

amputee
coalitionTM



Beginning Your New Journey



Being a Caregiver

WELCOME!

The Amputee Coalition is a national non-profit organization dedicated to supporting individuals affected by limb loss and limb difference. Established with a mission to empower this community through education, support, and advocacy, the Amputee Coalition provides a comprehensive array of resources to enhance the quality of life for amputees.



The organization offers extensive peer support programs, educational materials, and a wealth of information on health and wellness. They actively engage in advocacy efforts to improve public policy and healthcare access for amputees. The Amputee Coalition also hosts events and initiatives aimed at fostering community, raising awareness, and promoting positive change.



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Through their dedicated efforts, the Amputee Coalition strives to ensure that no amputee feels alone and that every individual has access to the tools and support they need to live life fully.



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This project was supported, in part, by grant number 90LLRC0001-01-00, from the Administration for Community Living, U.S. Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



We look forward to working with you as you embark on this journey.



You have received this booklet as the caregiver of an individual that has experienced an amputation. The amputation may have just occurred and you may feel that you need some guidance in managing the road ahead of you. Perhaps you have been caring for a loved one for some time and find yourself in a position of need for assistance and guidance. Regardless of what stage you are in, it is important to remember that the amputation did not just occur to the individual, it has impacted all involved, including you. You have limitations – everyone does – and it is OK to seek help when you need it.

Take time to read through this booklet and make note of any lingering questions you might have. If you need additional information, contact the Amputee Coalition National Limb Loss Resource Center® and a resource specialist will walk you through the available materials and connect you to local resources in your community. A list of helpful resources has been provided at the end of this booklet. We look forward to working with you as you embark on this journey.



● INCIDENCE AND PREVALENCE

How does someone become a caregiver? For most, there is no one defining moment where you automatically begin to identify yourself as a caregiver. The role of caregiver is often one that is taken on out of necessity. It can begin slowly, with minimal involvement from you, and move into a more demanding role over time. A caregiver provides care to an individual such as a family member, friend, loved one or neighbor. The caregiving relationship is often unpaid and can require a great deal of sacrifice both in terms of time and finances. Reportedly, 85 percent of caregivers provide care to a relative.¹

It is estimated that 43.5 million Americans have provided care to either an adult or a child in the last 12 months. While a majority of caregivers are women, a significant number of men provide caregiving responsibilities as well.¹ An estimated 2 million individuals are living with an amputation.²

The statistics demonstrate that you are not alone on this journey. While there is no guidebook to teach you exactly how to be a caregiver, this booklet will walk you through

common themes frequently experienced by caregivers of an individual with an amputation. The topics include your role as a caregiver, caring for your loved one, intimacy and relationships, and caring for yourself. This booklet will also provide you with positive suggestions to identify and manage stress, provide guidance on steps to empower yourself as a caregiver, and teach you tips and tricks to manage inevitable stressors. Some topics may be relevant to your situation now or may become more appropriate as your journey progresses. Take notes, ask questions, and please feel welcome to reach out to the Amputee Coalition with any additional needs you might have.



● DID YOU KNOW?

