

CHARTING YOUR COURSE

A Guide for Caregivers of People Living with LVADs

PART THREE:

*Being a Partner
in Symptom Management*



BEING A PARTNER IN SYMPTOM MANAGEMENT

In supporting someone who has an LVAD, you may need to help this person manage his or her symptoms. In addition, it is normal for you, too, to experience a variety of symptoms and other feelings as you run the caregiver marathon. Symptoms are feelings or experiences that can be your body's way of saying that something isn't quite right. Symptoms can affect how you feel physically, emotionally, socially, and spiritually.



Ask the person you care for which symptoms are most bothersome.

Keeping track of symptoms can help you gain some control. Communicating with the health care team about bothersome and new symptoms will help them figure out how to help.



PHYSICAL AND EMOTIONAL HEALTH

Physical symptoms such as pain, fatigue, swelling, cough or congestion, difficulty breathing, dizziness, and loss of appetite can impact your loved one's ability to do the things he or she normally does.

You should call your health care team if the person you care for:

- Has pain
- Has trouble catching their breath even while resting
- Suddenly gets an irregular or very fast heartbeat that causes dizziness or nausea.
- Gains 3 pounds or more in two to three days
- Is coughing up foamy pink spit
- Has new chest pain or pressure
- Falls and has an injury
- Is seriously considering stopping medical care

Specific symptoms to look for in people with an LVAD:

- **Bleeding:** black, tarry stools, red blood during a bowel movement, coughing or vomiting blood, nosebleeds
- **Infection:** redness or discharge around the driveline, confusion, fever
- **Stroke:** trouble with balance or coordination, trouble with speaking, sudden numbness or weakness, changes in vision

▶ **ACTIVITY:** *Help Your Loved One Identify and Track Symptoms*

One way to identify and track symptoms is to use a log like the one below. Practice filling out the log with recent symptoms your loved one may have had.

<i>Date/Time</i>	<i>Symptom</i>	<i>When did it start and stop?</i>	<i>What things made this symptom better or worse?</i>	<i>Medical information at time of symptom</i>
EXAMPLE: 8/17/2020 8:30 AM	EXAMPLE: Shortness of breath	EXAMPLE: 2 days ago, still a problem	EXAMPLE: Better: Sitting up with pillow Worse: Walking up stairs	EXAMPLE: Blood pressure, weight, glucose, INR

There are also great apps and online resources to track symptoms. One recommended app is the Heart Failure Society of America Heart Failure Storylines available for free on Apple (<https://apps.apple.com/us/app/heart-failure-health-storylines/id1062725794>) and Google (<https://play.google.com/store/apps/details?id=com.selfcarecatalyst.healthstorylines.hf&hl=en>)



How to Talk to Your Loved One's Health Care Team About Their Symptoms

- Encourage your loved one to communicate their symptoms to their doctors and nurses.
- Make lists of questions and concerns before you visit the doctor or nurse. Have those lists with you during your visit.
- Write down what the doctor or nurse says or bring a tape recorder.
- When describing symptoms to doctors and nurses, here are a few tips on what to say:
 - Give them a basic description of the problem—one to two sentences should do it.
 - Tell them when and how often your loved one experiences the symptoms.
 - Let them know if anything makes the symptoms better or worse.
 - Tell them if your loved one has ever experienced the symptoms before.

EMOTIONAL, SOCIAL, AND SPIRITUAL SYMPTOMS EXPERIENCED BY YOU AND YOUR LOVED ONE



Emotional symptoms such as anxiety, depression, and grief are all things commonly experienced by people with heart failure and their caregivers.

For people with an LVAD, other symptoms may affect their daily life such as:

- Body image issues
- Acceptance of the LVAD as part of them
- Regret with decision to get an LVAD
- Adjustment to a “new normal”

These symptoms commonly occur after implant and lessen over time, but may continue for some patients the entire time with an LVAD.



ANXIETY

- Anxiety is a common and normal response to new or stressful situations.
- Caregivers of patients with LVADs have reported very high levels of anxiety in some studies.
- When someone is anxious, they may also feel physical symptoms like upset stomach, trouble breathing, fast heart rate, headaches, or sweaty palms.
- Anxiety may not go away completely. But, people can learn things to manage anxiety so that it is not seriously decreasing their quality of life.



