



DECIDING TOGETHER

A STEP-BY-STEP KIT
TO HELP YOU AND YOUR
FAMILY MAKE CHOICES
ABOUT AN LVAD AND YOUR
END-STAGE HEART FAILURE

YOUR DECISION STARTS HERE

*You're facing a big decision right now.
It will affect the rest of your life. Your heart is failing.
It will most likely become weaker, resulting in a backup of fluid into your lungs
and decreased blood flow to the rest of your body.*

Your healthcare team has recommended an LVAD (Left Ventricular Assist Device) as an option for you. You have to decide whether to have surgery to get an LVAD or to continue to manage your heart failure with medication. Both options have risks, benefits, and challenges. There is a choice that's right for you and the people close to you.

Talk about your options with your loved ones and with your medical team. This kit can help you with those conversations. It will give you the facts you need to make an informed decision.

YOU WILL LEARN:



- What an LVAD is
- How an LVAD might affect your health
- What happens during LVAD surgery and recovery from surgery
- What it's like to live your daily life with an LVAD
- What it's like to be a caregiver for someone with an LVAD
- What it means to choose medication management for your heart failure instead of getting an LVAD
- You will also find tools here to help you make your decision based on what's most important to you.
- Your values are the most important thing to consider as you make a decision.
- This kit is divided into different parts so that you and the people who are supporting you can look at it together and talk about your decision.

MORE INFORMATION ONLINE

For videos of patients and additional information about this kit,
visit the LVAD Decision Aid website at lvaddecisionaid.com

ABOUT HEART FAILURE

*"My heart was not getting better and it will never get better.
The medications were not working anymore."*

WHAT HEART FAILURE IS

It's time to make some serious decisions. Your heart is failing to do what it needs to. It no longer can pump enough blood through your body. Blood carries oxygen and nutrients to the body. Without enough blood flow, your body doesn't get enough of what it needs to stay alive. Parts of the body – such as the kidneys or liver – start dying. People cannot continue living when major organs such as the kidneys or the liver stop working unless they receive therapy.

As the heart gets weaker, it pumps less and less well. Your heart is now in end-stage heart failure. This means that it has arrived at the end of its life. It will become weaker and weaker over time. Heart failure is not any one thing; rather, it is a group of worrisome signs. Most people with this stage of heart failure have shortness of breath either at rest or with light exertion and can feel fatigued.

HOW YOU GET HEART FAILURE

CORONARY ARTERY DISEASE

Sometimes end-stage heart failure is the result of blocked arteries.

HYPERTENSIVE HEART DISEASE

Sometimes high blood pressure, which puts a lot of stress on the heart, leads to heart failure.

OTHER CAUSES

Sometimes people are born with weak or incorrectly formed hearts. Viruses and pregnancy can cause heart failure, though this doesn't happen often.

People arrive at end-stage heart failure in different ways.

The cause of your heart failure can affect your treatment. It will also affect what will happen if you get an LVAD.

HOW HEART FAILURE FEELS

You may have the following:

- shortness of breath
- swollen legs
- feeling weak
- feeling lightheaded or confused

You may be taking medicines that treat these symptoms and make you feel better. Your medicine may make you feel better, but you may not be getting better. Even if your medicine makes you feel OK, you may still be in end-stage heart failure. You still need to make a decision about what to do next.

OPTIONS FOR TREATING END-STAGE HEART FAILURE

You have three main options for addressing end-stage heart failure. They are:



Your doctor may recommend that you get an LVAD. If so, this kit provides you with an overview of that treatment.

"I was going normally as usual after I found out about my heart condition. But recently I started progressively getting worse and got put in the hospital."



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ABOUT THE LVAD

WHAT IS AN LVAD?

LVAD stands for Left Ventricular Assist Device. An LVAD helps the heart pump blood through the body.

An LVAD does not cure heart failure. It does not replace the heart, and it's not an artificial heart. It is a device that attaches to the heart.

It's possible that a patient's heart might be able to repair itself while it is attached to an LVAD, but this is extremely rare. It only happens 1% of the time.

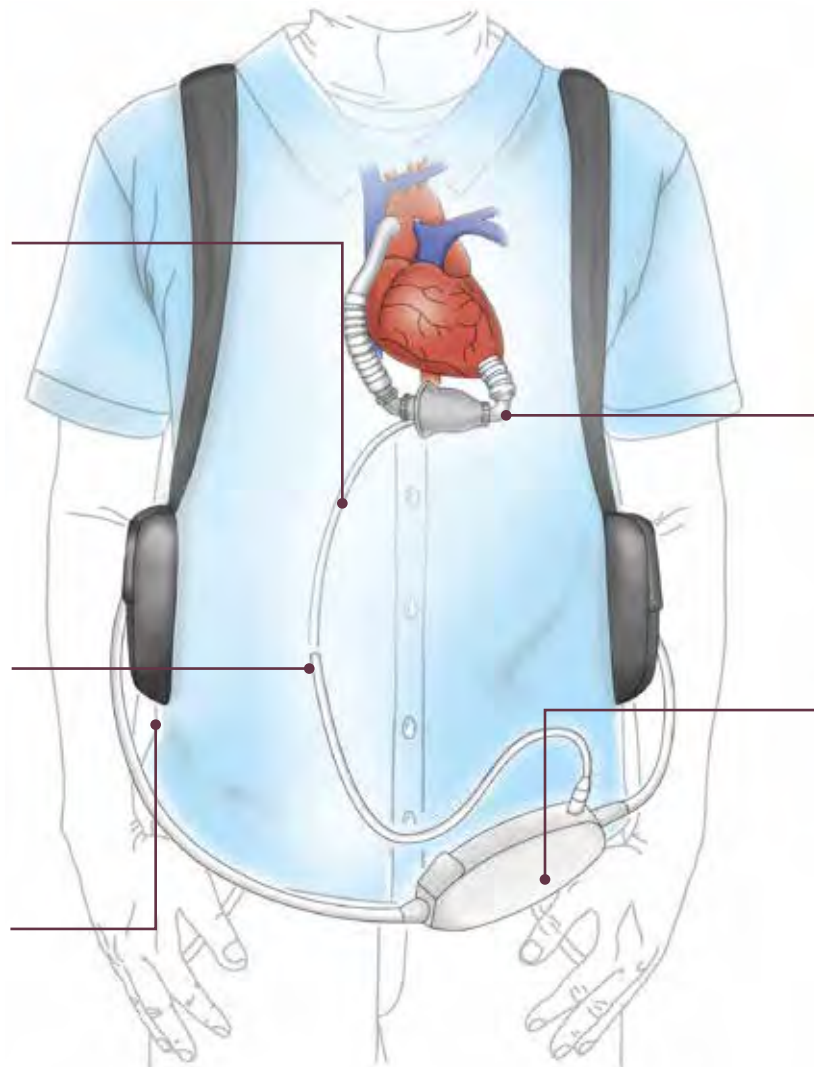
Thousands of people have received LVADs since 2006.

BELOW ARE THE WORKING PARTS OF AN LVAD INSIDE AND OUTSIDE THE BODY.

The **Driveline** is your LVAD's power cord. This cord delivers power from the controller outside your body to the LVAD pump attached to your heart.

