



○ Being a Caregiver: Beginning Your New Journey

The Amputee Coalition offers *Being a Caregiver: Beginning Your New Journey* as an introductory guide to help families and spouses of individuals who have recently lost a limb adjust to their new role. The booklet offers an overview of the topics related to being a family member or spouse of someone with limb loss including: caring for your loved one, intimacy and relationships, community and support resources and coping with the stress of caregiving. You can contact the Amputee Coalition to request this resource be mailed to you.

Web: amputee-coalition.org/limb-loss-resource-center/ask-an-information-specialist

Phone: 888.267.5669

○ National Resources

AARP: Family Caregiving:

AARP: Family Caregiving offers articles, tools, worksheets and tips on how to plan, prepare and succeed as a caregiver.

Web: aarp.org/relationships/caregiving

Phone: 877.687.2277

Administration for Community Living: Support to Caregivers

The ACL is committed to the fundamental principle that people with disabilities and older adults should be able to live at home with the supports they need and be able to participate in their communities. The ACL is focused on increasing access to community supports while focusing attention and resources on the unique needs of older adults and individuals living with a disability.

Web: acl.gov/programs/support-caregivers

Phone: 202.401.4634

ARCH National Respite Network and Resource Center

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

Web: archrespite.org

Caregiver Action Network (CAN)

CAN reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well-being.

Web: caregiveraction.org

Phone: 202.454.3970

E-mail: info@caregiveraction.org

Caregiver.com

Caregiver.com produces *Today's Caregiver* magazine, as well as an e-newsletter that can be viewed on their website.

Web: caregiver.com

Family Caregiver Alliance (FCA)

FCA offers programs at national, state and local levels to support and sustain caregivers. FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective programs and policies for caregivers in every state.

Web: caregiver.org

Phone: 800.445.8106

Email: info@caregiver.org

Medicare.gov

Medicare has compiled resources for caregivers of an individual. The resources are designed to help caregivers address challenging issues and work effectively with Medicare to ensure their loved ones receive the best possible care.

Web: cms.gov/Outreach-and-Education/Outreach/Partnerships/Caregiver.html

National Alliance for Caregiving (NAC)

NAC is a nonprofit coalition of national organizations focusing on issues of family caregiving. The Alliance was created to conduct research, do policy analysis, develop national programs, increase public awareness of family caregiving issues, work to strengthen state and local caregiving coalitions, and represent the U.S. caregiving community internationally.

Web: caregiving.org

Phone: 301.718.8444

Email: info@caregiving.org

National Caregivers Library

The National Caregivers Library is a source of free information for caregivers.

Web: caregiverslibrary.org

Rosalynn Carter Institute for Caregiving

The Rosalynn Carter Institute for Caregiving establishes local, state and national partnerships committed to promoting caregiver health, skills and resilience.

Web: rosalynncarter.org

Phone: 229.928.1234

Well Spouse Association (WSA)

The WSA advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner. The organization educates healthcare professionals and the general public about the special challenges and unique issues of "well" spouses and facilitates a mentor program. Peer-to-peer support is offered through a national network of support groups.

Web: wellspouse.org
Phone: 800.838.0879

Community Resources

Aging and Disability Resource Centers (ADRC)

An ADRC serves older adults, individuals with a disability, caregivers, veterans and family members. This is a “no wrong door” and a “one-stop shop” system where you can obtain information on available long-term services and benefits, regardless of your income.

State Resource Map: amputee-coalition.org/limb-loss-resource-center/resources-by-state

Area Agencies on Aging (AAA)

Your local Office on Aging is an excellent resource for in-home and community-based services. Services provided by an Office on Aging vary from benefits screenings to home-delivered meals, transportation and senior centers. Typically, a social worker will work with you to assess your needs and offer referrals to appropriate and available services in your area. The benefit of working with an Office on Aging social worker is that they can stay in touch with you long-term and address your needs as they arise. It is not a service that ends after a certain period of time. Your local Office on Aging is a great first contact when looking for what types of services are available to help an older adult maintain independence and continue to live safely in his or her home.

Web: n4a.org
Phone: 202.872.0888

Centers for Independent Living (CIL)

CIL agencies are community-based, cross-disability, nonprofit organizations that are designed and operated by individuals with disabilities. They provide services such as peer support, information and referral, and individual and systems advocacy, as well as independent living skills training.

State Resource Map: amputee-coalition.org/limb-loss-resource-center/resources-by-state

Eldercare Locator – Home and Community-Based Services (HCBS)

HCBS services include home-delivered meals, home healthcare, homemaker/chore services, transportation and caregiver support services, among others.