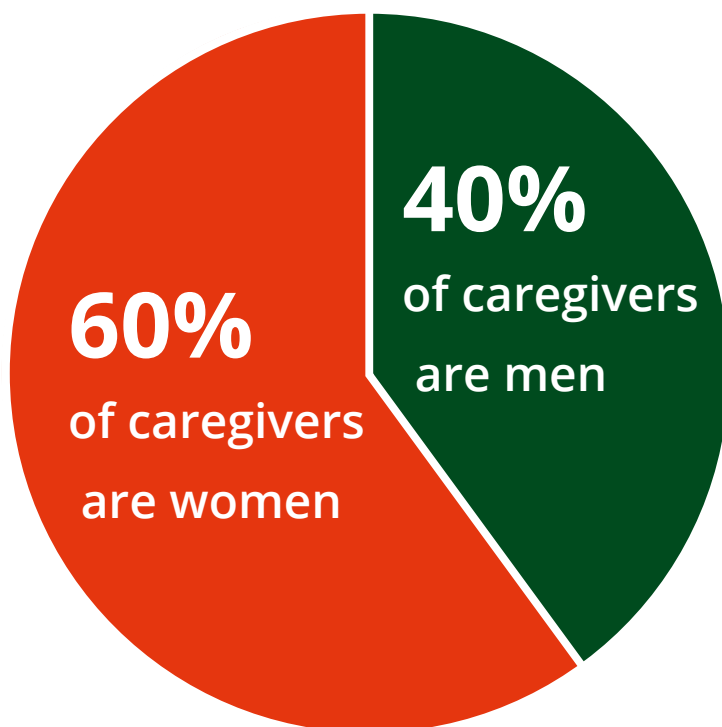


85%

of caregivers are caring
for a family member.

43.5 Million

Americans have provided
care in the last 12 months.



Source:

Caregiving in the U.S.: 2015 Update – AARP and National Caregiving Alliance

● BECOMING A CAREGIVER

Oftentimes, we stumble into our role as caregivers. Caregiving can become a necessity as our loved ones age and slowly lose their ability to perform general activities of daily living, such as transportation, meal preparation, bathing, dressing, etc. It may begin with assistance with just a few tasks and transition into more advanced levels of care. Some may find their role to be stressful while others are equipped with coping strategies to manage the increase in commitment and responsibility. Caregiving is a different experience for everyone, which also means differences in perceived burden and stress.

Your awareness of stress or burdens of caregiving can be related to how you became a caregiver. The slow, natural progression of the aging process can ease you into your role as a caregiver and you may not feel overwhelmed or burdened until the individual's needs increase.

Traumatic events quickly change the life of the individual with the amputation, as well as the lives of their loved ones, thrusting those involved into new roles. Stress may be much more apparent, as you have not had time to adjust to your role or prepare mentally for the amputation.

An amputation might also be the result of a long history of trying to salvage a limb due to cancer, injury, diabetes or vascular-related issues. While there has been a great deal of time and energy focused on preventing the amputation, you may or may not have had time to realize what your role entails after the amputation occurs. You may be familiar with an entirely different means of providing care to your sick loved one. Your role might change dramatically once the amputation has occurred and the needs are suddenly different from what you are used to.

People become caregivers for a variety of reasons. As the spouse or child of an individual with an amputation, your caregiving role may have begun out of devotion to your loved one. You may have made a conscious decision to be the provider of care. You might have merged into the role out of necessity or guilt as you are the only individual able to function in this role.

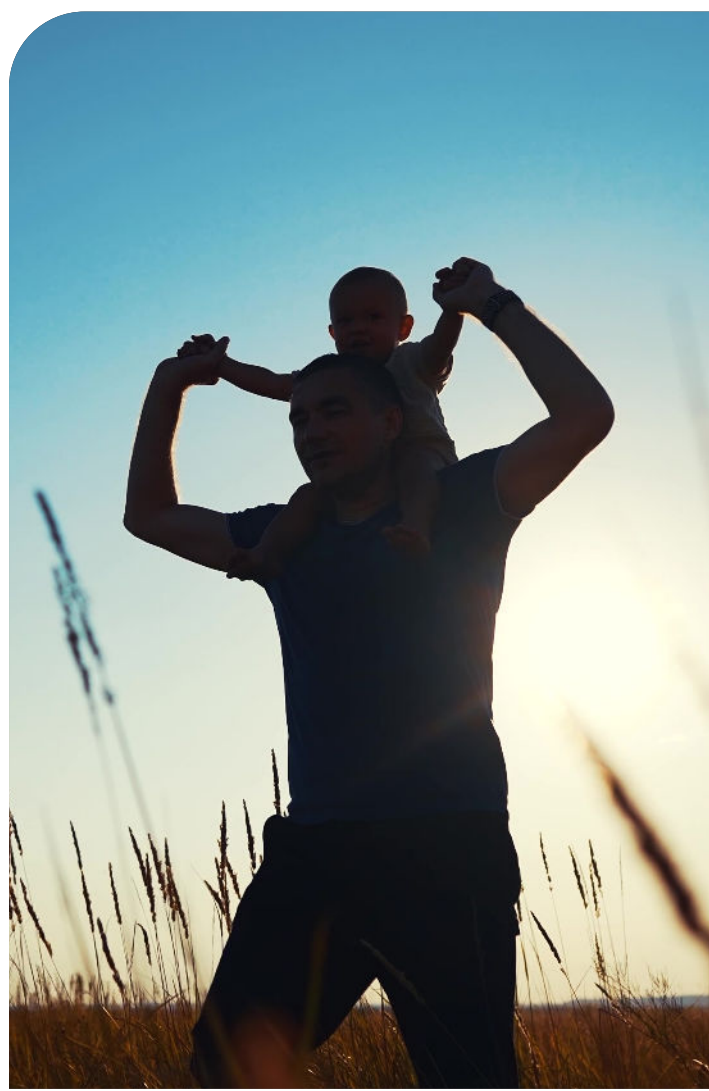
However you became a caregiver, it is important to recognize that the ripple effect of an amputation impacts family, friends, coworkers and all involved.