The **Driveline Site** is where the power cord exits the body to connect with the controller.

The **Batteries** provide electrical power to the LVAD Pump and controller. Without power, the LVAD will eventually stop working.



The LVAD **Pump** contains a motor which helps circulate your blood through your body.

The **Controller** communicates with the LVAD Pump and batteries. It will alert you with important messages about your LVAD, like when your batteries need to be replaced.

LVAD AND HEART TRANSPLANT

The LVAD can be used as a “Bridge to Transplant.” This means the LVAD would be temporary. It would be used only until a heart becomes available for a transplant.

Other times, the LVAD is used as “Destination Therapy.” This is for people who do not qualify for transplant. Someone who has a Destination Therapy LVAD will likely have the pump for the rest of his or her life. People with Destination Therapy LVADs can’t turn them off (without experiencing heart failure symptoms again or dying).

Sometimes a person who gets an LVAD as a Destination Therapy can get stronger or improve in other ways that make him or her eligible for a transplant. However, for most people, the LVAD is a Destination Therapy.

Talk with your doctor about how getting an LVAD can affect your chances of changing status from Destination Therapy to Bridge to Transplant.

LEARN MORE



LVAD BY THE NUMBERS

Please see the part of this kit called LVAD by the Numbers to get the most up-to-date information on LVADs. The information there includes:

How many people have LVADs

Survival statistics for LVAD patients

Percentages of LVAD patients designated Bridge to Transplant and Destination Therapy

Percentage of Bridge to Transplant patients who receive a heart transplant within the first year after their surgery.

*“What I value and what I asked my doctors about was,
Will an LVAD give me a better lifespan? Will it improve my quality of life?”*



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HOW TO DECIDE

*"I read, informed myself, watched videos and talked one-on-one
with two patients who had an LVAD."*

Thousands of people have been in the same situation you are in now. Here are some ways that they and the people close to them have made the right choices for them. These ideas can help as you make your decision.

WHAT'S IMPORTANT TO YOU?

People make different choices about whether to get an LVAD. No single option is right for everyone. The key to making a decision that you are satisfied with is making that decision based on your own values. What is most important to you about how you live the rest of your life? Talk about your values with your loved ones and with your medical team. You can use the tool in this kit called **LVAD and Your Values** to help others understand what is most important to you.

GET THE INFORMATION YOU NEED

This kit has lots of general information that can help you decide whether to get an LVAD. But it's also important to ask questions about your specific situation. For example, your overall health can make it more likely or less likely that you would experience complications during LVAD surgery. In this kit, you will find a list of questions that you can ask your healthcare team.

You should also talk with someone who has an LVAD. This kit includes questions to ask a current LVAD patient as well.



LEARN MORE



OTHER PARTS OF THIS KIT
EXPAND ON THE INFORMATION
IN THIS TABLE

The **LVAD Surgery** section of this book has more information about the risks of the operation.

The **Living with an LVAD** section of this book gives details on how people with the device may feel, what LVAD maintenance involves, and the complications that send LVAD patients back to the hospital.

The **About Palliative & Supportive Care** section of this book has more information on medication management of heart failure and "comfort care."

The **Caregivers' Guide** explains how life changes for people caring for a loved one who has an LVAD.

LVAD by the Numbers lists survival rates for LVAD patients and LVAD decliners. It also lists the frequency of LVAD medical complications.

COMPARE YOUR OPTIONS

BENEFITS OF GETTING AN LVAD

The LVAD can prolong life.

People with LVADs feel better
(feel less shortness of breath, walk
farther without getting tired).

BENEFITS OF NOT GETTING AN LVAD

People who choose not to get the device
avoid the medical risks of surgery and
living with the LVAD.

People who opt not to get an LVAD avoid
the lifestyle changes associated
with the device.

RISKS & CHALLENGES OF GETTING AN LVAD

The surgery carries risks, such as
bleeding, stroke, renal failure, and
respiratory failure.

People living with LVADs are at risk for
infections and stroke that can happen
over time and send them back
to the hospital.

An LVAD requires maintenance such
as caring for the driveline site and
monitoring battery life.

An LVAD requires lifestyle changes for
both the patient (special preparations
for showering, carrying the device and
batteries on all trips outside the home)
and his or her caregiver (helping the
patient with daily needs in the
first weeks after surgery, managing
medical appointments).

RISKS & CHALLENGES OF NOT GETTING AN LVAD

People who decline an LVAD deal with
continuing heart failure symptoms
and hospitalization.

People who decline an LVAD have lower
one-year survival rates than people
who get the device.

For more details about these risks and benefits,
see the **LVAD by the Numbers** section.

*"The family meeting with the doctors was really good.
We got to ask a lot of questions, and I was so glad that we had it."*

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LVAD SURGERY

BEFORE SURGERY

You are sick and getting sicker. How sick you are affects how you'll do during LVAD surgery and with the LVAD. Your doctor will tell you if you are eligible for an LVAD. If you decide to have the LVAD surgery, you will need to take a couple of steps to get ready for it.



HOME INSPECTION

You will have to make sure your home is ready for you to live in it with an LVAD. Your LVAD team can give you instructions and suggestions on how to prepare your home. Ask your LVAD coordinator or social worker.



MEDICAL TESTS

You will undergo multiple medical tests. Your team needs up-to-date and accurate information about your health before the surgery.



MEET THE TEAM

Your health care team will have several members. It may include a cardiologist, surgeon, LVAD coordinator, social worker, psychiatrist, financial resources worker, and specialist in ethics. You may meet all of them.

DURING SURGERY

The surgery may take up to 4 hours. The surgery may be a little bit different for every patient. Your surgeon will talk more with you about what will happen in your surgery.

ALL SURGERY HAS RISKS.

THE RISKS FOR THIS SURGERY INCLUDE

- bleeding, requiring blood transfusions (this is common)
- stroke
- infection
- right side heart failure
- renal failure and respiratory failure

The LVAD surgery also has the same risks as every other major surgery. These include the risks that come with being under anesthesia, the risks of being in the hospital, and the risks that come with using a breathing machine.

Your surgeon will talk to you more about the risks. In the event that there are complications during your surgery, please discuss Advance Care Planning with your healthcare team.

AFTER THE SURGERY

Recovery from the surgery is different for every patient. For some people it is easier than others.

SOME OF THE FACTORS THAT MAY AFFECT YOUR RECOVERY INCLUDE



- your age
- how healthy you were before surgery
- how motivated you are to get well
- how healthy you are mentally
- how much support you have from family and friends
- how well your caregiver understands the LVAD

Some people are so sick before the surgery that they stay in the Intensive Care Unit (ICU) and hospital for a longer time compared with patients who are less sick. They also spend more time in physical rehabilitation (rehab).

**Most people stay in the ICU for 7-10 days, but this may be different at different hospitals.
Ask how long the average stay is at your hospital.**

The surgery is major. You will have tubes in your chest and mechanical sleeves on your legs. You may also have temporary pacing wires, IV drips to provide continuous medications, and a breathing machine. You will most likely be in some pain, though it soon gets better for many patients. Pain can also be managed with medication.