Web: Services Locator: eldercare.acl.gov
Web: Transportation: eldercare.acl.gov/Public/Resources/LearnMoreAbout/Transportation.aspx
Phone: 800.677.1116

National Association for Home Care & Hospice (NAHC)

The NAHC is a nonprofit organization representing home care and hospice organizations. The NAHC represents the interests of the chronically ill, disabled and dying Americans of all ages and the caregivers who provide them with in-home health and hospice services.

Web: Home Care/Hospice Agency Locator: agencylocator.nahc.org

National Center on Senior Transportation (NCST)

The NCST strives to increase transportation options for older adults to support their ability to live

independently in their homes. NCST provides a wealth of information about transportation and offers resources specifically for caregivers. The NCST website focuses on education about transportation services and options. It also provides a link to search for transportation in your area:

Web: nadtc.org

○ Benefits Assistance

BenefitsCheckUp

The National Council on Aging offers a free screening to individuals aged 55 and older who need help paying for prescriptions, food, healthcare, utilities and other basic needs.

Web: benefitscheckup.org

Benefits.gov

The official benefits website of the U.S. government, benefits.gov educates citizens about available benefits and provides information on how to apply for assistance. [Benefits.gov](http://benefits.gov) also offers a screening to determine eligibility for assistance.

Web: benefits.gov

Disability.gov

A website for people living with a disability, their families, and caregivers to assist in locating helpful resources on topics such as how to apply for disability benefits, find a job, get healthcare or pay for accessible housing.

Web: disability.gov

U.S. Department of Health and Human Services

Social services, health insurance, prevention, and wellness are just some of the programs offered by the U.S. Department of Health and Human Services. Every state and many local governments have a Department of Social Services, sometimes called Department of Health and Social (or Human) Services. The department offers information, referrals and assistance for seniors and helps them identify community resources that can help with their care, including transportation and nutrition services. It also assesses medical and supportive needs and coordinates a variety of services.

Web: hhs.gov

○ Emergency Response and Medication Reminder Systems

Personal Emergency Response System (PERS)

A PERS is an electronic device that can be worn on the wrist or as a pendant. In an emergency, pushing a button on the device will send a signal to an emergency response service center that monitors the device, which will call the emergency contact or notify the appropriate emergency personnel (medical, fire or police). In addition, many PERS services will also remind subscribers when to take medications, when they have doctor appointments, etc. Many devices now provide fall detection as well.

Emergency response systems can vary widely in price and the services they offer. It is best to do your homework and identify what you need the service to do and how much you have budgeted for it. Contact your local Area Agency on Aging for guidance in choosing a provider.

The following article from the Federal Trade Commission is a great resource for understanding emergency response systems and key questions you should ask a provider:
consumer.ftc.gov/articles/0316-personal-emergency-response-systems-health-information-older-people

Medication Reminder System

A Medication reminder system acts as an alarm to alert an older adult to take their medication. This service can take many forms. It can be as simple as an application on a cell phone or as complex as a dispenser that releases the exact dose at specified times. Before making a decision on the type of service that will work best for your loved one, consult with your local Area Agency on Aging for guidance.

○ Advance Care Planning

Advance Directives

One of the most difficult conversations to have is end-of-life decision-making. As an older adult, or the caregiver of an older adult, it is essential to have a plan surrounding the care that you or your loved one wishes to receive at the end of life. Although you may find it an uncomfortable topic to bring up, it does not have to be. Remember that, in reviewing your desires with your family members, you will remove the stress of emergency decision-making that may not go along with your wishes. Review your options and consider meeting with an elder law attorney if you have questions regarding a living will or power of attorney document. You might also consider meeting with a social worker at your local Office on Aging.

The following resource, prepared by the National Institute of Health, provides general information surrounding advance directives:

[Nlm.nih.gov/medlineplus/advancedirectives.html](https://nlm.nih.gov/medlineplus/advancedirectives.html)

The National Institute on Aging's overview of Advance Care Planning also provides detailed definitions for what you should consider:

nia.nih.gov/health/publication/advance-care-planning

○ Additional Resources

Canine Companions for Independence (CCI)

CCI is a nonprofit organization that provides free assistance dogs for eligible people with disabilities.

Web: cci.org

Phone: 800.572.2275

Rebuilding Together

Rebuilding Together provides home rehabilitation and modification services to low-income homeowners across the country. The work is completed by volunteers and skilled tradespeople with the support of local business and corporate sponsors. If Rebuilding Together is not available in your area, contact the Limb Loss Resource Center, your local Office on Aging or City Hall for information on assistance programs in your area.

