



Pennsylvania
Department of Aging

The First 5 Steps

A Get-Started Guide for Grandparent Caregivers

PA CareKit

Elizabeth and Sal's Story

Elizabeth and Sal met in high school and have been married for many years. Sal used to be a plumber, but had to take a desk job because of knee and back pain. He was also diagnosed with Parkinson's, which causes shaking in his hands and numbness in his legs.

Elizabeth works at a dental office, and she really likes her job. She drives Sal to work since he can no longer drive. She has always helped care for her grandson, Jason. His mother, Beth, struggled with drug use problems for many years. Six months ago, Beth died of an overdose, and now Elizabeth and Sal are raising Jason by themselves.

Dealing with grief is hard. Elizabeth is trying to keep Jason in the same school with the same group of friends. Her days are very busy, and time feels short. She also spends hours on the phone with Jason's school. Things like signing him up for sports or finding a mental health counselor have been complicated without legal custody. Jason's father is not around, and Elizabeth doesn't know where to start. She constantly worries – about Sal's health, Jason's grief, and her own stress.

The PA CareKit offers several opportunities for Elizabeth and her family. Elizabeth can find information on Parkinson's to manage Sal's symptoms. She could get connected to the PA Link to learn more about home and community support. Elizabeth could find the SeniorLAW Center, which offers free legal help, to get guidance on custody and medical consent.



Elizabeth could access the Caregiver Support Program which provides education, training, financial help, and care management. Elizabeth could use these resources that give her more time to focus on her own needs, like taking care of her health and grieving her daughter. 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 does caregiving change your relationship with your grandchild?** Reflect on this relationship dynamic and find ways to nurture your grandparent-grandchild bond.
- **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 the positive moments that bring purpose 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 behavioral challenges.
- **Are you communicating openly with your entire grandfamily?** 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 the legal requirements.
- **Do you have legal guardianship of the person you are caring for?** Ensure that important documents are organized and protected, and their locations recorded, including personal identification, medical records, insurance or other health care coverage information, and other legal documents.
- **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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Strengthen the Support System

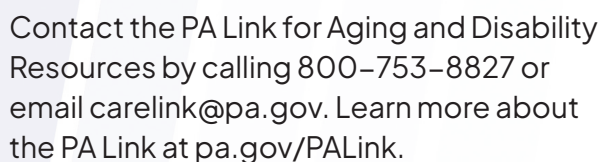
- **Who can offer help?** List family, friends, neighbors, or others.

- **When can they help?** Coordinate responsibilities.

- **What information do you need from health providers?** Prepare a list of questions.

- What community or professional resources are available?

- **Do you know where to seek additional help?**

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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 your 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 education, career, and social life.

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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.

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**For more caregiving information and resources,
find the PA CareKit at pa.gov/CareKit.**