**After you leave the ICU, you'll stay in the hospital or in a rehab facility for another several days.
For the average patient, the hospital stay (including intensive care and rehabilitation) after surgery is at least two to three weeks. You'll have physical and occupational therapy to help you get strong enough to go home.**

Recovery occurs on a spectrum and every patient may recover differently.



MORE INFORMATION ONLINE

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LIVING WITH AN LVAD

*"The hardest part when you first get home is that you have to rely on someone else a lot.
But slowly I got stronger and was able to do things by myself,
like make my bed and stand at the stove and cook."*

Life with an LVAD looks different for every patient, and it changes over time. This section will explain more about what to expect if you decide to get an LVAD.

THE FIRST 8–12 WEEKS AT HOME

In the first eight weeks after an LVAD patient returns home from the hospital or rehab center, he or she will need lots of help from a caregiver. During this time, caregivers help people with LVADs with daily activities like preparing meals, going to the bathroom, and showering.

People with LVADs must not lift anything heavier than 10 pounds during their first eight weeks of recovery at home. And they may not be able to drive for at least 6-12 weeks after the surgery. When or whether a patient can start driving again depends on what his or her doctor recommends.

After the first weeks of recovery at home, patients can typically start resuming daily activities. How much they are able to do depends on how their health is improving and how much they work to be independent.

LEARN MORE



LVAD INFORMATION

Refer to your device manual for more information on how your device works and instructions on maintenance.



LVAD EQUIPMENT AND MAINTENANCE

The LVAD pump is inside the body. The pump must be plugged in to either a wall outlet or batteries that LVAD patients carry. People with LVADs also carry a controller. **When they leave the house, patients should carry 2 extra batteries and 1 extra controller.**

LVAD patients and their caregivers learn to act on the LVAD's alarms and understand LVAD readings. For example, when LVAD battery life is getting low, the controller beeps loudly.

The LVAD driveline connects the pump inside the body with the controller outside the body. LVAD patients and caregivers learn how to recognize potential problems with the driveline, such as kinking or pulling.

The spot where the driveline leaves the body is called the driveline site. People with LVADs and their caregivers learn how to change the dressings at the driveline site. **They have to change the dressings at least once a day.** It's very important to change the dressing correctly each time. This helps decrease the chances of getting a dangerous infection at the driveline site.

Patients and caregivers should call their LVAD team if the driveline site becomes red or irritated, if the device makes a sound they don't recognize, if there is blood in the patient's stool, and any other time they have questions about the LVAD.

Because the LVAD can't get wet, people who have the device can't take a bath or swim. Showering with an LVAD takes special preparations.

If the LVAD stops for a prolonged period, heart failure symptoms would return and the patient would likely die. Because of this, LVAD patients must take two extra batteries and an extra controller with them whenever they leave the house. Patients and caregivers may also have to take special actions to prepare for and deal with emergencies that might disrupt electrical power. For example, they may need to have a backup generator.

Changing the dressing requires supplies such as gauze, gloves, and cleaning supplies, which most patients have to pay for out of pocket. See the **More Resources** section of this book for medication and medical supply resources.

"You will have some limitations because of the weight of the batteries, plus the controller, and that feels heavy by the end of the day. That's why I wear a vest that distributes the weight."



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WHAT LVAD PATIENTS CAN (AND CAN'T) DO

LVAD patients typically feel better and have more energy once they get past the first weeks of recovery. They may be able to take part in more activities than they could before they got an LVAD.

Keep in mind that every LVAD patient is different. What a patient is able to do after surgery depends on factors like his or her overall health and whether the patient experiences medical complications from the LVAD.

ACTIVITIES THAT LVAD PATIENTS **CAN** TYPICALLY DO OR DO MORE OF

Being mobile
Spending time with family
& friends
Gardening
Cooking
Cleaning house
Exercising (lightly to moderately)
or playing non-contact sports
Traveling short distances by car
Sleeping (it takes a little getting used
to, but for most is not a problem)
Having sex
Fishing (if safely guarded from water)

ACTIVITIES THAT LVAD PATIENTS **MAY** BE ABLE TO DO

(Depending on their age, their other
health issues, and the support
they have)

Returning to work
(depending on their job)
Exercising or playing sports
more intensely
Traveling by plane, taking longer
car trips or other kinds of more
extensive travel
(packing and transporting LVAD
equipment is extra work, and the
patient's LVAD team must
be notified)

ACTIVITIES THAT LVAD PATIENTS **CANNOT** DO

Swimming
Bathing (LVAD patients can take
showers only)
Fishing from a boat or boating
(risky because of proximity
to water)

HOW LVAD PATIENTS FEEL EMOTIONALLY

Living with the LVAD may also bring emotional changes that affect patients' and caregivers' lives.

- People with LVADs may feel depressed, anxious, or stressed.
- They may not like feeling dependent on others.
- They may worry about money or about how they are affecting their caregivers.
- Many LVAD patients report that being attached to the machine is uncomfortable and inconvenient at first, but that they get used to it over time.
- They may feel self-conscious about having to carry the LVAD equipment in public.
- People who have LVADs also may feel happy that they can do more activities and grateful for added time with loved ones.

All of these feelings are normal. And they can all affect patients' relationships with caregivers and other people close to them in both negative and positive ways.

"Before the LVAD I couldn't run and now I can run a little. And I can walk far without shortness of breath or getting tired and stopping. I can clean my house, cook for myself, lots of personal things I am really proud of."

MAINTAINING YOUR HEALTH

People who have LVADs still have to take medications. They commonly take blood thinners such as **Coumadin that help prevent blood clots from forming**. Many patients also require follow-up treatment for pre-existing high blood pressure. Patients and their caregivers manage the medication schedule.

LVAD patients also go to regular medical appointments to make sure the device is working right. For the first three months, patients have frequent visits for equipment checks, driveline inspections, blood work, and heart ultrasounds. After that, LVAD clinic visits may occur less often. Talk to your LVAD team about your follow-up schedule.

Patients also do daily health checks, such as recording their vital signs and weight. They take that information with them to medical appointments.

Many patients may have to stay on a heart failure diet, which restricts fluids and salt.

Doctors may ask patients to make other changes so that they can stay as healthy as possible with the LVAD. These can include quitting smoking and losing weight.

THE RISK OF MORE HEALTH PROBLEMS

Doctors can't predict everything about how a patient's body will respond to an LVAD. But in the two years after surgery, most people who get an LVAD will have to go back into the hospital. The reasons they have to go back to the hospital include:

- They get an infection.
- They keep having heart failure symptoms such as shortness of breath.
- They experience bleeding in their GI tract (most commonly in the stomach and upper small intestines).
- A blood clot blocks their blood flow.
- They suffer a stroke.
- The device stops working and needs to be replaced.

Talk with your healthcare team about how your age, your overall health, and other factors that affect whether you would experience any of these problems with the LVAD.

LEARN MORE



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 this book.

"You're going to have to take care of yourself even with an LVAD, which means no drinking, smoking, or going back into those habits because you think you feel better."

MORE INFORMATION ONLINE

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ABOUT PALLIATIVE & SUPPORTIVE CARE

"I chose to make this decision with my wife. I would never have made a decision that she wasn't agreeable to. And she wanted to know what I felt."

