

Section 5: Resources



In this section:

- Caregiver Resources
- Caregiver Self-Care Plan
- Helpful Tips for Caregivers
- Handwashing
- For amyloidosis resources visit <http://amyloidosis.org/resources/>

How to use this section:

- Use this section to keep track of resources you encounter.
- These could be support groups, neighborhood assistance groups; an individual who provides a service you might need.
- Even if you don't need a resource right now, you might in the future. This section is a good place to keep this information so you can find it when you need it.
- We have included some information that caregivers have found helpful.

Notes:

Caregiver Resources

AARP Family Caregiving

www.aarp.org/caregiving/

Find free care guides, legal checklists, care options and an online community that supports all types of family caregivers.

AARP Free CARE Act Wallet Card

Download and print this card to keep with your loved ones medical cards at <https://www.aarp.org/caregiving/local/info-2017/care-act-aarp-wallet-card.html?intcmp=AE-CAR-R4-C2-LL7>

Advance Directive Forms for your State

<https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/> AARP.ORG provides Advance Directive forms for each state. Every adult should have an advance directive in which you explain the type of health care you do or do not want when you can't make your own decisions. You should also appoint someone who can speak for you to make sure your wishes are carried out.

ARCH National Respite Network and Resource Center

www.archrespite.org

Find programs and services that allow caregivers to get a break from caring for a loved one.

The Assistance Fund

<https://tafcares.org/>

855-845-3663

Provides various services to help patients with chronic or serious illnesses cover the cost of FDA-approved medications.

Caregiver Action Network

www.caregiveraction.org

Formerly known as the National Family Caregivers Association, it provides information and education for family caregivers, including a volunteer support network in over 40 states.

Caregiver Resources

eCare Diary

<http://www.ecarediary.com/>

Provides comprehensive information, tools and resources to help those seeking and providing long term care. A unique feature is the Care Diary, a set of online tools designed to make coordination of care and sharing of information easy amongst family members and other caregivers. eCare Diary also has a comprehensive database of nursing home and home care services, guides on long term care financing and information on important health care documents everyone should have.

Connects caregivers to local services and resources for older adults and adults with disabilities across the United States.

Family Caregiver Alliance

www.caregiver.org

800-445-8106

Information, education and services for family caregivers, including the Family Care Navigator, a state-by-state list of services and assistance.

Global Genes

www.globalgenes.org

<https://globalgenes.org/wp-content/uploads/2018/11/Navigating-Health-Insurance-DIGITAL-spread-op.pdf>

Booklet titled "Navigating Health Insurance"

Good Days

<https://www.mygooddays.org/>

877-968-7233

Provides help to patients with specific life-altering conditions. Assistance includes help with the cost of medications and travel.

Hospice Foundation of America

www.hospicefoundation.org

800-854-3402

Provides information on issues related to hospice and end-of-life care

Caregiver Resources

Lotsa Helping Hands

www.lotsahelpinghands.com

Lotsa Helping Hands is a free caregiving coordination web service that provides a private, group calendar where tasks for which a caregiver needs assistance can be posted. Family and friends may visit the site and sign up online for a task. The website generates a summary report showing who has volunteered for which tasks and which tasks remain unassigned. The site tracks each task and notification and reminder emails are sent to the appropriate parties.

Medicare

www.medicare.gov

800-Medicare

Provides information about the parts of Medicare, what's new and how to find Medicare plans, facilities or providers.

National Alliance for Caregiving

www.caregiving.org

A coalition of national organizations focused on family caregiving issues.

National Institute on Aging Information Center

www.nia.nih.gov

800-222-2225

Research leader on aging issues; information on common age-related health problems.

The National Clearinghouse for Long-term Care Information

www.longtermcare.gov

Information and tools to plan for future long-term care needs.

Patient Advocate Foundation

www.patientadvocate.org

800-532-5274

Provides case management assistance for the uninsured or underinsured with *life-threatening or debilitating illnesses*. Services include help with the following: access to care; co-pay assistance; social security disability applications; and insurance appeals. PAF also has a National Financial Resource Directory that allows patients to find resources within a given state.

