



Pennsylvania  
Department of Aging

# The First 5 Steps

A Get-Started Guide for Long-Distance Caregivers

**PA CareKit**

# *Gloria and Anna's Story*

Gloria is the oldest of three children. Her mother, Anna, lives alone in Pennsylvania, while Gloria lives about seven hours away in Indiana. Her younger siblings live even further away. Gloria travels often for work as a regional sales manager.

Gloria and Anna are close and talk almost every day. Anna has diabetes and high blood pressure but always makes her health concerns sound small. She does complain about the cost and number of medications she must take.

Recently, Anna tripped over a rug and hurt her wrist. A neighbor named Sarah took her to the hospital. When Gloria spoke with Sarah, she learned Anna had been struggling with moving around the house and navigating her home's narrow stairs, so she has not been using the second or third floor of the house at all. Anna had also stopped driving due to vision issues and had not picked up her medicines in weeks. Gloria was grateful for Sarah's help, but felt guilty that she was not able to be there in person for her mother.

Anna raised her children to be independent and does not want to burden Gloria with her health concerns. When Gloria called Anna's doctor, she was told they couldn't share information without Anna's consent. Gloria wanted to help but wasn't sure how, especially with her job's travel demands. Her siblings wanted to help, but she didn't know what to ask for.

The PA CareKit offers several opportunities for Gloria and her family. Gloria and her siblings could use the Communication Tips to have a conversation with Anna to better understand what is important to her, so they can provide her with care that will



meet her needs. Gloria and her siblings can use the Caregiving Coordination Worksheet to divide tasks to help Anna and any hired support workers. They could use the Home Safety Checklist during a visit to reduce fall risks and keep Anna safe in her own home. They could also use the Visit Checklist to track changes in Anna's health whenever they are in-person with their mother.

Gloria could use the Medical Appointment Worksheet to share information, questions, and notes before, during, and after a doctor's appointment. They could help Anna track her prescriptions more safely with the Medication Management Worksheet.

Gloria and her siblings could also find their mother's local Area Agency on Aging and arrange transportation services through the local senior shared ride so Anna could get to her medical appointments. 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.

- **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 positive moments that bring meaning to your caregiving journey.

- **What realistic goals can you set?** Focus on what is achievable given your distance and resources, prioritizing tasks that make the greatest impact.

- **How can you make the most of in-person visits?** Plan visits strategically to address complex tasks like home repairs, medical appointments, or updating care plans.

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## **Step 2** Gather Information

Being informed will empower you to make confident decisions.

- **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 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?** Apps can line up tasks: reminders, scheduling, or virtual health consultations.
- **What can you realistically manage from a distance?** Determine which tasks, such as scheduling appointments or coordinating finances, can be handled remotely.

This image shows a full page of blank, lined paper. It features approximately 20 evenly spaced horizontal grey lines across its entire width, providing a guide for handwriting or typing. The paper itself is a clean, off-white color.





## Step 3 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 to share your experiences and feelings.
- **What information do you need from health providers?** Prepare a list of questions.
- **What are the emergency contacts and procedures?** Compile a list of local contacts, including doctors, neighbors, and emergency responders, and ensure everyone is aware of the plan.
- **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?**



Contact the PA Link for Aging and Disability Resources by calling 800-753-8827 or email [carelink@pa.gov](mailto:carelink@pa.gov). Learn more about the PA Link at [pa.gov/PALink](http://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.
- **What tasks can be simplified or automated?** Consider delivery services, pre-prepared meals, or automatic medication dispensers.
- **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?** What signs indicate an emergency? 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 documentation do you need to access remotely?** Keep digital copies of medical records, insurances, and legal documents.
- **Who will act on your behalf locally?** Designate a trusted person with power of attorney or emergency authority if you can't be there.

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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 to recharge.
- **What support do you need to feel balanced?** Explore counseling, support groups, or talking with a trusted friend to share your experiences.
- **How do you manage feelings of guilt?** Acknowledge that distance limits what you can do and focus on the meaningful ways you contribute to their care.
- **Are you staying organized to reduce stress?** Use calendars, to-do lists, or caregiving apps to keep track of tasks.
- **What support do you need as a long-distance caregiver?** Seek guidance from support groups, online forums, or counseling to share experiences and gain insight.
- **Do you know where to seek additional help?** Connect with caregiver support groups, counseling services, or respite providers if you feel overwhelmed.

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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](http://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](http://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](http://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](mailto:carelink@pa.gov). Learn about the PA Link at [pa.gov/PALink](http://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](http://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](http://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](https://pa.gov/CareKit).**