You may have heard these terms mentioned as alternatives to getting an LVAD.

WHAT IS PALLIATIVE CARE?

Palliative care focuses on giving physical and emotional relief to people who have serious illnesses. It focuses on caring for, rather than curing, the patient.

Both people who get an LVAD and people who decline the device can make use of palliative care to control pain and manage symptoms.

Palliative care takes a team approach. The patient and his or her family work with doctors and other specialists to help give the patient the best quality of life possible. Everyone works to help the patient avoid suffering.

Through the different stages of the patient's illness, the palliative care team addresses his or her physical, intellectual, emotional, social, and spiritual needs.

Most hospitals have a palliative care doctor working with the heart team. If you are interested in learning more about palliative care, your doctor can help you talk with an expert.

WHAT IS ADVANCE CARE PLANNING?

Advance care planning is a term that refers to plans you make ahead of time to let your family and your doctors know about your preferences related to future medical care. In the case you are unable to speak for yourself, an "advance directive" helps others to make decisions in line with your values. As you are making major decisions about your health, ask your doctor about your advance care planning options.

LEARN MORE



PALLIATIVE & SUPPORTIVE CARE

The **More Resources** section of this book lists websites where you can learn about palliative care and hospice, as well as advance care and end-of-life planning.

MORE INFORMATION ONLINE

For videos of patients and additional information about this kit, visit the LVAD Decision Aid website at **lvaddecisionaid.com**

WHAT IS HOSPICE?

Hospice is not a place. It's a type of healthcare for people with serious illnesses who are nearing the end of their lives.

People receive hospice care in their homes, in hospice centers, and in other medical facilities.

Hospice focuses on making the end of life natural and as comfortable as possible. People in hospice don't receive treatments to try to prolong their lives. Instead, a hospice care team focuses on relieving patients' pain, if any, and offering emotional and spiritual support to the patient and his or her family. Hospice also helps the family in the immediate time after the death.

Some people decide that the LVAD is too much work or that they would prefer to make the best of the days they have left instead of taking on the risks and challenges associated with surgery. These people often turn to hospice and palliative care to help them feel as good as possible and enjoy their remaining time as best they can.

"Things are different. I'm used to being more independent and now I depend more on others. But that can bring people closer as well."



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PHILLIP

LVAD PATIENT

*"I know I'm going to keep
my strength up to come
out strong."*





PHILLIP

"I know I'm going to keep my strength up to come out strong."

Phillip's sister passed away from heart failure when she was 45. Phillip began to experience the same symptoms himself around the same age. Feeling short of breath and unable to walk for even short periods of time, he knew that he wanted to intervene sooner rather than later.

When his health began to decline further, he had the option of getting an LVAD. He felt scared to undergo a major surgery. He worried that he might not be strong enough to get through it. But he and his wife remained optimistic.

He decided to get an LVAD, because he hoped it might give him the chance to get back to his hobby of building model cars, and more importantly for him, to be alive and spend more time with his 4-year-old granddaughter.

"I know I'm going to keep my strength up to come out strong," he said.

He also hoped that the LVAD might be a bridge to one day getting a heart transplant, if he needed one. But he knew being listed for a transplant was no guarantee.

He felt happy to have caregivers close by to help him through his decision and his recovery. "My family is all local," he said, "and I like the idea of having them here for moral support."

He was concerned that caretaking might be a lot of responsibility for his wife. So he told her, "You're not going to be stuck, because I'm going to do the best I can to help you at the same time you're helping me."

Phillip is now scheduled to get his LVAD. He is using his time in the hospital to ask his healthcare team as many questions as he can. He wants to learn more about what to expect from his treatment. He is asking questions about how to pay for his treatment on his limited income. He also wants to know how to prepare both himself and his wife for challenges that may come.

*"It's a change,
but it's manageable."*

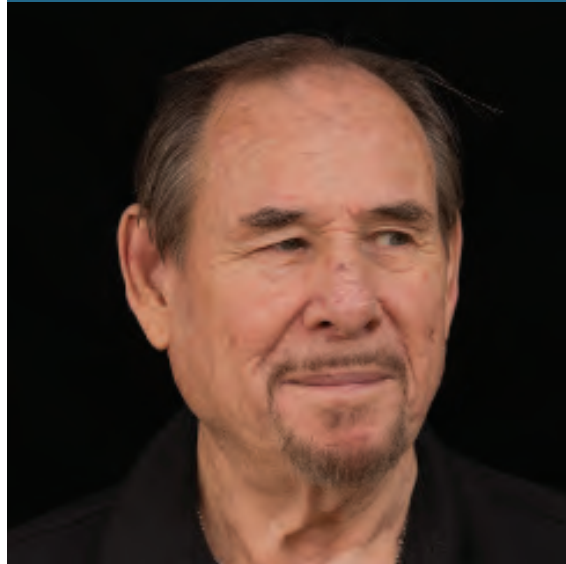


JEFF

LVAD PATIENT



LVAD PATIENT



JEFF

"It's a change, but it's manageable."

Jeff, 70 years old and a former engineer, found out that he was not eligible for a heart transplant. His doctors recommended he get an LVAD as "destination therapy." That meant he would live with the device for the rest of his life.

The first thing Jeff wanted to know was what would happen if he didn't get the LVAD.

"Will I have a heart attack?" he wondered.

He was also concerned about the risks of serious surgery, especially at his advanced age. He talked to his healthcare team about these concerns. He weighed the pros and cons and then decided, "Let's go with the LVAD."

Jeff had not realized how much the LVAD would change his lifestyle. He had to get used to carrying the battery pack around with him. He also takes blood thinners. They cause him to bleed easily if he nicks himself during his favorite activities, like gardening or metal detecting.

Despite these drawbacks, Jeff is glad to get back to his hobbies. Learning as much as he could about the device helped Jeff to feel more comfortable living with the LVAD.

An engineer by trade, he "loved delving into the science behind LVAD technology," he said.

He likes to talk to other patients considering LVAD therapy about what they can expect. He knows that everyone is different, but he likes to share his own experiences and knowledge. He feels that it is especially important to talk with both the patient and the patient's caregiver. He remembers how it helped him and his wife to talk to other patients when they were deciding. He likes to reassure other patients that "It's a change, but it's manageable."

"It was overwhelming at first."



ELIZABETH

LVAD CAREGIVER





ELIZABETH

"It was overwhelming at first."

Elizabeth's husband, Jeff, had been suffering with heart issues for a few years. After speaking with the medical team, they decided together that he should get an LVAD.

Once they decided, Elizabeth considered her role as a caregiver. At 69, the former teacher hoped that she could effectively encourage him at every stage of the operation.

"Even pre-operation, I tried to help him mentally to get stronger, to eat right, and to try to keep him exercising," she said.

At first, the idea of her husband having an LVAD was hard to accept. "He's on batteries," she said, "for the rest of his life." But she told herself, "You can do this. You can do this."

Elizabeth's family waited with her during her husband's surgery. She knew she could use their support.

When her husband came home from the hospital, she found it difficult to care for him by herself.

"It was overwhelming at first," she said. With no kids, Elizabeth longed for some help. But she was afraid to ask her neighbors and friends. "I'm the type of person, I guess, that I just like to do it myself," she said. It got easier as she shared responsibilities with her husband.