Sudden or gradual role changes can have a direct impact on the relationship you previously shared with your loved one and, naturally, the impact can be both positive and negative. The care recipient may require a great deal of hands on care and attention, which can make you feel as if your previously held role of spouse or child is being neglected. It is necessary to recognize these feelings in order to address them.

Role changes – such as that of a spouse to a hands-on caregiver or a transition to the sole breadwinner for the family – can create feelings of uncertainty, anxiety and anger. While it is normal to feel a roller coaster of emotions pertaining to the perceived loss of the relationship you had before the amputation, it is important to communicate with the care recipient about your feelings. You may find that you would benefit from communication with an outside individual, such as a support group or a counselor, to better understand your own feelings. Role changes do not mean an end to the relationship you had prior to the amputation but they do require attention to avoid snowballing into greater issues later on.

Why do individuals become caregivers?

- Choice
- Necessity
- Devotion
- Sense of duty and responsibility
- Financial concerns
- Guilt
- Past promises
- Merge into the role
- Need to be wanted



● CARING FOR YOUR LOVED ONE

A question often asked is “HOW do I provide care to an amputee?” This question is loaded with various subsets of questions and statements that may be running through your mind, such as “How do I provide wound care?” “I don’t want to overstep my bounds – how do I talk to my partner or parent about what they need from me?” “I feel a lot of responsibility and pressure to make sure my spouse/parent follows the instructions they were given by the doctors and therapists.” “I feel like my partner isn’t trying hard enough.” “My partner is completely reliant upon me.”

Sit down with a notepad and pen and jot down the thoughts and questions that are running through your mind. Take a look at any themes you might see in the questions you have written down. Your questions may center around a very specific area, such as wound care, or they may be much more general. Organize your list of questions and make note of where and from whom you might seek answers. If you are at a loss for who to turn to, take your list of questions to a healthcare professional, such as a prosthetist or physician. Contact the Amputee Coalition National Limb Loss Resource Center® to assist you in your journey to obtain answers.



- **Here are some general topics and recommendations to consider when becoming the caregiver of an individual with an amputation:**

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Communicate with your loved one about their needs, limits and expectations.

Communicate about your limits and needs as a partner and a caregiver. Talk with your partner about their needs, limits and expectations as the care recipient. How involved do they want or need you to be in doctor's appointments, daily activities (e.g., bathing, dressing and transportation), etc.? With a better understanding of what the needs are, you can begin to determine what is reasonable for you to take on yourself or what tasks might require you to seek assistance from others.

Both you and the care recipient may decide to establish boundaries for which your involvement is not needed in order to keep a healthy balance in your relationship. If your spouse or parent is uncomfortable with relying on you to provide assistance with a

specific task, such as bathing, talk together about what options you might have. Discuss the possibility of hiring an outside individual to assist or look into what assistive devices and additional training might be available in order for the care recipient to complete the task on their own. It may be difficult to isolate or anticipate what the needs will be, especially in the beginning. Continue to keep the communication lines open between you and your loved one. Open communication will allow you to address issues as they arise rather than bottling them up.