Web: rebuildingtogether.org

SeniorNet

SeniorNet is a nonprofit organization that offers education to older adults about computer technology, including the Internet, and how to access it.

Web: seniornet.org

Phone: 239.275.2202

○ Survival Guide for Caregivers: De-stressing to Stay Healthy

Caregiving can be a tough and stressful job. It is a role that is often unrecognized and can feel thankless. It requires great levels of physical, emotional and mental strength. A caregiver is usually an unpaid family member or friend. According to AARP statistics, the estimated value of caregivers was \$375 billion in 2007 (1). That number will only grow as the population continues to age. While stressful, caregiving can be a very rewarding experience. Providing care to an individual that you love can be an opportunity to treasure. It is important to note that you must care for yourself as well in order to provide a good quality of care to your loved one.

The following information will explore ways to help you manage your stress. Make note of how you might fit these de-stressing activities into your life. Think of activities that you enjoy and how you might fit them in as well.

Organize your life

- **Recognize what you have control over and what you do not.** Try to avoid allowing yourself to worry or stress about something that is out of your control. Use that energy on something more productive, such as a project or task in which you are in control of the outcome.
- **Write down and prioritize your daily routine.** Get rid of anything unnecessary.

- **Be flexible.** When something happens that is out of your control, be flexible and change priorities.
- **Organize your loved one's financial, legal and medical records.** They should be easily accessible and in an order that makes sense to you and to your loved one. Having these materials readily available in case of an emergency can reduce stress.
- **Keep important information within reach.** Post lists of phone numbers, medicines and other important information where they are easily accessed. Consider keeping this document handy with a pocket magnet on the refrigerator or even inside your refrigerator.
- **Know your limits.** Taking on more than you can handle will increase your stress level.

Eat a well-balanced diet

- **Be mindful of your eating habits.** Eat a diet with plenty of fruits, vegetables and whole grains. Be aware of over (or under) eating and mindless snacking.
- **Prepare meals in advance.** Consider preparing extra portions when you cook. You can freeze the extras and use them for quick, ready-to-eat meals. If you are short on ideas for how to cook extra portions, try searching the Internet for quick, pre-planned meal menus. You will find websites that offer recipes to make meals in bulk and often include a shopping list as well!
- **Avoid convenience foods.** While fast food is convenient when you are short on time, it is important to consider that your body needs nutrients that you will not get from a pizza or a burger and fries.
- **Drink plenty of water.** Your body needs to rehydrate, and water is the healthiest way to do so.
- **Limit your caffeine intake.** Caffeine can negatively impact your sleep, among other things. Instead of reaching for a cup of coffee to get you through the afternoon, try reaching for a healthy snack. Snack on an apple, have a glass of water, or take a quick walk instead.

Get enough rest and sleep

- **Get a good night's rest.** Lack of sleep can take a significant toll on your body and mind. In addition to higher rates of depression, "growing evidence shows that a chronic lack of sleep increases your risk of obesity, diabetes, cardiovascular disease and infections (2)."
- **Keep a regular sleep schedule.** If possible, try to go to bed around the same time each night to get your body on a schedule.
- **Limit caffeinated or alcoholic beverages in the evenings.** While you may feel that a drink in the evening helps you to fall asleep, the quality of your sleep actually diminishes with alcohol.
- Consider doing a meditative exercise like deep breathing as a routine before bed.
- Talk with your doctor about your sleep habits. Your doctor cannot know how to help you if he or she does not know about the problem.

Monitor your physical health and exercise regularly

- **Schedule a checkup.** Schedule and keep regular appointments and checkups with your doctors. Ask yourself, "How can I help my loved one if I am not caring for myself?"
- **Increase your physical activity.** This does not mean spending hours in the gym. Consider activities you enjoy and incorporate those activities in your day-to-day life. Take a walk, swim or spend time in your garden. Take 15 minutes for yourself and stop at a park to walk around on

your way home. Think of those 15 minutes as a time to decompress and recharge your batteries and get back to the task at hand when you are finished.

- **Combine exercise with time to catch up with friends.** It is easy to make the excuse that you do not have time to exercise or meet with friends. Ask your friend to meet you at the park for a walk and use that time to catch up and remind yourself that you have an identity outside of being a caregiver.
- **Stretching** is free and can be done anywhere. Take a couple of minutes to stretch your whole body, starting from your head and working down to your toes. That little break will release tension in your muscles and allow you to refocus.
- **Take a walk.** A 2005 study found that “walking fast for 35 minutes a day five times a week or 60 minutes three times a week had a significant influence on mild to moderate depression symptoms (3).”