DEPRESSION

- When a person is sad, discouraged, gloomy, or hopeless for several weeks or months – and when these feelings interfere with being able to manage day-to-day affairs – we say that he or she is suffering from depression.
- When someone is depressed, they may feel symptoms like difficulty sleeping, lack of energy to do things, difficulty paying attention, and changes in eating (more or less).
- Some depression is a normal response to the stresses that come with illnesses.
- People can reduce and manage depression so that it is not seriously decreasing their quality of life.



You should call your health care team if you or your loved one is having anxiety and/or depression that is interfering with daily activities or is very upsetting to you or your loved one.

You should call your health care team or 911 immediately if you or your loved one are thinking of harming yourselves or others.

SYMPTOMS EXPERIENCED BY CAREGIVERS

Caregivers can experience physical symptoms related to their caregiving responsibilities.

Be sure to take care of yourself so that you are able to take care of your loved one. This includes ensuring enough sleep, good nutrition, taking time for yourself, and seeing your own health care team.

Burden



Burden is a major challenge experienced by caregivers. Burden can be due to many things like:

- Increased responsibilities and tasks
- Social isolation
- Financial strain
- Loss of former identity
- Decreased quality of life

Rewards



Caregiving can cause a lot of negative symptoms, but caregivers of people with LVADs have also reported positive symptoms such as feelings of accomplishment, satisfaction, and meaning.

Grief and Loss

- Grief is a natural response to loss. It's the emotional suffering someone feels when something or someone you love has been taken away. The more significant the loss, the more intense the grief can be.
- Feelings of grief can be due to things besides the death of a loved one, including: loss of the ability to do things you could do before, loss of health, loss of a job, loss of a friendship, and a loved one's serious illness.
- Everyone grieves differently. There is no "normal" timetable.

▶ **ACTIVITY:** *Identifying Losses, Strengths, and Resources*

It is sometimes helpful to recall earlier significant losses in your life to help you cope with a new loss. Allow yourself to remember the feelings around those experiences as you list them. Then list the resources that you depended on in order to cope with those losses.

Fill in the chart below with some of the new losses you are experiencing as a caregiver, and provide some strengths and resources for coping with those losses.

<i>Losses</i>	<i>My Strengths and Resources</i>
EXAMPLE: Time to myself	EXAMPLE: Calling friends and family to help with my loved one so I can do an activity I enjoy



Change in Relationship

People with LVADs and their caregivers have reported relationship changes. These can be normal in the process of becoming a caregiver and adjusting to a new way of life.

Some common changes experienced:

- Communication challenges
- Suppression of symptoms and feelings
- Conflict or resentment
- Effects on relationship quality - can be strengthened or stressed
- In couples, changes in sexual relationship

Spirituality

Spirituality is a broad concept that includes all the ways we look to find meaning in life. It is an expression of how a person relates to a larger whole, be it God, a higher power, family, or an aspect of nature.

- Communicating with the health care team about your loved one's spiritual beliefs can help them understand preferences, concerns, and wishes.
- Be aware of your feelings around spirituality and how it affects caregiving.
- Taking time to think about the 'Four R's' can help bring meaning to life:
 - **REMEMBERING:** Reflect on your life and its events, accomplishments, relationships.
 - **REASSESSING:** See your life as a whole.
 - **RECONCILING:** Forgive yourself; be at peace with yourself.
 - **REUNITING:** Be at peace with loved ones.



▶ ADDITIONAL RESOURCES

- **Animation of Heart Failure (AHA):**
 - <https://watchlearnlive.heart.org/index.php?moduleSelect=hrtflr>
A short animation on the pathophysiology of heart failure for patients and caregivers.
- **Self Check Plan for Heart Failure Management (AHA):**
 - <https://www.heart.org/-/media/files/health-topics/heart-failure/hf-symptom-tracker.pdf?la=en>
A 1-page PDF which provides green, yellow, and red zones for patients' symptoms.
- **Healthier Living with Heart Failure: Managing Symptoms and Reducing Risk (AHA):**
 - <http://ahaheartfailure.ksw-gtg.com/publication/?m=46677&i=461880&p=1>

50-page interactive web-based PDF that includes 7 chapters:

1. Understanding Heart Failure
2. Heart Failure's Effects on the Body
3. Making Healthy Eating Choices
4. Making Health Lifestyle Changes
5. Treating Heart Failure: Taking Medications
6. Other Heart Failure Treatment Options
(small paragraph on LVADs on page 41)
7. Living Well with Heart Failure

For more caregiver support resources, including a discussion board to connect with other caregivers and ask questions, visit:
<https://patientdecisionaid.org/lvad-caregiver-support/>