She also learned to give herself breaks. Even though she knows how to change his bandages and batteries, "Sometimes I knew he wanted to do it himself," she said, "so I just let him do that."

She discovered that she could draw on the LVAD team for help whenever she needed anything. Having them on-call is an important source of comfort to her. Elizabeth said what has helped her the most was developing a good relationship with her doctors and the LVAD team. This allows her to feel more involved, informed, and supported.

"You just get used to it," she said. "The changes in your lifestyle simply become a 'new normal.'"

"I really want to get a new heart."



BRENDA

LVAD PATIENT





BRENDA

"I really want to get a new heart."

Brenda's doctor recommended the LVAD. But the idea of surgery scared her.

"What if I die on the operating table?" she feared.

Still, she was tired of feeling out of breath. She also wanted to move around more easily.

At 56, the former facilities operator is used to being on the go.

She talked with an LVAD patient to get more information. He told her how the device helped him get back to activities he enjoyed. Brenda felt that maybe the LVAD could help her, too. She still wasn't sure, but she decided to try it.

Since Brenda got her LVAD, she has been going to her medical appointments regularly and feeling pretty good.

Sometimes she still gets a little tired. But she can make her bed, sweep, dust, and even mop a little bit when it doesn't require too much bending over.

Brenda lives alone with her daughter nearby. She appreciates the support of the LVAD team whenever she has a concern.

"They are so nice," she said. "They treat you like family."

She also feels that her faith helped her to gain strength and independence during recovery.

Most LVAD patients have only one device in their lifetime. But Brenda has had to replace her LVAD twice. This was because of infections in the driveline. The surgeries have been hard on her mentally and physically. But she believes the LVAD has saved her life.

"I don't want to keep the LVAD for the rest of my life," Brenda says. "I really want to get a new heart."

She is waiting to see whether certain health improvements will make her eligible for a transplant.

"Until that time comes," she said, "I'm satisfied with the LVAD."

*"Find out as much
information as you can."*

SUSAN

*"We might have looked
for other alternatives."*

SAM

A photograph of a woman, Susan, and a man, Sam, standing in a brightly lit hospital hallway. Susan is in the foreground, wearing a black short-sleeved button-down shirt and black trousers. She has short brown hair and is looking towards the camera. Sam stands behind her, wearing a blue Houston Astros baseball cap, a light blue denim jacket over a dark shirt, and blue jeans. He is also looking towards the camera. The hallway has white walls, a polished floor, and a wooden door with a silver handle is visible on the left. A red exit sign is mounted on the wall in the background.

SUSAN

LVAD PATIENT

SAM

LVAD CAREGIVER



SUSAN

"Find out as much information as you can."

Before Susan got an LVAD, she had trouble moving around.

"I could walk, but I couldn't hardly breathe," she said. "If I could breathe, I couldn't walk."

Susan's main motivation for getting the LVAD was to return to the way she had been when her health was better.

"I wanted my life to at least get back to some kind of normalcy to where I could enjoy my grandkids and do what I want to do," she said.

She felt the LVAD team was very knowledgeable about her condition, and "they didn't try to sugarcoat it."

"The main thing the doctors kept saying was this is a life-changing situation," Susan said.

After her surgery, she experienced unexpected complications. She began to feel discouraged. She had a number of blood transfusions, and her doctors struggled to figure out the source of the bleeding in her intestines.

She also didn't like how heavy the LVAD battery was.

"I don't have any problem with it being a life-changing treatment, but the battery is very heavy," she said.

"I didn't know it would be so hard to maneuver."

Susan's recovery was difficult on her husband, Sam, too. Her strong dependency on him became frustrating for them both, causing arguments and tension in their relationship. But Sam remained supportive throughout her recovery. Susan also feels grateful that she can now see her grandchildren growing up. For her, that makes the complications of her recovery worthwhile.

She said her biggest challenge is the uncertainty of recovery. "It's just the not knowing," she said.

Her advice for other patients considering LVAD treatment is to "Know what you're getting into.
Find out as much information as you can."



SAM

"We might have looked for other alternatives."

Sam is 65 and a retired police officer. His wife, Susan, suffered a heart attack. After that, her health got worse. She couldn't walk without stopping many times to catch her breath.

Sam and his wife asked their healthcare team what treatments were available for congestive heart failure. They learned about LVAD therapy.

"A lot of people told us different things about the LVAD," he said. "And my wife got a book to read through, but it was hard to understand."

They felt they did not understand the risks and benefits of LVAD. But they agreed to LVAD therapy.

The outcome was not as easy as they had hoped. Sam's wife had a difficult recovery in the ICU. She had to return to the hospital many times to treat intestinal bleeding.

With their kids grown and moved out, Sam took on most of the caregiving responsibility.

"We really didn't have anybody else to help us except for me," he said. "I did all the bandage changing, managed the batteries, everything."

Even though he knew he did his best to help his wife, Sam sometimes felt guilty.

"She's an outgoing person and wants to go and do a lot of things," Sam explained. "All of a sudden, here she is, hospitalized again. I felt it was my fault for pushing her."

After a 10-week hospital stay, his wife's bleeding finally stopped. She began to look much better. Still, Sam wishes there were other options.

"My wife said that if she had known more about the potential complications, we might have looked for other alternatives," he said.

Sam encourages other caregivers to talk to other LVAD patients about their experiences. He says this will help them understand the range of experiences that patients and caregivers have.

Funding acknowledgement:

