

# SCAD Caregivers

If you are helping someone who has experienced a spontaneous coronary artery dissection (SCAD) with her or his daily needs, you are a caregiver. You may be a spouse or partner, a parent or child, an in-law, a friend or a neighbor. The person receiving your caregiving may need a lot of support or occasional support and the need may change over time. You may not think of yourself as a caregiver but instead as someone who is “just helping out” What you are doing, however, is extremely important. Your caregiving can be both rewarding and difficult, wearing on you physically and emotionally, but there are many things that you can do to make caregiving easier.



## Caregiver Strategies

- ♥ Acknowledge to yourself the one you are caring for has the right to make her or his own decisions.
- ♥ Do only those things that she or he cannot do.
- ♥ Be prepared to follow through on what you promise to do. Often those who receive care find it difficult to depend on others and worry about being a burden.
- ♥ Speak from the heart with encouragement, understanding that the SCAD survivor may not always be able to be positive. Acknowledge and support their moments of legitimate fears, pain, sadness, and grief.
- ♥ SCAD survivors may experience cognitive issues, sometimes referred to as “brain fog.” Typically, it is a short-term issue but you should be aware and understanding if they cannot remember things or seem confused.
- ♥ Be sensitive and ask permission as to what information you share or post on social media. The SCAD survivor may not want others knowing some or all of their personal situation.
- ♥ Although many SCAD survivors experience a heart attack, do not compare them to a “classic” heart attack survivor as their experience is likely to be very different.
- ♥ Take care of yourself and schedule time to give yourself a break. If you become exhausted, you are likely to make poor decisions or take frustrations out on the one you care for.
- ♥ Don’t be afraid to reach out for help.
- ♥ If there are multiple caregivers, remember that each person may manage and cope with caregiving differently. Try to be open with communication and support each other.
- ♥ Get all appointment logistical questions answered ahead of time including medical provider’s name, appointment location, parking information, documents/information needed at or in advance of the appointment, etc.
- ♥ Help prepare running lists of questions for the health care team between appointments.

## Caregiver and SCAD Survivor Conversations

Below are examples of questions that you could ask when beginning as a caregiver to set boundaries and expectations. These questions will need to be readdressed as the SCAD survivor's health and needs change.

- ♥ Would you like your healthcare team to share medical information with me? If yes, clarify which provider(s) should be included and have the SCAD survivor complete a release form for each healthcare provider.
- ♥ Who is the main contact person for each member of the healthcare team? What is their contact information?
- ♥ Who will schedule appointments and does this differ for appointments with different members of the healthcare team?
- ♥ Will you need assistance with transportation to medical appointments?
- ♥ Do you need assistance with managing your medication (remembering to take medication, creating/completing a medication schedule document/app/phone reminder, picking it up at the pharmacy, renewing prescriptions with doctors or filling a daily/weekly pill sorter)?
- ♥ What daily/weekly/monthly tasks do you need assistance with? What specific parts of those tasks can I help you with and what do you want to complete yourself?
- ♥ Do you have a Health Care Proxy and/or Advanced Directive? If not, could I help you get it created? If so, does it need to be updated? Where can I find copies of these documents?
- ♥ What is the best way for us to communicate (when I am with you in person, by phone, text, email, etc)?
- ♥ Are you comfortable about telling me when you need space or are feeling overwhelmed? What signs should I be aware that would indicate that you may need some space or that you are feeling overwhelmed?
- ♥ Is there anyone you would like me to share your needs and/or experience with? Is there anyone you would like me not to share your needs and/or experience with? How would you like that information communicated or not communicated (phone, email, caregiver app, webpage, social media, etc).
- ♥ If there is more than one caregiver, clearly define and communicate who will be responsible for each task. If tasks are shared, create a clear schedule of who is responsible on what date and/or time.

## Being a Caregiver for Your Significant Other

You and your significant other may find that your relationship dynamics change at least for a short time following a SCAD. The aspects of the relationship may not be as equal, defined or consistent as they were before. If the SCAD patient has to stop working or completing household/family tasks, she or he may feel guilty. You may feel more of the daily task burden in addition to carrying the new tasks of being a caregiver. Do not hesitate to ask for help from another caregiver to relieve some of your burden.