Caregiver Resources

Social Security Administration

www.socialsecurity.gov

800-772-1213

Information on retirement and disability benefits, including how to sign up.

<https://www.ssa.gov/planners/disability/qualify.html>

The SSA has information about How to Qualify for Social Security Disability Benefits.

State Health Insurance Assistance Program

www.shiptacenter.org

A program that offers one-on-one insurance counseling and assistance to people with Medicare and their families.

USA.gov

www.usa.gov

844-872-4681

<https://www.usa.gov/help-with-bills#item-36707>

There are state and federal programs to help people who cannot afford medical care or prescription drugs. USA.gov provides links to federal resources that help with medical bills at the link above or you can contact the number listed above.

Veterans Administration

www.caregiver.va.gov

855-260-3274

Support and services for families caring for veterans. Maintains a VA caregiver support line.

Well Spouse Association

www.wellspouse.org

800-838-0879

Provides support for spousal caregivers.

Caregiver Self-Care Plan

Self-care is

- Taking action to maintain or improve your own mental, emotional and physical health, especially during times of stress
- Intentionally doing things that improve your mood and lower your stress levels.

Use the following prompts to create a self-care plan. It's easy to say you want to take more time for yourself, but it can often be hard to actually find the time. You will have to consciously make time and set self-care goals.

Physical Self-Care Plan. As a caregiver, if you are not physically well, you will not be able to take care of your loved one.

Check all the following statements that are true:

- I eat a well-balanced diet that includes a variety of fruits and vegetables, proteins, whole grains and healthy fats.
- I drink at least eight 8-oz glasses of water or fluid a day (an 8x8 goal).
- I sleep well each night and wake up feeling rested.
- I exercise for 30 minutes at least 3 times a week.
- I do not smoke tobacco.
- I only drink alcohol in moderation.
- I keep up with my own medical needs, such as getting an annual checkup from my primary care provider and getting regular dental cleanings.

Did you leave statements unchecked? If so, you may need to consider improving those aspects of physical self-care. Talk to your primary care provider about ways to improve your health and well-being.

What are some ways in which you can improve your physical well-being?

Example: Drink more water to stay hydrated.

Write down a few short-term goals to improve your physical well-being.

Example: I will keep a water bottle with me throughout the day to make sure I meet the 8x8 goal.

Mental & Emotional Self-Care Plan. Taking care of your mental and emotional health is just as important as caring for your physical health. It's important to take time for yourself each day and to keep up with activities that you enjoy. With the daily responsibilities of caregiving, you may forget to do these things. Make a conscious effort to take time to care for your mental and emotional health.

What activities do you enjoy? Check all that apply.

- Listening to music, playing an instrument or singing
- Reading or listening to audiobooks
- Exercising or participating in group exercise classes
- Playing sports or organized games with friends
- Hiking, fishing, or other outdoor sports
- Meditating or practicing yoga
- Painting, drawing, or other artistic pursuits
- Journaling or creative writing
- Attending religious or spiritual services
- Activities with friends or family
- Practicing personal care, such as taking long baths, having manicures or using face masks
- Cooking or baking
- Watching movies or TV Shows
- Playing video or computer games
- Yard work or gardening
- Other: _____
- Other: _____

Any of these activities can be part of a self-care plan. Pick one or two of your favorite activities and make them a priority in your day-to-day life. Then fill out the following statements to create goals for emotional self-care:

I will set aside time to _____ once a day.

Examples: Drink coffee on the front porch, meditate and stretch, write in journal.

I will set aside time to _____ once a week.

Examples: Have dinner with friends, go to an art or exercise class.

Change the activity and frequency to accommodate your lifestyle and needs, but do make sure that you make all the time for yourself.

Stay Calm Strategy. When caring for a loved one with amyloidosis, there will be times that are difficult and emotional. It's unavoidable. Prepare for these moments by having a strategy in place to help yourself calm down if you feel anxious or overwhelmed. Having a plan in place, in advance, will help you better manage unexpected intense emotions.

