



Pennsylvania
Department of Aging

The First 5 Steps

A Get-Started Guide for Youth Caregivers

PA CareKit

Casey, Sam and Donna's Story

Casey lives with his dad, Sam, and his grandmother, Donna. Donna has lived with Sam and Casey since Casey was born. Sam works seven days a week, so Casey and Donna spend a lot of time together. Casey doesn't mind – Donna helps with homework, and he likes learning from her too.

Donna uses a walker and wants to do things on her own, but she struggles with daily tasks like cooking, laundry, and taking out the trash. When Sam works early or late, Casey does these household chores. He also helps Donna get dressed and shower before school when his dad isn't home.

Sometimes, Casey stays home when Donna isn't feeling well. One time, when she was weak and dizzy and Casey was at school, she forgot to use her walker, fell, and got a huge bruise. Last month, Casey got in trouble at school for being late and missing too many days.

Casey worries about his grandmother but also feels stressed about school. He even said no to playing basketball with his friends because he didn't want to leave her alone. He knows his dad is busy and doesn't know what to do.

The PA CareKit offers several opportunities for Casey and his family. Casey could check out the video library to learn how to help Donna safely, like assisting her in the bathroom. His family could work together to complete the Care Needs Worksheet to



help understand what Donna needs and how Sam and Casey can help. 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 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

- **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?** Use apps for medication 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 help?** List family, friends, neighbors, or others.
- **When can they help, what task?** Coordinate responsibilities.
- **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?**
- **Are you communicating openly with your support system?** Hold family meetings to discuss challenges and plan for the future.
- **What community or professional resources are available?** Research agencies that offer transportation, meal delivery, housekeeping, or companionship.
- **Are you using school or workplace resources?** Inform your teachers, professors, or employer about your caregiving role to access flexibility or accommodations.
- **Can you connect with other young caregivers?** Join support groups or online communities to share experiences and learn from peers.



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.
- **How can you prepare for school or work conflicts?** Develop strategies for juggling caregiving and personal responsibilities during stressful times.

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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.
- **What activities bring you joy?** Engage in hobbies, sports, or creative outlets to recharge emotionally.
- **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 mental health support?** Reach out to counselors, therapists, or youth-focused support groups if you're feeling overwhelmed.
- **Are you celebrating your successes?** Recognize and reward yourself for the hard work you do, balancing caregiving with personal growth.
- **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.

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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.**