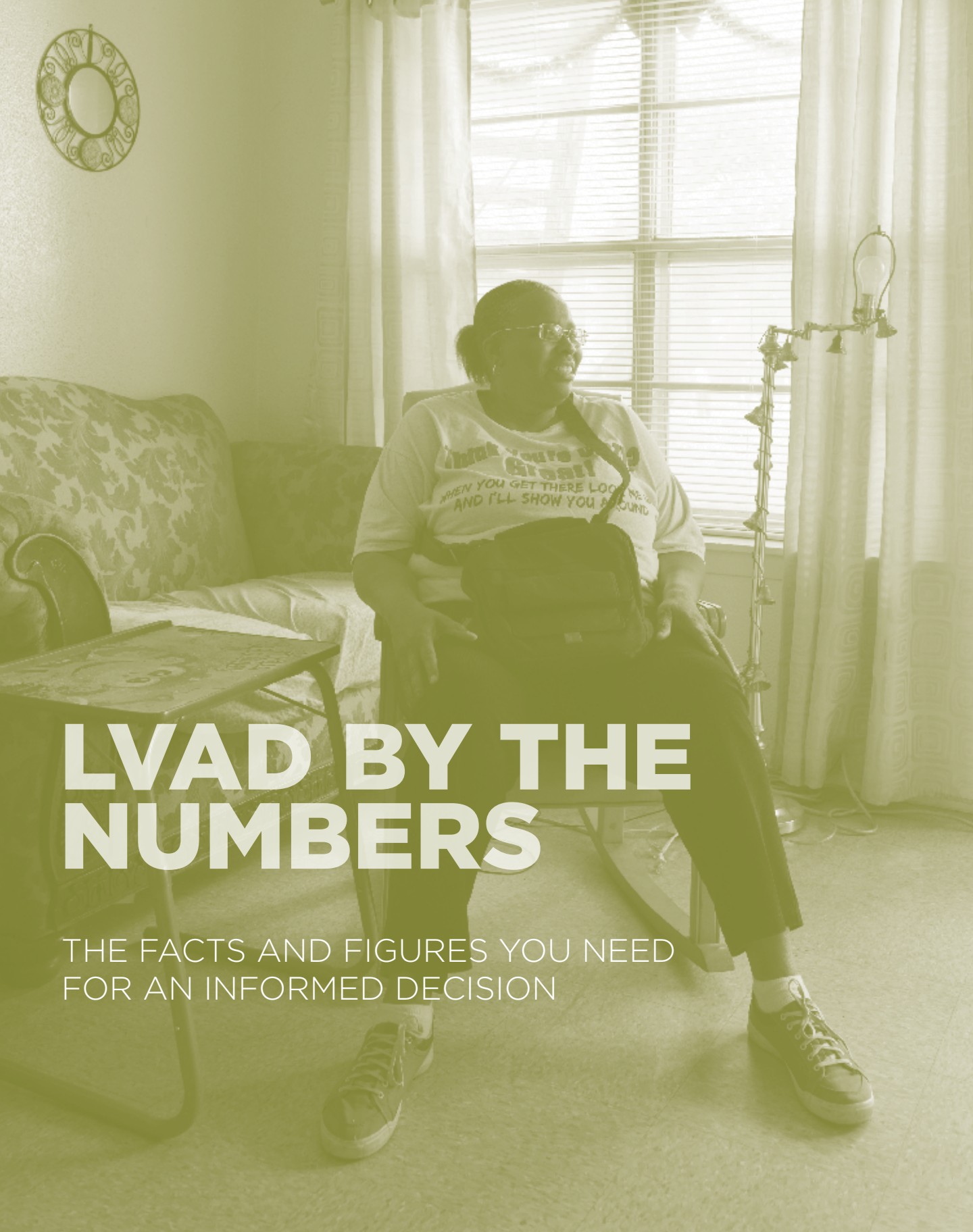
This work was supported through a Patient-Centered Outcomes Research Institute (PCORI) Program Award (1306-01769).

Disclaimer: All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee. This decision aid was developed by J.S. Bumenthal-Barby PhD; Jerry Estep MD; Robert Volk PhD; Courtenay Bruce JD, MA; Charles Minard PhD; Sheryl McCurdy PhD; Matthias Loebe MD, PhD; Kristin Kostick PhD; Estevan Delgado BA; Lidija Wilhelms BA; Holland Kaplan BA, Mackenzie Nettlow. The following institutions participated in development: Baylor College of Medicine, Houston, Texas; The Houston Methodist Hospital, Houston, Texas; MD Anderson Cancer Center, Houston, Texas; University of Texas School of Public Health, Houston, Texas. The following institutions participated in testing: The Houston Methodist Hospital; CHI Baylor St. Luke's Medical Center, Houston, Texas; Cleveland Clinic, Cleveland, Ohio; INTEGRIS Baptist Medical Center, Oklahoma City, Oklahoma; Ochsner Health System, New Orleans, Louisiana; Aurora St. Luke's Medical Center, Milwaukee, Wisconsin; and the The Miami Transplant Institute, Miami, Florida.

Conflicts of interest: The developers of this decision aid have no conflicts of interest to report. Estep and Loebe receive consultant and research support from Thoratec Corporation. The corporation had no role in the funding or development of this decision aid. The material provided on this decision aid is for informational purposes only and is not provided as medical advice.

All medical decisions should be made in consultation with a doctor.

Last update: 8/29/2018. Reading level: 8.o.



LVAD BY THE NUMBERS

THE FACTS AND FIGURES YOU NEED
FOR AN INFORMED DECISION

HOW MANY PEOPLE HAVE LVADS?

Over 18,000
people in the United States
received an LVAD between
2006 and 2016.

More than 40%
of those 18,000 people got
their LVADs between
2014 and 2016.

More than 2,500
patients will receive an
LVAD over the
next year.

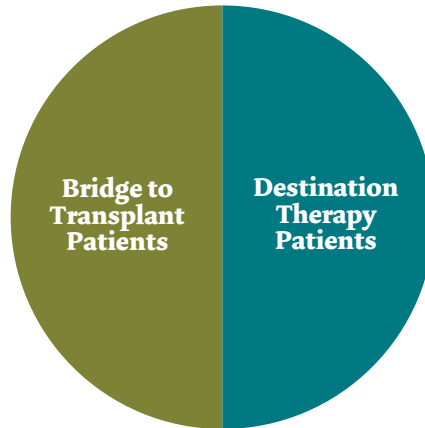
WHAT SHOULD I KNOW ABOUT LVAD AND HEART TRANSPLANT?

50%

of patients are designated
“Bridge to Transplant”
when they get an LVAD. That
means they are eligible to get
a heart transplant.

50%

of patients are designated
“Destination Therapy” when they
get an LVAD. That means they are
not eligible for heart transplant
and they will most likely have the
LVAD for the rest of their lives. This
should be discussed upfront with
your LVAD team.



In other words, about
5 out of 10 people
getting an LVAD are designated
Bridge to Transplant.

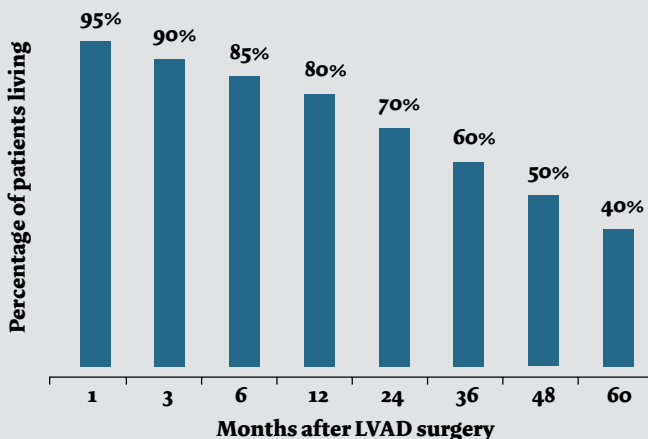
How many Bridge to Transplant
patients receive a heart transplant
within the first year after
their surgery?

9%

How many Destination Therapy
patients are able to move to the
Bridge to Transplant status?

15%

HOW LONG DO PEOPLE LIVE AFTER THEY GET AN LVAD?



While it is uncertain how long each
individual patient will live, our best
estimate is indicated in this graph.

Sometimes the LVAD has to be
replaced. 65% of patients who get a
second LVAD are still alive one year
after that surgery. 60% of patients who
get a third LVAD are still alive one year
after surgery.

Only 25-50% of people with end-stage heart failure will be alive one year later without an LVAD.

WHAT ARE THE EARLY RISKS AFTER SURGERY?