Seek specialized information in areas in which you feel you are lacking.

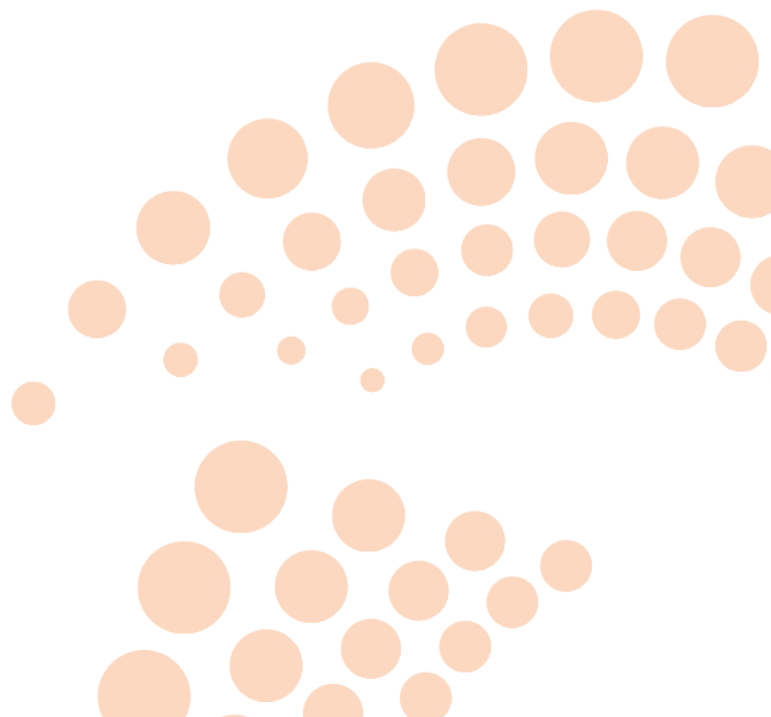
If your questions center around medical needs, such as caring for wounds post-surgery or how to assist with transferring or bathing, write your questions down and ask the hospital team before the individual is discharged. If the hospital or rehabilitation discharge has already occurred, call the primary care provider to find out how you might get your questions answered. If possible, the care recipient should be involved in the process. Discuss the materials you have received and the information you have learned. Remember that it is impossible for you to know all of the answers. Know your limits and seek help from those who specialize in the area. What might take you hours to research can often be answered in just a few minutes by a professional.

Balance roles and responsibilities.

Recognize that you are a partner first and a caregiver second. It is not your sole responsibility to provide care to your loved one. Your loved one must take responsibility

for their care and recovery. If you feel you are carrying much of the burden of the recovery process, share your feelings with the care recipient. If it is difficult for you to have this conversation on your own, seek assistance from a professional, such as a counselor, to allow an opportunity to safely discuss your feelings.

Talk together about a plan to achieve better balance in your responsibilities. It is important to continue to nurture the relationship you had prior to the amputation. Communicate your needs with your partner and work together as a team to ensure the needs are met. If unmet needs are discovered, work together to brainstorm how to meet those needs. Again, if this is too difficult to manage on your own, seek the help and experience of a professional.



- **Communicate with the individual you are caring for and be mindful of changing roles in your relationship.**

Can caregiving become enabling?

Yes, it can. It is very important that the individual with the amputation take an active role in their recovery process. Losing a limb is a traumatic experience. It is normal to provide love and support to your loved one but it should not transition into an enabling situation. While it may be easier to do something on behalf of your loved one, independence and taking ownership of the recovery is important to the recovery process as a whole and should be encouraged.

Encouragement vs. Overbearing

Recognize the difference between encouraging progress and becoming overbearing. Not only is it stressful for the care recipient to be pushed to reach recovery milestones, it can be stressful for you, as the caregiver, to feel that you need to push them harder than you perceive them to be working. Have a conversation with your loved one about how involved they want and need you to be in their recovery process. Set limits for yourself. Remember, the recovery process is dependent upon having buy-in from the care recipient. You can do many things for your loved one, but you are not solely responsible for making them better.