Monitor your emotional health

- **Check-in with yourself.** Ask yourself about how you are coping emotionally. Caregivers often neglect their responsibility to care for themselves. Your emotional health is important, and can take a big toll on your body.
- **Share your feelings.** Instead of bottling up your stress and emotions, express yourself with someone you know and trust. If you are struggling to find someone you trust to unload your feelings onto, consider talking with a counselor.
- **Keep a journal.** You can both express and monitor your feelings by keeping a log for yourself. You can use this journal as a tool to track your habits. If you notice more entries about lack of sleep or an increase in feelings of anxiety or overwhelming feeling of dread and sadness, call your healthcare provider or consider making a change.
- **Know your limits.** You lose your ability to problem-solve and address issues when there is too much on your plate to handle.
- **Try a calming exercise.** Learn calming exercises, such as deep breathing and meditation. Try a deep breathing exercise or a stretching and relaxation exercise when you feel stressed. You can search for quick calming exercises on the Internet or try a yoga class. When you feel your stress level increasing, try taking a few deep breaths. A deep breath should be felt in your belly. Inhale slowly through your nose, and exhale out of your mouth. Try this a few times, counting as you inhale and exhale.
- **Take up an activity that offers emotional satisfaction.** This activity can give you time away to focus on yourself and give you a break from your situation. If you like to drive, try making a playlist of your favorite songs to jam out to and hit the road. If you prefer a more calming activity, try taking a nature walk or carving out time and space to read a book.
- **Do not self-medicate with alcohol, work or drugs.** While these activities add a distraction, they are just that. You will cause yourself more harm than good.
- **Spend some time with your four-legged friends.** Studies have shown that pet therapy can reduce stress and anxiety, and improve mental and physical health (4).
- **Know the common signs of depression.** Learn to recognize the common signs of depression in yourself. Common signs of depression include loss of appetite, sleeplessness, irritability, crying, inability to concentrate and forgetfulness. If you find yourself experiencing these symptoms, contact your healthcare provider for a referral to a mental health professional.

Know your resources and accept help from others

- **Take a break.** Use your family, friends, church and local organizations to arrange to take a break. Contact your local Office on Aging, Aging and Disability Resource Network, or Center for Independent Living to determine whether there is a respite program in your area. Meals on Wheels might be an option to ensure the individual you are caring for has a hot meal delivered at lunchtime, which will free you up to do other things.
- **Let others help you with general tasks.** Keep a list of common chores and jobs and show it to those who offer to help.
- **Be clear in your request for help.** What, specifically, do you need help with? Is it mowing the lawn, preparing meals or just sitting with your loved one while you do the grocery shopping?
- **Know that you are not alone.** If you feel you are in a place to do so, consider joining a caregiver support group.

Set aside time to care for yourself

- **You deserve time away.** Accept that it is perfectly fine to do things that you enjoy. Take time for yourself at least once per week. If you're able to take more time, even just a few minutes per day, do so.
- **Accept help.** If people offer to help, accept it.
- **Reward yourself.** This does not have to mean spending money on an expensive spa day. Try treating yourself to a movie or a dinner date. The work that you do is important and valuable. You deserve a treat.
- **Nurture your spiritual self.** If your spirituality is important to you, nurture that relationship. Be sure to do what makes you feel connected to your spirituality. Attend services, speak with your church leaders, pray or participate in a church group.
- **Recognize the significance of your role as caregiver.** Your role has positive meaning, and you can be made stronger through it.

References

1. "Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update."
AARP
assets.aarp.org/rgcenter/il/i13_caregiving.pdf
2. "Your Guide to Healthy Sleep."
nhlbi.nih.gov/health/resources/sleep/healthy-sleep
3. "Exercise and Depression."
Harvard Health
health.harvard.edu/mind-and-mood/exercise-and-depression-report-excerpt
4. "Psychosocial and Psychophysiological Effects of Human-Animal Interactions: The Possible Role of Oxytocin."
Beetz, A., Uvnas-Moberg, K., Julius, H., & Kotrschal, K.
ncbi.nlm.nih.gov/pmc/articles/PMC3408111

It is not the intention of the Amputee Coalition to provide specific medical or legal advice but rather to provide consumers with information to better understand their health and healthcare issues. The Amputee Coalition does not endorse any specific treatment, technology, company, service or device. Consumers are urged to consult with their healthcare providers for specific medical advice or before making any purchasing decisions involving their care.

National Limb Loss Resource Center, a program of the Amputee Coalition, located at 900 East Hill Ave., Suite 390, Knoxville, TN 37915 | 888.267.5669

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