



Pennsylvania
Department of Aging

The First 5 Steps

A Get-Started Guide for Sandwich Caregivers



Nicole and Martha's Story

Nicole lives with her husband, David, their two children, and her mother, Martha. Martha moved in five years ago to help with the kids so Nicole could go back to work full-time.

Though her kids are in school, Nicole juggles their schedules along with her own. Her day starts before 5 AM and often runs late into the evening. David works the night shift at the hospital, so he is not always available to help during the day.

Over the past year, Martha's health has gotten worse. She tires easily, struggles with simple tasks, and can't drive anymore because of poor vision. She also forgets to take her medications. One night, Nicole had to rush her to the ER for high blood pressure and chest pain. After that, Nicole took over managing her mother's medications, scheduling appointments, and driving her to the doctor.

Nicole spends hours each day helping both her kids and her mother. Recently, she came home to find Martha hadn't eaten all day and had slipped when climbing the stairs and injured her knee. Nicole can work from home sometimes, but not enough to provide the full-time care Martha needs.

While Nicole is grateful for her mother, the stress of balancing work, caregiving, and parenting is too much. She feels like she is always on call and rarely has time for herself or David. Her husband and kids help where they can, but her siblings rarely visit or offer help. This has caused problems in the family, and Nicole even argued with her brother at Thanksgiving. She used to be close with her siblings but now feels alone.



The PA CareKit offers several opportunities for Nicole and her family. She could learn how to manage her frustration and communicate better with her family. She can find tips on holding a family meeting and look into respite care options. An Adult Day Center might be a good option for Martha. Nicole and Martha could use the Managing Medications Worksheet to track Martha's prescriptions. 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.
- **How do your caregiving roles overlap?** Look for areas where caregiving for both generations can be integrated, like shared meals or family activities.
- **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 the positive moments that bring purpose to your caregiving journey.

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

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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.
- **When can they help, what task?** 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.
- **What community or professional resources are available?** Research agencies that offer transportation, meal delivery, housekeeping, or companionship.
- **How can you involve your children in caregiving?** Assign age-appropriate tasks to help them feel involved while teaching empathy and responsibility.
- **How can you maintain stability for your children?** Preserve routines like school activities, bedtime schedules, and family time.



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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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.

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.**