Recognize yourself as a partner first and a caregiver second.

This is a crucial step that can often be overlooked. You shared a relationship with the care recipient before their amputation. That relationship is still relevant and important to both you and the care recipient. You are still a spouse, child or other family member. Be mindful of your feelings and the feelings of your loved one, especially when you feel strain in other areas of your relationship. Take a step back and talk together about how to move forward positively. You may unintentionally neglect your relationship to avoid having such personal conversations, but the issues do not go away on their own. This is especially true if you feel guilty for having such feelings. You are an important piece in the recovery process. Your recovery is important too.

Work effectively with healthcare providers and the care recipient.

You will encounter many different healthcare disciplines as you work through the recovery process with your loved one. Talk with your loved one about the extent to which they

want you to be involved in communicating with these various professionals. It can be beneficial to have another person in the room to help understand and remember the information and advice that is given. However, your loved one may prefer that you not ask questions. You may also need to remind the healthcare professional to direct their questions and responses to your loved one.

The individual with limb loss should be empowered in their care. They need to be encouraged to take primary responsibility for their recovery. This includes all aspects of the recovery process and continual work with healthcare professionals, such as their prosthetist. Be careful not to feel that you need to police your spouse or loved one into following the advice of their healthcare providers. The primary responsibility for care needs to lie with the individual with limb loss.

The primary responsibility for care needs to lie with the individual with the limb loss.

● INTIMACY AND RELATIONSHIPS

Some individuals experience a severe reaction to their post-amputation body. Individuals who have recently lost a limb commonly experience body image and self-esteem issues. They may view themselves as less than desirable and project those feelings onto their partners, friends, relatives and strangers. They can shut themselves off to avoid the anticipated pain of rejection. Lack of intimacy and bottled-up emotions can negatively impact self-esteem and the recovery process. Mental recovery after an amputation is an important and crucial step in the recovery process.

It is important to communicate with your partner about intimacy. Be mindful that your partner may be experiencing a number of concerns such as a negative self-image, inability to perform due to pain or medication, and/or logistical concern about how to be intimate after an amputation. Communication and emotional support are essential to rebuilding the relationship and restoring intimacy. It is important for both you and your partner to communicate any concerns you might have. Open communication about insecurities can ease concern, allowing for a strong

and healthy intimate relationship to grow and develop. You may need to take time to re-explore each other and what it means to be intimate together after the amputation. After talking with one another, you may find it beneficial to ask specific questions to a healthcare professional.

In addition to changes in self-image, a shift in relationship roles can create confusion and blurred lines between being viewed as a caregiver and as an intimate partner. A shift or a reversal of roles such that might be required of a caregiver (assisting with bathing/dressing, assuming the responsibility of providing financially for your family) may create confusion and unsettlement about your role as an intimate partner. Communicate your thoughts and concerns with your partner and seek the assistance of others if necessary. Consider resources, such as books and peer support, that are available to you. If you are having difficulty in locating resources, contact the Amputee Coalition National Limb Loss Resource Center to help guide you in your search.

● COPING WITH STRESS OF CAREGIVING

While a rewarding experience, caregiving can also be the cause of a great deal of stress.

What causes caregiving stress?

- A change in living situation
- Economic hardships
- No relief or respite from responsibilities
- Continuous losses and changes
- Feeling of becoming captive in an unwanted role
- Juggling of multiple roles and responsibilities
- Day-to-day activities
- Decisions
- Physical caregiving
- Family conflicts
- Inability to meet own personal needs
- Changing roles and relationships



Some caregivers may not recognize their situation as stress-inducing or may feel guilty for admitting their stress. Stress can manifest itself in both physical and emotional symptoms.

To maintain a healthy lifestyle, it is critical that you remain aware of your stress level and the impact of events on your stress. In order to effectively care for your loved one, you must care for yourself. Take note of the symptoms you are experiencing. If there are avoidable circumstances that cause you to have heightened stress levels, consider rethinking your role in being a part of them. If stress is negatively impacting your mental or physical health, you should talk with your healthcare provider.

