



Pennsylvania
Department of Aging

The First 5 Steps

A Get-Started Guide for Solo Caregivers

PA CareKit

Rebecca and James's Story

Rebecca lives with her father, James, who is a Vietnam Veteran. She has no other family members nearby. Rebecca has struggled with anxiety, chronic pain, and knee issues since a car accident in her twenties. She moved in with James after her accident, and they have remained close, enjoying baseball and playing cards together. She works part-time at a convenience store and loves cooking and reading.

Their lives changed when James had a stroke. Rebecca's days became filled with medical appointments, pharmacy trips, and daily caregiving. She helps James with stairs, getting in and out of bed, and using the bathroom. They value their privacy, so this change in James' needs has been an adjustment. Rebecca's own health issues make caregiving even harder.

After months of rehab, James regained some independence but still needs daily help with dressing, eating, and moving around. Doctors say he won't return to his previous level of functioning. Rebecca tries to take things one day at a time, but her knee pain has gotten worse. She's tired, often gets upset easily, and struggles without family support.

The PA CareKit offers opportunities for Rebecca and James. The Toolkit could connect Rebecca to an online caregiver support group to help with her anger and feelings of isolation and loneliness. Rebecca could use the Caregiver Decision-Making and Care Needs Worksheets to document James' needs and plan for future emergencies. With a call to the PA Link, Rebecca could find in-home support for James and get connected to the Veterans Affairs system. Caregiving is hard, but the PA CareKit offers resources and support to make it a little easier.





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 5 | Strengthen the Support System

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

- **Who can offer assistance?** Who is nearby that you can trust for updates? Build relationships with neighbors, friends, or local contacts who can check on the person you are caring for.
 - **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.
 - **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?**
-  **PA Link**
TO AGING AND DISABILITY RESOURCES
- 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.

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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.**