Experiencing a SCAD, both for the SCAD survivor and significant other, can make intimacy a challenge. If you are a caregiver for a romantic partner, know that intimacy and sex may change after a SCAD event. Ask the cardiac healthcare provider if it is safe for your loved one to engage in sexual activity and inquire if extra precautions are needed because of healing, treatment or possible pregnancy. Be open and discuss this topic with each other, the healthcare team, and if necessary, consider speaking with a mental health provider/therapist individually and/or as a couple.

Routinely set aside time to simply be with your loved one, setting a boundary that you are not providing caregiver tasks or discussing care needs but only enjoying each other as a couple.

## Being a Caregiver for Your Parent

It may be a significant role reversal and may initially feel odd to become a caregiver to your parent. The parent SCAD survivor may also be reluctant to accept care from you and may perceive herself or himself as a burden to you. The parent may struggle with losing independence and feel guilty.

As a caregiver stress may occur in your relationships with your significant other or your own children as more of your time is devoted to your parent. Routinely set aside time simply to be alone with your significant other so that you can focus on one another - not your parent.

If you have young children, be aware and understanding that your co-parent may be taking on more of the childcare responsibilities while you are focused on caring for your parent. This potentially could lead to exhaustion, frustration and resentment. Ask family and friends to help with childcare so that these responsibilities do not all fall to one parent, you, as you are providing additional SCAD patient care for your parent.

If you are a young adult or adolescent caregiver, it is especially important to care for your own wellbeing and mental health. Communicate with your parent(s), healthcare providers, community resources, family, friends, etc. to obtain the support you need. Do not hesitate to ask for help or, seek mental health care, and be sure to take time for yourself.

## Feeling Overwhelmed?

This is a sensory awareness grounding technique that can help you relax or work through difficult emotions. To yourself, name the following:

- ♥ 5 things you see in the room
- ♥ 4 things you can feel
- ♥ 3 things you hear right now
- ♥ 2 things you can smell right now or think of 2 smells that you enjoy
- ♥ 1 favorite thing about yourself

At the end you should feel calmer and more present. Repeat these steps when needed.

## Self-care

Making sure you are routinely caring for yourself is important for healing and maintaining health. Self-care is:

- ♥ Taking action to maintain or improve your physical and mental health, especially during periods of stress
- ♥ Creating a support system by calling upon family and friends when you need help or someone to simply listen to you
- ♥ Responding to your needs with compassion and care
- ♥ Practicing mindfulness
- ♥ Intentionally doing activities that you enjoy to improve your mood and lower your stress
- ♥ Prioritizing actions and emotions that boost how you feel about yourself
- ♥ Taking a break
- ♥ Eating well - don't forget to eat a well-balanced, healthful diet
- ♥ Having a place that you can go for personal space and time
- ♥ Setting aside personal time to get your most important tasks completed
- ♥ Maintaining proper healthcare for yourself including medical and dental appointments, and by taking your medications as prescribed
- ♥ Staying connected to your social network even if you need to cut back on your social activities
- ♥ Seeking a connection with those who have had similar experiences, such as a support group
- ♥ Routinely participating in some form of exercise
- ♥ Trying to get a healthy amount of sleep each night and/or rest throughout the day

## Mental Health

Mental health, like physical health, is important to your overall well-being as a caregiver. After a loved one experiences a SCAD, feelings of sadness, anxiety, anger, fear, irritability, and/or moodiness are normal. However, if these feelings are interfering with your daily life or if you have a sense of hopelessness, please seek support. Talk to members of your own healthcare team about your mental health. You may benefit from the support of a medical health professional, such as a therapist or counselor, or in some cases, medication to help with depression or anxiety.

Do not be afraid to ask for help! Reach out to your physician or call your insurance provider for a mental health referral. If you are having difficulty coping and are experiencing a mental health crisis, contact the 988 Suicide and Crisis Lifeline by calling or texting 988.

## The SCAD Toolbox

- ♥ For more information on Spontaneous Coronary Artery Dissection visit the SCAD Alliance website at [scadalliance.org](http://scadalliance.org)
- ♥ For links to support groups visit [scadalliance.org/get-support/#online-support-groups](http://scadalliance.org/get-support/#online-support-groups)
- ♥ For more information on participating in the iSCAD Registry or to find a SCAD specialized doctor visit [www.scadalliance.org/iscad-registry/](http://www.scadalliance.org/iscad-registry/)