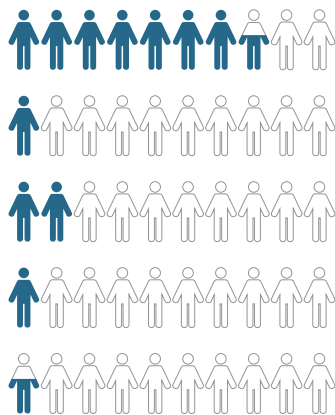
During surgery and in the first 3 months after surgery:



- 4 out of 10 patients will have bleeding
- 2 out of 10 patients will get a infection
- 2 out of 10 patients will have respiratory failure
- 1 out of 10 patients will experience renal failure
- 2 out of 10 patients will have right heart failure
- 0 to 1 out of 10 patients will have a stroke

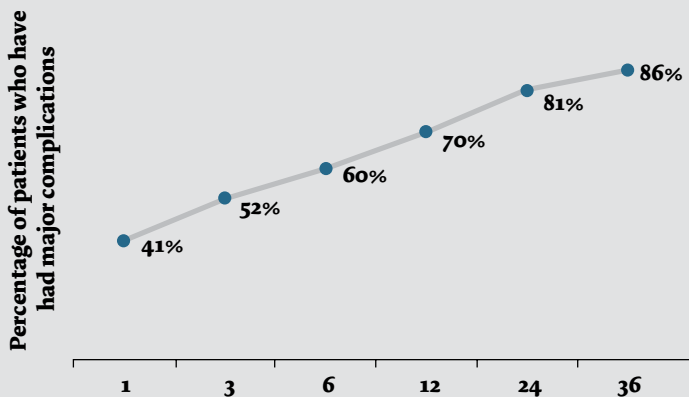
HOW OFTEN DO LVAD COMPLICATIONS HAPPEN?

In the first year after LVAD surgery:



- 7 to 8 out of 10 patients (75%) have hospital readmissions
- 1 out of 10 patients will get a pump-related infection
- 2 out of 10 patients will have a serious bleed
- 1 out of 10 patients will have a stroke
- 0 to 1 out of 10 patients will need surgery to replace their LVAD

PERCENTAGE OF PATIENTS WITH MAJOR COMPLICATIONS OVER TIME AFTER LVAD SURGERY:



36 months after LVAD surgery, 86% of patients have experienced at least one major complication.

Chances of longer-term complications are more uncertain.



MORE INFORMATION ONLINE

For more details about the sources and quality of the evidence presented here, visit the LVAD Decision Aid website at www.lvaddecisionaid.com.

A photograph of a man and a woman standing outdoors in front of a brick building with a staircase. The woman is on the left, wearing a dark t-shirt and glasses. The man is on the right, wearing a dark t-shirt, shorts, and glasses, with a bag slung over his shoulder. The image has a teal overlay.

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?

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

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

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

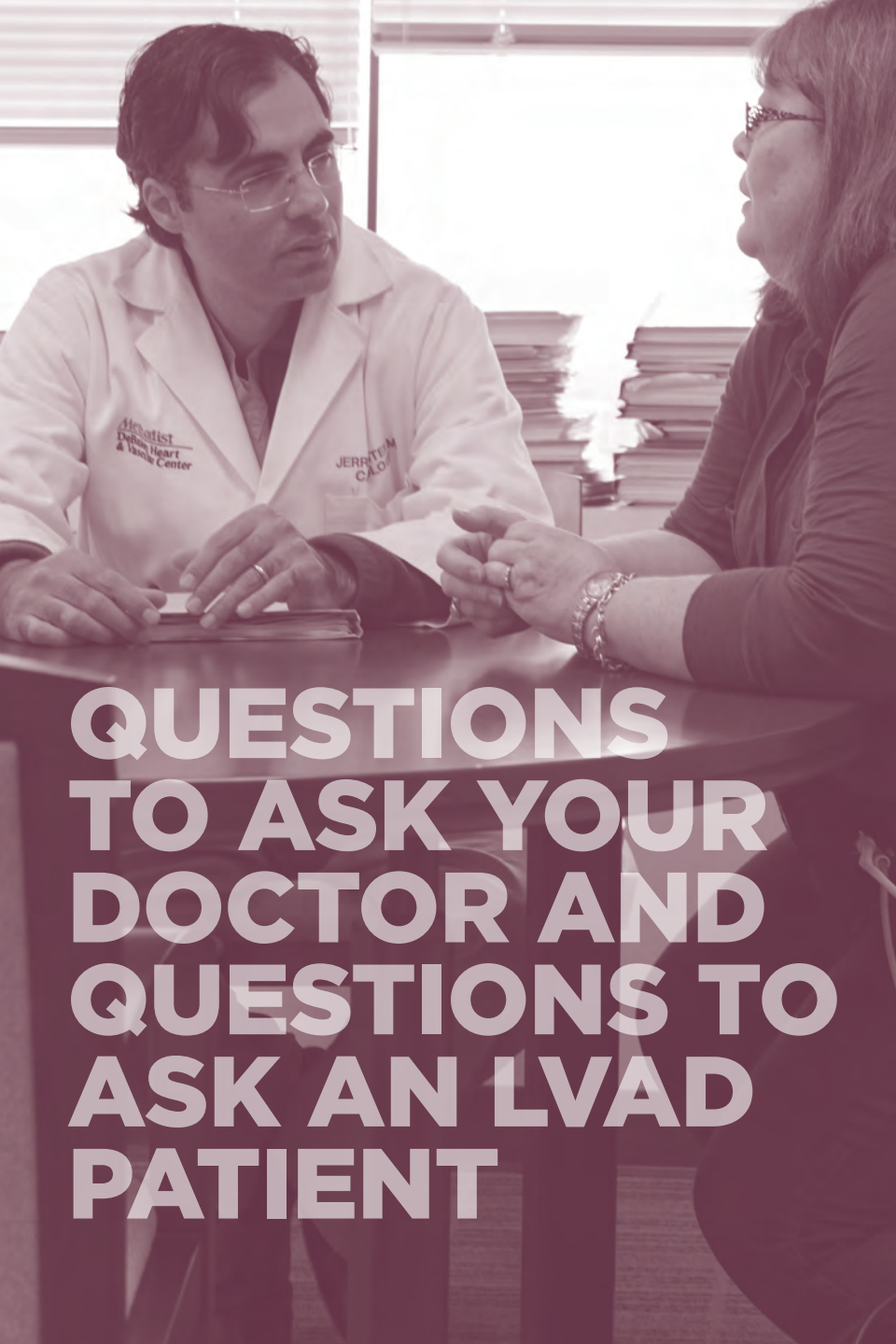
What helps in dealing with the stress of being a caregiver?

"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:

NOTES:



QUESTIONS TO ASK YOUR DOCTOR AND QUESTIONS TO ASK AN LVAD PATIENT



QUESTIONS TO ASK YOUR DOCTOR

Your doctor can't predict everything that will happen to you if you get an LVAD. But he or she can tell you how things like your age and your overall health might affect your surgery, recovery, and daily life. Your healthcare team can also help you learn more about hospice and palliative care.

QUESTIONS ABOUT LVAD AND HEART TRANSPLANT

Will I be eligible to receive a heart transplant, or will the LVAD be “destination therapy” for me? (In other words, will I have the LVAD the rest of my life?)

If I am eligible for a transplant, how likely is it that I will receive a new heart?

QUESTIONS ABOUT SURGERY AND RECOVERY

How might my age and other health conditions affect how I do during LVAD surgery?

