



Pennsylvania
Department of Aging

The First **5** Steps

A Get-Started Guide for Parent Caregivers

PA CareKit

Joe and Eric's Story

Joe lives with his son, Eric, and has cared for him alone since Eric's mother passed away. Eric, who has Down syndrome, works part-time at a coffee shop and plays basketball with friends. Joe helps with daily tasks like cooking, laundry, bills, and health care coverage. He also makes sure Eric gets to work and appointments. At home, Eric doesn't like to be left alone for too long, sometimes not even an hour.

Recently, Joe was diagnosed with COPD, making it harder to breathe. Their daily walks have become shorter, and Joe struggles to drive Eric to see friends. Household chores, like cleaning and helping Eric get ready for work, have become more difficult. Managing finances and health care coverage for both him and Eric has also become overwhelming.

Since his diagnosis, Joe has been thinking about his and Eric's future. He wants to make sure Eric is secure if he can no longer care for him.

The PA CareKit offers several opportunities for Joe and Eric. Joe might not expect aging services to apply to him, but he could be connected to a care manager through his local Area Agency on Aging. As someone over 55 who cares for a relative with a disability, Joe may also be eligible for the Caregiver Support Program. CSP can help with benefits applications, insurance or other health care coverage forms, and financial planning for Eric.



Joe may also be eligible to secure reimbursement for a personal care aide to assist Eric in the mornings on workdays and give Joe time to focus on his own health.

His AAA care manager can connect him with legal services for estate planning. Joe could use the Important Documents Worksheet to organize important financial and legal documents, such as banking information and tax records. 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 your child 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 motivates you to embrace this role?** Reflect on your commitment to your child and the importance of your role.
- **How has caregiving changed your relationship?** Take time to think about how caregiving affects your relationship and how you feel. Consider sharing them with your child when appropriate.
- **What areas of caregiving feel most challenging or overwhelming?** 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?** Identify the positive moments that bring purpose and meaning to your journey.
- **How does caregiving affect your personal goals?** Reflect on how your responsibilities impact your education, career plans, or family and social life.

[illegible]



Step 2 Gather Information

Being informed will empower you to make decisions with confidence.

- **What does your child value the most in this stage of their life?**

Have a candid conversation about their priorities and wishes to ensure care aligns with 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 type of health conditions is your child 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.

- **Do you know where your child's important documents are?**
- 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.

- **How can you promote independence for your child?** Look for ways to involve them in their care – small tasks or making decisions.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



Strengthen the Support System

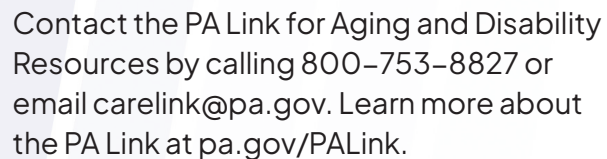
- **Who can offer help?** List family, friends, neighbors, or others.

- **When can they help?** Coordinate their availability.

- **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?

This image shows a single page of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page, leaving small margins at the top and bottom. There are no vertical margin lines, text, or other markings on the page.



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 your child?**

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 your child 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 their personal goals.

[illegible]



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.

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.

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.

Paid for with Pennsylvania Taxpayer Dollars.

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