Try the following strategies:

- Do a breathing exercise
- Repeat a meaningful mantra, affirmation or prayer.
- Close your eyes and sit in silence.
- Stand up and stretch.
- Take a walk outside.
- Call a close friend or family member.

When I feel overwhelmed I will:

Deep-Belly Breathing Exercise

1. Sit in a comfortable position and close your eyes.
2. Place one hand on your stomach and your other hand on your chest.
3. Take a deep breath through your nose. The hand on your stomach should rise. The hand on your chest should not move much.
4. Exhale through your nose. The hand on your stomach should move, and the on chest should not move much. Focus on your breathing and your hands.

You can find a variety of breathing exercises online. Try several different ones until you find one that works for you.

Ask for Help and Delegate Tasks. As a primary caregiver for a loved one, you may worry that if you don't take care of your loved one, then no one else will. More than likely, there are friends and family members who really want to help-they just may not know how, so let them know!

What tasks could you delegate to someone else? Use the chart below to think of some tasks and some friends and family members who can help you with your caregiver responsibilities.

TASK	HELPER	NOTES
Example: Take John to appointment on Monday	Aunt Pat	Pat doesn't work on Mondays and she lives close by.

Helpful Tips for Caregivers



Caring for a loved one can be physically challenging and emotionally draining. Here are some tips from other caregivers and the Amyloidosis Foundation staff.

- **Set up a support system...for YOU.** Friends, a spiritual advisor or counselor can help you emotionally during this time. Find a support group near you.
- **Take care of yourself.** Eat well-balanced meals, exercise and sleep. You can't be a good caregiver if you are exhausted or sick.
- **Take time for yourself.** Make arrangements to get away and take care of your own priorities.
- **Carry this binder with you.** It will help you organize information and keep documents in one place. It's also helpful to share with other caregivers.
- **Learn to delegate and accept help.** Let family and friends help with care, errands, meals, shopping, chores and driving. Use the 'Patient Support Team' roles and contact information list in this binder to organize your team.
- **Set up a system to provide patient updates.** Delegate someone to post updates via emails, Facebook, Twitter, CarePages.com, Lotsahelpinghands.com, or other social media networks. Remember to keep medical information private.
- **Ask questions** about the patient's needs and how they are being met. In this binder, helpful documents include 'Questions for the Doctor' and 'Patient Health Goals'.
- **Try to maintain a sense of humor.** Taking things one day at a time helps.

For more information, contact the Amyloidosis Foundation at: info@amyloidosis.org or (248) 922-9610.

Website: www.amyloidosis.org



Handwashing: A Family Activity

Keeping Kids & Adults Healthy



Handwashing is an easy, inexpensive, and effective way to prevent the spread of germs and keep people healthy.

For kids, washing hands can be a fun and entertaining activity. It is simple enough for even very young children to understand. Handwashing gives children and adults a chance to take an active role in their own health. Once kids learn how to properly wash their hands, they can—and often do—show their parents and siblings and encourage them to wash hands, too.

Parents can help keep their families healthy by:

- Teaching them good handwashing technique
- Reminding their kids to wash their hands
- Washing their own hands with their kids



Improving Health

- Handwashing education in the community:
 - » Reduces the number of people who get sick with diarrhea by 31%
 - » Reduces diarrheal illness in people with weakened immune systems by 58%
 - » Reduces respiratory illnesses, like colds, in the general population by 21%

Saving Time and Money

- Handwashing is one of the best ways to avoid getting sick and spreading illness to others.
- Reducing illness increases productivity due to:
 - » Less time spent at the doctor's office
 - » More time spent at work or school



Helping Families Thrive

Children who have been taught handwashing at school bring that knowledge home to parents and siblings. This can help family members get sick less often and miss less work and school.

Despite widespread knowledge of the importance of handwashing, there is still room for improvement. A recent study showed that only 31% of men and 65% of women washed their hands after using a public restroom.

For more details, visit www.cdc.gov/handwashing.