Do you recognize any of the following symptoms in your life?

Physical

- Elevated heart rate
- Dry mouth
- Muscle tremors
- Sweating
- Nausea, upset stomach
- Difficulty breathing
- Difficulty sleeping

Emotional

- Anxiety
- Depression
- Anger
- Frustration
- Fear
- Hopelessness
- Irritability
- Denial
- Guilt



Keys to Managing Stress

There are practical things you can do to manage stress. A good starting point is to improve your understanding of how stressors impact your life.

Change the Situation

Avoid the Stressor

Learn to say no when necessary. Know your limits and stick to them. This is important for both your personal and your professional life.

If someone consistently causes stress in your life, limit the amount of time you spend with that person or end the relationship entirely.



Take control of your environment by avoiding activities that add to your stress. For instance, if watching the evening news before you go to bed causes you stress, try switching to a different television program. Avoid arguing politics with a friend or coworker. If a specific hot button subject causes an argument every time, avoid the topic. Take a break from social media if you find you cannot pull yourself away from reading about the stress in others' lives. Prioritize your to-do list and distinguish between the "should" and the "must" events. Take responsibility to avoid any unnecessary stressors.

Alter the Stressor

When experiencing symptoms of stress, express your feelings instead of bottling them up. Communicate your concerns in an open and respectful way. Express your feelings before any resentment builds.

To effectively alter the stressor, it is sometimes necessary to be willing to compromise. If you are asking someone to change their behavior, you must be willing to do the same. Do your best to anticipate any problems so that you can deal with them head-on. It is important to manage your time as effectively as possible. Unplanned situations and events will arise but you can change their negative impact by managing your time and to do list. Know your limitations and be assertive when you have reached your limit.



Change your Reaction to Stress

Adapt to the Stressor

If the stressor cannot be avoided or altered, try to reframe how you think of the problem. Make a conscious decision to think positively about the stressor. For example, if you are stuck in a traffic jam, consider it an opportunity to regroup or to listen to an audiobook rather than using the time counterproductively to complain about the traffic.

If you are powerless to change the stressor, you do have the power to change how you react to it. Look at the big picture and take perspective of the stressor. How important will it be in the long run? Will it matter in a month or a year? If it is not worth getting upset over, focus your time and energy elsewhere.

You may find that you need to adjust your standards. Do not set yourself, or others, up for failure by demanding perfection. Set reasonable standards for yourself and those around you.



Accept the Stressor

In some situations, it is necessary to accept the unavoidable stressor you are faced with. Do not try to control the uncontrollable. Instead, focus on what you can control. It is within your power to control the way you choose to react to the problem.

Consider major challenges as opportunities for personal growth. If a poor choice or decision contributed to a stressful situation, reflect on it and learn from any mistakes that were made. Re-evaluate what might be done differently next time and you will be better prepared to manage the situation in the future.

One of the most difficult challenges you may ever face is learning to forgive. You must learn to forgive yourself as well as others for what has happened. Free yourself from negative energy by forgiving and moving on.

If you find it difficult to cope with the stressor you are faced with, consider talking to a trusted friend or make an appointment with a therapist to share your feelings. Discussing your thoughts and feelings can relieve pressure and help you to normalize your situation. Peer support can be a wonderful tool in recognizing that you are not alone in this caregiving journey.



Adjust to the Stressor

It is easy to forget that how you think can have a profound effect on your actual emotional and physical well-being. The mind is a very powerful instrument. If you are focused solely on negative thoughts, you may find that your stress level increases and you experience negative symptoms, such as a decrease in your ability to sleep or increasing anxiety. Try adjusting to the stressor by reframing your thoughts. Instead of focusing solely on the negative, reframe your thoughts into positive statements. For example, instead of complaining that “I probably only have 15 minutes to myself today!,” try saying, “I’m going to take 15 minutes for myself and take a walk today – with the phone on silent.” With practice, you will begin to think more positively about the various stressors in your life and might also begin to notice a positive impact on your emotional and physical well-being.

