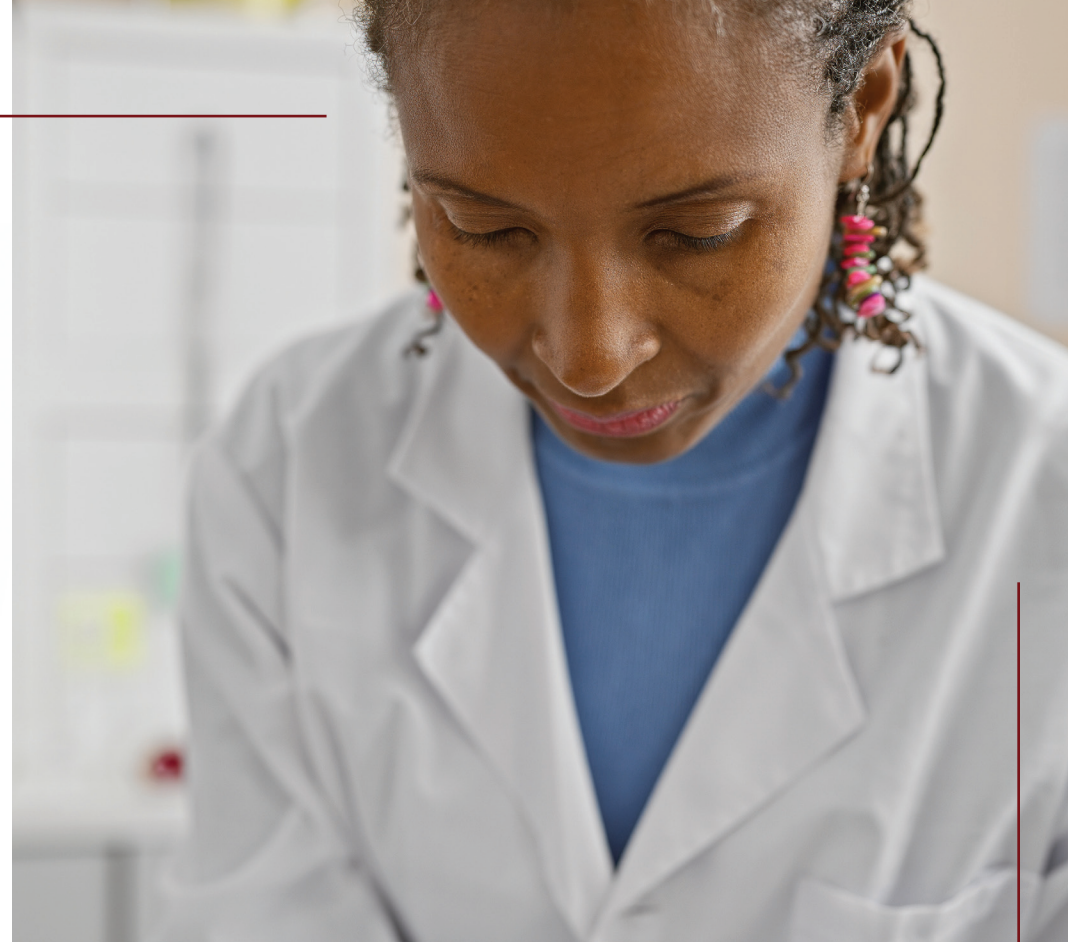
Elise and Dorothy's Story

Elise is a dental hygienist who lives 30 minutes from her mother, Dorothy. Dorothy's arthritis has become so severe that she needs help with most daily tasks. For the past year, Elise has visited daily to help with chores. Dorothy has lived in her home for over 50 years and doesn't want to move, but her house has stairs that make daily life difficult. Elise does her laundry, cleans, and brings groceries. She also visits twice a day to cook meals and take Dorothy to frequent doctor's appointments.

The extra time adds to Elise's commute and often makes her late or leave work early. Her supervisor is understanding but recently suggested switching to part-time, which would mean a pay cut and loss of health care coverage. Elise also worries that caregiving will hurt her chances for a promotion. Elise misses having more time to spend with her friends and go for walks on the trail with her dogs.

Elise is increasingly concerned about Dorothy being alone. Dorothy's neighbor Pam occasionally visits with her during the day, but otherwise, Dorothy is often alone, and she seems increasingly sad and down when Elise visits her. Between working and caring for her mother, Elise sometimes feels like she has two full-time jobs with no break. She also feels guilty for sometimes resenting the demands of caregiving. A friend suggested hiring a home care worker, but the cost was too high for Elise and Dorothy's budgets.

The PA CareKit offers several opportunities for Elise and Dorothy. The CareKit could help Elise find a Senior Community Center near



Dorothy's home. Dorothy could attend the Center to enjoy meals, socialize, and find engaging activities. The local Area Agency on Aging could connect Elise and Dorothy to a shared ride service to take Dorothy to the Center on weekdays. This would help Dorothy with social isolation and assure Elise that Dorothy would get a nutritious meal.

This freedom from 24/7 supervision would help Elise focus on her career without having to worry about her mother's health and safety. Caregiving is hard, but the PA CareKit offers resources and support to make it a little easier.



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.
- **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, then, prioritize tasks, seek help, or delegate responsibilities to others.
- **What aspects of caregiving feel rewarding to you?** Identify the positive moments that bring purpose and 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.
- **How can you set boundaries at work?** Communicate your availability and avoid overcommitting to manage both roles.

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- **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.

- **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 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 tools and technology assist you in caregiving?** Use apps for reminders, scheduling, or virtual health consultations.


- **What workplace policies support caregivers?** Research benefits like FMLA leave, remote work options, or employee assistance programs.

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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?** Build relationships with neighbors, friends, or local contacts who can be trusted for updates.
 - **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 to 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.
 - **Who can you rely on for workplace support?** Connect with HR, colleagues, or supervisors to explore resources.
 - **Do you know where to seek additional help?**
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Contact the PA Link for Aging and Disability Resources by calling 800-753-8827 or email carelink@pa.gov. Learn more about the PA Link at 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.
- **What caregiving tasks can you handle during breaks?** Make use of downtime for phone calls, appointment scheduling, or online shopping for supplies.

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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.

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.

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.

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. Learn about the PA Link at 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.

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.

- 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.**