

CdLS Foundation Caregiver Toolkit

Caregivers are responsible for many different roles that often go unseen. Caregivers provide personal and medical care, maintain the household, coordinate appointments, services, and transportation for all family members, manage finances, and so many more responsibilities.

1. Take Care of Yourself

Being the best caregiver also means caring for yourself. It is easy to say but hard to do. Remember you are **PRACTICING** self-care, which means it is an ongoing process. You can start small with just one thing and go from there.

- **Take care of your health.** Keep up with checkups. Do not ignore signs of illness.
- **Watch for signs of depression and anxiety and seek help when needed.** Mental health concerns can make it hard to concentrate and get the rest you need. It can deplete your energy, self-esteem, and ability to function.
- **Find someone who will listen without judgment.** Seek a listening ear, counseling, and mental health support.
- **Find simple ways to help manage stress.**
- **A Parent's Guide to Self-Care** for when you don't know where to begin. Take it one step at a time.



2. Seek Support from Other Caregivers

Finding your community and identifying your tribe can be life-changing. Seek support from those who understand your journey.

- **Connect with a family** through the CdLS Foundation.
- **Find in-person or virtual support groups** near you:
 - **The Lucas Project**
 - **We Are Brave Together**
 - **Caregiver Action**
 - **Caregivers Connect**
 - **Hey Peers**



3. Communicate, Advocate, Organize

Being a caregiver means wearing many hats. Your time is limited. Advocating for your loved one's medical needs is essential. Getting the most out of your healthcare plan, organizing medical information in one place, and learning more about CdLS can make you a stronger advocate.

- **Navigating your Health Plan Webinar** - Accessing and coordinating care in one easy and manageable place using the **CdLS Health Care Notebook**
- Submit your or your provider's questions to the Foundation Clinical Advisory Board members through the **Ask the Expert process**.
- **Patient Advocate Foundation**
- **Request a professional packet** containing vital CdLS information from the CdLS Foundation.



4. Help Is Not a Four Letter Word

Support is terrific, but it does not necessarily relieve you of some of your responsibilities. The word for that is **HELP**. Some of us have difficulty admitting we need help or feel guilty when we can't juggle everything ourselves. Like all jobs, caregiving comprises many individual tasks that do not all require the same set of skills.

- **Send them this** when someone asks how they can support you and you don't have the words.
- **Give them this** when friends and family don't know what to say.
- **Provide this** when you need ideas on how someone can help.
- **Look into Respite Services** when you need a rest.
 - **Mother's Rest** coordinates respite retreats.
 - **The Lucas Project**



5. Make Your Workplace More Caregiver Friendly

One in five working Americans are caregivers. Your company may not be aware of employees who are also caregivers. Many employees worry their caregiving negatively impacts their job performance, job stability, or chances for promotion. It is possible to help your employer develop more caregiver-friendly policies that benefit both employees and your employer.

- **Find information about State Family and Medical Leave Laws (FMLA).**
- **Talk to your employer about taking time off.**
- **Explore guides and resources to start building a more caregiver-friendly workplace.**
- **Four main areas to focus on when developing caregiver support policies in the workplace.**



6. Financial and Legal Tools

When caring for a loved one, there are legal decisions you may need to make throughout your journey. You may explore becoming a healthcare proxy, pursuing guardianship, or establishing a conservator. You may need legal representation for assistance or advocacy.

- **What is guardianship?**
- Deciding if **guardianship** is suitable for your loved one.
- In need of advocacy? **A Better Balance**.
- Know your Disability rights; find **a Disability Rights Network in your state**.
- Find an attorney for special needs law near you with **Special Needs Alliance**.



7. Identify Your Needs and Seek Out Resources

- **Start the conversation.** Every family's journey and resource needs are different.
- **Reach out** to the CdLS Foundation and speak with the Family Service team to discuss how to get the help you need.