Avoid any self-defeating thoughts. Words such as “always,” “never,” “should” and “must” can be removed from your vocabulary. Recognize that you are doing the best that you can. Be aware of times when you are being critical of yourself. Remember that you are human and remind yourself of how far you have come.

Managing stress can feel like hard work. It is natural to feel as if you can skip a few steps toward feeling less stressed by picking up unhealthy habits. Be mindful of unhealthy habits to cope with stress.

Unhealthy Habits to Cope With Stress

- Smoking
- Drinking
- Over or undereating
- Withdrawing from friends, family, and activities
- Using pills, drugs or alcohol to relax
- Sleeping too much
- Procrastinating
- Taking out stress on others



Information accessed from:

[Helpguide.org/articles/stress/stress-management.htm](https://helpguide.org/articles/stress/stress-management.htm).

CARING FOR YOURSELF

One of the most difficult concepts to accept is that in order to care for others, you must make a commitment to care for yourself. Caregivers often neglect their own needs to focus more attention on the individual they are caring for. This can eventually have a negative impact on the caregiver's mental state, as well as their health. There are a number of ways you can incorporate healthy coping mechanisms by engaging in stress-reducing activities.

- **Increase your physical activity.**

This does not mean spending hours in the gym. Consider activities you enjoy and incorporate those activities in your daily 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. Get back to the task at hand when you are finished.

- **Incorporate activities you enjoy.**

Think back to activities you enjoyed before this period of stress began. Which activities can you continue to incorporate? Be careful not to overcommit yourself, as you can create unnecessary stress.

- **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.

- **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!

- **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, a lack of sleep can negatively impact your health as well. 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.

- **Nurture the relationship you have with yourself.**

Set aside time to unwind and regroup each day. Maintaining your sense of identity is important.

- Set aside “me” time.
- Connect with others. Spend time with friends or seek out a support group for caregivers. Peer support can be a powerful tool in your recovery process.
- Do something you enjoy every day.
- Keep your sense of humor – including laughing at yourself. You are human, after all.
- Accept help when it is offered and seek it out, if you need it.



For more ideas on how to incorporate de-stressing activities, call the Limb Loss Resource Center at 888-267-5669 or visit the Amputee Coalition’s Caregiver Resource page, [Amputee-Coalition.org/limb-loss-resource-center/resources-for-specific-groups/caregivers](https://www.amputee-coalition.org/limb-loss-resource-center/resources-for-specific-groups/caregivers).

Communicating Your Needs

Communicate with yourself about how you are feeling. Do a daily check-in and take note of how you are feeling and reacting. If you find yourself snapping at others or resorting to unhealthy coping mechanisms, seek help. Know the common signs of depression and learn to recognize them 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, communicate with your healthcare provider and request a referral to a mental health professional.

It is important to monitor your emotional health and it is OK to ask for help. You, and the individual you are caring for, may benefit from individual and/or joint sessions with a

professional therapist. Working with a professional can help you to work on establishing healthy communication about your wants and needs as both the caregiver and the individual receiving care.

Rather than bottling up your feelings and allowing them to fester, take an opportunity to share your feelings with others. Seek out and accept the support of well-meaning people.

Stay Organized

A key to managing stress is organization. You can avoid last-minute stress by organizing your calendar, paperwork and to-do lists to ensure they are readily available when you need them. Make sure that financial, legal and other medical records are organized and easily accessible.

Write down and prioritize your daily routine and eliminate anything unnecessary. Avoid over-scheduling yourself. Of course, situations arise and it becomes necessary to be flexible and change your priorities. A structured to-do list will provide a great visual tool to keep you on task and keep you from over-scheduling yourself.

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.

To maintain a healthy lifestyle, it is critical that you remain aware of your stress level and the impact of events on your stress.



● COMMUNITY AND SUPPORT RESOURCES

Finally, one of the most important hurdles is to recognize when additional help is needed. There are many community and support resources. Check with your local community offices, such as City Hall or a Senior Center, to determine what services might be available in your community.

