



# CAREGIVERS' GUIDE

WHAT YOU SHOULD KNOW  
ABOUT CARING FOR A  
LOVED ONE WITH AN LVAD





*"My family is all local, and I like the idea of having them here for moral support."*

# IF YOUR LOVED ONE DECIDES TO GET AN LVAD, IT WILL MEAN BIG CHANGES IN BOTH OF YOUR LIVES.

Your loved one will need a lot of help from you with daily activities in the first few weeks after he or she returns home. And even after that, caregivers continue to help with things like cleaning the driveline site and managing medical appointments.

Caregiving may get easier over time as your loved one feels better and develops more independence. You may also find that it gets easier as you and your loved one adjust to the new routines of life with an LVAD.

But there will also be new challenges over time. For example, most people with LVADs have to go back into the hospital within the first year after surgery because of medical complications.

We can't tell you exactly what life with an LVAD will be like. It's different for every patient. But we can share advice from current caregivers based on their own experiences.

## LEARN AND ENGAGE

- Read the other parts of this kit to learn what to expect during LVAD surgery and recovery and after your loved one comes home.
- Attend as many doctor visits as you can with your loved one.
- Build a good relationship with your doctors and LVAD team. They are there for you and understand the difficulties you might face.
- Ask your healthcare team questions and work with them to set up timelines and goals for your loved one's improvement.
- Learn as much as you can about how the LVAD works.
- Talk with staff at places like your local energy company, local clinics, and doctors offices that might not be familiar with the LVAD. Their services – or lack of services – could affect you in an emergency. If needed, plan ahead for alternatives.

### GET SUPPORT

- You'll probably need help from a backup caregiver at some point. Arrange this backup support well before you need it.
- If you have children, involve them in caregiving in ways that work for you and your family.
- Some caregivers and patients find that communities of faith and prayer provide comfort, hope, and support.
- Find online or local support groups for LVAD caregivers. There are many active ones.

### PAY ATTENTION TO YOUR OWN NEEDS, TOO

You can provide the best care for your loved one when you take care of yourself, too. Here are some ways to do that.

- You might experience mixed emotions as a caregiver. You may feel grateful for more time with your loved one while also feeling stress, fatigue, resentment, and frustration. Prepare now for times that you feel negative emotions. Think about how you can handle these feelings. For example, "When I start to feel overwhelmed, I will give myself some quiet time or read something inspiring."
- Give yourself time and space to vent your emotions instead of letting them build.
- Make time for your own hobbies and interests. Even a quick, simple activity can make a real difference. For one caregiver, going to garage sales and getting a coffee and a doughnut every Saturday morning was a welcome time to herself.
- If necessary, talk to your employer about taking time off or working from home.

### FOCUS ON THE BIG PICTURE

- Many caregivers say they are motivated by reminding themselves about their loved one's reasons for getting an LVAD.
- Sometimes it helps to accept that your life has changed. Things won't go back to how they were before your loved one received an LVAD. Accepting that changes are a part of life with the LVAD helps you prepare for them.
- Remember that your loved one's mood and behavior don't always reflect his or her feelings about you. People with LVADs might be in pain or discomfort. Or they might feel stressed, guilty, anxious, or self-conscious about their body and appearance. All of this can affect how they act toward others.
- Some caregivers say that the their biggest message for other caregivers is not to be afraid. They say that caring for someone with the LVAD is doable, and not as hard as it first seems.





## MORE RESOURCES FOR CAREGIVERS



*DECIDING TOGETHER*, THE MAIN BOOKLET IN THIS KIT, HAS LOTS MORE USEFUL INFORMATION FOR CAREGIVERS.

The **More Resources** section of that booklet can tell you where to find

- more information about the LVAD
- organizations that help caregivers
- information about home health services
- help covering medical costs

*"Be prepared for mood swings. Be prepared for frustration. But the main thing is to try to have patience because just like anything else it takes getting used to."*

# QUESTIONS FOR CAREGIVERS TO ASK

Now that you've read more about being a caregiver, think about what questions you have and what you need more information about before your loved one's LVAD surgery. Here are some ideas for questions to ask.

How much time will I spend daily on caregiving? How will that change over time?

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When I have questions about the LVAD, whom should I contact?

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What should I do if we need to hire someone to help with caregiving?

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How can we get help paying for additional help with caregiving?

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What helps in dealing with the stress of being a caregiver?

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*"I had to kind of pull back – instead of wanting to do everything for him, I let him do more himself."*

*"At first we were scared, but taking care of the LVAD becomes part of a routine. You adjust to a new normal."*

MY OTHER QUESTIONS ABOUT BEING A CAREGIVER ARE:

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NOTES:

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*"Talk to other caregivers about how they cope – because it's not just physical, it's emotional too."*

## LEARN MORE

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### PATIENT & CAREGIVER STORIES

LVAD patients and caregivers share what living with the device has been like for them in the **Patient & Caregiver Stories** section of *Deciding Together*, the main booklet of this kit.



### MORE INFORMATION ONLINE

For videos of patients and additional information about this kit, visit the LVAD Decision Aid website at **[lvaddecisionaid.com](http://lvaddecisionaid.com)**