

CHARTING YOUR COURSE

A Guide for Caregivers of People Living with LVADs

INTRODUCTION:

*Background to
the Resources*



WELCOME

Living with an LVAD can be stressful... and not just for the patient but also for caregivers, families, and loved ones.

We can help you take steps to lower stress and make the best of things. We want to provide you with coaching and guidance to navigate the challenges you currently face and prepare for those that lie ahead.

The resources provided will help address different aspects of caregiving. The four parts can be viewed on their own and contain activities to help you get the most out of the content.



Summary of Booklet's Contents

Introduction: Background to the Resources

Part 1: How to Handle Problems

Part 2: Taking Care of You

Part 3: Being a Partner in Symptom Management

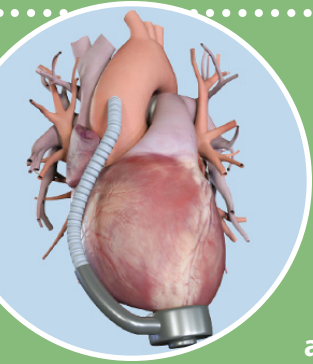
Part 4: Talking About What Matters Most and Making Choices

▶ WHAT IS SUPPORTIVE CARE?



- Supportive Care is specialized care for people with serious illness. It provides an extra layer of support. It focuses on providing individuals with the highest quality of life possible for as long as possible—whatever the diagnosis.
- It is appropriate at any age and at any stage in a serious illness.
- It can be provided at the same time as heart failure care.
- Want to learn more? Visit: [getpalliativecare.org](https://www.getpalliativecare.org)

▶ WHAT DOES CARING FOR SOMEONE WITH AN LVAD LOOK LIKE?



Caregiving for someone with an LVAD means learning new skills and changing your way of life. Caregiving duties can be different for everyone, depending on how well the person does with the LVAD. For some, caregiving is a full time commitment that will last for many months or years. Along with using existing caregiving skills for heart failure management, caring for an LVAD also requires learning the controller alarms and response, battery care, and driveline dressing changes. And if complications occur, even more responsibilities can arise. All of this can be a lot for someone to take in.

However, you are not alone. These resources can help you learn how to engage people around you with what you are going through. Your family, friends, and your loved one's health care team all want to be there for you and your loved one.

▶ HOW DO THESE RESOURCES WORK?

1. THE TOOLS



This guide has four parts. Each part has information about topics that can help you take control of your situation. Topics include:

- How to stay healthy and take care of yourself.
- How to manage your loved one's symptoms.
- How to link with community resources in your area.
- How to cope with serious illness and solve problems.
- How to make decisions that take into account what matters most to you and your loved one.
- How to communicate with health care providers and family members about your loved one's health.

Activities within each part can help you think through each topic. Practice the activities, discuss them with others.

2. THE COACH



At some programs, a specially trained coach may work with you to go over the topics in this guide. They may invite you to share your own thoughts and experiences. They can help you work on challenges you are facing, no matter how big or small. These interactions may occur one-on-one over the phone or through in-person or virtual support group settings.