If you have additional questions about educational materials, programs or information on caregiving, contact the Limb Loss Resource Center at 888-267-5669 or visit the Web page at Amputee-Coalition.org/limb-loss-resource-center/ask-an-information-specialist. The Amputee Coalition's resource specialists are waiting to connect you to the help you need.

Community Resources

Aging and Disability Resource Centers (ADRC)

An ADRC serves older adults, individuals with disabilities, 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.

- Find your local ADRC at: Eldercare.acl.gov/Public/Index.aspx

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.

- Find more information at aoa.acl.gov.
- You can search for a local AAA by calling 202/872-0888 or visit: N4A.org.

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.

- Search for your local Center for Independent Living in the ILRU Directory: ILRU.org/projects/cil-net.

Vocational Rehabilitation

Vocational Rehabilitation offices help individuals living with a disability to prepare for and find employment. They typically offer job counseling, training, assistive device technology and support services.

- Search for your local Vocational Rehabilitation office at: Askjan.org/concerns/State-Vocational-Rehabilitation-Agencies.cfm

Local Amputee Support Group

The Amputee Coalition maintains a network of support groups across the country. Support groups are run by volunteers and vary in the types of programs they provide. Some support groups are open to caregiver participation.

- Search for a support group in your area: Amputee-Coalition.org/support-groups-peer-support/support-group-network.

Virtual Support

If you are unable to locate a support group in your area, or if you are not yet comfortable venturing out for support, try exploring avenues for virtual support. One of the many benefits of virtual support is that you do not need to leave your home to participate.



Facebook Community

The Amputee Coalition operates a large Facebook group offering virtual support to individuals with limb loss and those who care for them.

- [Facebook.com/AmputeeCoalition](https://www.facebook.com/AmputeeCoalition)

Peer Visitation

The Amputee Coalition has a robust community of certified peer visitors across the country. Peer visitation offers tremendous

benefit and helps to normalize the recovery process. No one knows what you are going through like another individual who has lived through a similar experience. Call the Amputee Coalition at 888-267-5669 to see whether a caregiver peer visit might be available.

- For more information about the program, visit: [Amputee-Coalition.org/support-groups-peer-support/certified-peer-visitor-program](https://www.Amputee-Coalition.org/support-groups-peer-support/certified-peer-visitor-program).



● CAREGIVING SUPPORT RESOURCES

Amputee Coalition NLLRC Resources for Specific Groups: Caregivers

[Amputee-Coalition.org/limb-loss-resource-center/resources-for-specific-groups/caregivers](https://amputee-coalition.org/limb-loss-resource-center/resources-for-specific-groups/caregivers)

Caregiver Action Network [Caregiveraction.org](https://caregiveraction.org)

Eldercare Locator [Eldercare.acl.gov/public/index.aspx](https://eldercare.acl.gov/public/index.aspx)

Family Caregiver Alliance National Center on Caregiving [Caregiver.org](https://caregiver.org)

Caring.gov Caregiver Resource Center [Caring.com/caregivers](https://caring.com/caregivers)

National Alliance for Caregiving [Caregiving.org](https://caregiving.org)

National Council on Independent Living [NCIL.org](https://ncil.org)

HHS.gov Caregiver Resources [HHS.gov/programs/providers-and-facilities/resources-for-caregivers/index.html](https://hhs.gov/programs/providers-and-facilities/resources-for-caregivers/index.html)

Intimacy for Wounded Veterans: A Guide to Embracing Change

by Kathryn Ellis and Caitlin Dennison

References

1. Caregiving in the U.S.: 2015 Update - AARP and National Caregiving Alliance.
2. Ziegler-Graham K, MacKenzie EJ, Ephraim PL, Trivison TG, Brookmeyer R. Estimating the prevalence of limb loss in the United States: 2005 to 2050. Arch Phys Med Rehabil, 2008 Mar; 89(3):422-9.

About the Amputee Coalition

The Amputee Coalition is a donor-supported, voluntary health organization serving the nearly 2 million people with limb loss and more than 28 million people at risk for amputation in the United States.

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