Am I at higher risk for any surgery complications because of my age and my other health conditions?

How might my age and other health conditions affect my recovery after surgery? (For example, how long will I need to be in the hospital? Will I need to spend time in a rehab facility before going home?)

QUESTIONS ABOUT LIVING WITH AN LVAD

Will my health improve if I get an LVAD? What will happen if I don't?

How might my age and other health conditions affect my daily life with the LVAD? (For example: How will I feel, and how much independence can I regain?)

What other changes do I need to make to be the healthiest I can be? (For example: How will losing weight affect my health?)

How will this impact my caregiver?

How will the LVAD affect my work life? Will I need to stop working?

QUESTIONS ABOUT LVAD COSTS

Will my insurance cover the cost of LVAD surgery? What about the cost of the time I spend in the hospital or a rehab facility after the surgery?

How do I find out if I am eligible for financial support or cost-sharing from the hospital?

Are there out-of-pocket expenses that I should be prepared to pay?

QUESTIONS ABOUT PALLIATIVE AND SUPPORTIVE CARE

What is an advance care plan, and how do I make one?

How does hospice work?

What are the advantages of hospice?

What are the advantages of simply taking my medications?
The disadvantages?

QUESTIONS TO ASK YOUR DOCTOR AFTER LVAD SURGERY

When should I call you? If the alarm goes off? If I can't breathe?

When should I call 911?

What can I do to improve my chances for a speedy recovery?

How am I doing and what can I do better?

QUESTIONS TO ASK ANOTHER LVAD PATIENT

Your care team will help you set up a time to meet with someone who has been living with an LVAD. This is a great chance to talk about your decision with a person who understands what you're going through right now. Think about what you would want to ask someone who has already received an LVAD. Maybe you're wondering what this person's surgery was like, or what his or her life is like now. Here are some more questions you could ask:

How long have you had an LVAD?

How do you feel with the LVAD?

What information did you need from your medical team to make your decision?

What do you wish you had known about life with the LVAD before you got one?

QUESTIONS TO ASK

How did you adjust to the ways your life has changed after getting an LVAD?

How has the LVAD affected your independence?

What types of things do you have to rely on your caregiver for?

What is easier than you expected about life with the LVAD?

What is harder than you expected about life with the LVAD?

How has your decision affected your family's life?

How has the LVAD affected your relationship with your family caregivers?

Would you make the same decision again?

What do you think are the most important things for me to know as I decide whether to get the LVAD?

MY OTHER QUESTIONS FOR MY HEALTHCARE TEAM ARE...

MY OTHER QUESTIONS FOR AN LVAD PATIENT ARE...

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There are no margins, text, or other markings on the paper.

NOTES

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There are approximately 20 lines visible. The paper has a slight shadow on the right side, suggesting it's resting on a surface.



MORE INFORMATION ONLINE

For videos of patients and additional information about this kit,
visit the LVAD Decision Aid website at

www.lvaddecisionaid.com

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

LEARN MORE



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**

RESOURCES FOR LVAD PATIENTS & CAREGIVERS

WHERE TO GO FOR MORE
INFORMATION AND SUPPORT



TECHNICAL AND SOCIAL SUPPORT

Your LVAD Team

Contact your LVAD coordinator for any reason at all.

Contact information: _____

LVAD Team Social Worker

Contact information: _____

MyLVAD

Learn more about LVAD technology and living with an LVAD. Connect with other LVAD patients and caregivers through blogs and forums.

www.mylvad.com

LVAD Hospital Locator

Find an LVAD hospital or support center near you, or in areas where you plan to travel.

www.mylvad.com/hospital-locator

Monthly Community VAD Support Groups for VAD Patients, Candidates, and Caregivers

Contact information: _____

SUPPORT RESOURCES FOR CAREGIVERS

Family Caregiver Alliance

www.caregiver.org/caregiving-issues-and-strategies

Caregiver Action Network

www.caregiveraction.org

Family Voices Inc.

www.familyvoices.org

National Alliance for Caregiving

www.caregiving.org

National Caregivers Library

www.caregiverslibrary.org

HOME CARE SUPPORT

Home Health Agencies

Find home healthcare agencies in your area.

www.medicare.gov/homehealthcompare/search.html

Nursing Services in the Home

Find an Interim HealthCare location (available in 43 states).

www.tinyurl.com/p88aynf

MEDICATION AND MEDICAL SUPPLY RESOURCES

NeedyMeds.org

Provides information on assistance programs and drug discounts; offers its own drug discount card.

(215) 625-9609

www.needymeds.org

Healthwell

Helps people with ongoing, serious illnesses cover co-payments, deductibles, and health insurance premiums.

800-675-8416

www.healthwellfoundation.org

The Medicine Program

Helps people get prescription medicines for free or nearly free of charge through Patient Assistance Programs.

(573) 996-7300

www.themedicineprogram.com

Patient Access Network

Helps people with ongoing, serious health problems pay for care costs that are not covered by insurance.

866-316-7263

www.panfoundation.org

"It's no different than when you're a baby and all of a sudden you've got to start brushing your teeth. It's just a new process, and I have got it down now. I can shower, shave, change my bandage, and change the batteries in 45 minutes."



FOR SUPPLIES, PRODUCT REVIEWS, AND RATINGS

Vitality Medical

www.vitalitymedical.com

Allegro Medical

www.allegromedical.com

Amazon

www.amazon.com

FINANCIAL CONCERNS

For financial questions related to your LVAD treatment, please contact any of the following:

Your Hospital's Financial Counselor

Contact information: _____

Your State Department of Insurance

Contact information: _____

Benefits Check-up

Explore your financial coverage options.

(202) 479-1200

www.benefitscheckup.org

COBRA Information

Extend your current healthcare coverage.

866-275-7922

www.dol.gov

Healthcare Exchanges

Enroll in health coverage if you are uninsured.

800-318-2596

www.healthcare.gov

Centers for Medicare and Medicaid Services

800-MEDICARE (633-4227)

www.medicare.gov

HelpHopeLive

Get help raising money to help pay for your healthcare treatment.

800-642-8399

www.helphopelive.org

"Just relax, be calm, call the LVAD team for any health questions no matter how small."

INFORMATION ABOUT HEART TRANSPLANT THERAPY

National Foundation for Transplants

800-489-3863

www.transplants.org

Get definitions of and more information about “Bridge to Transplant” (BTT) versus “Destination Therapy” (DT).

Bridge to Transplant (BTT)

www.tinyurl.com/VADBTT

Destination Therapy (DT)

www.tinyurl.com/DestinationTherapy

PALLIATIVE AND SUPPORTIVE CARE

GetPalliativeCare.org

Learn about palliative care and whether it is right for you and your family.

www.getpalliativecare.org/whatis/

ADVANCE DIRECTIVES

National Hospice and Palliative Care Organization

Get more information on advance care and end-of-life planning.

www.tinyurl.com/j9dh7gc

*“Things are different. I’m used to being more independent,
and now I depend more on others. But that can
bring people closer as well.”*





MORE INFORMATION ONLINE

For videos of patients and additional information about this kit, visit the LVAD Decision Aid website at lvaddecisionaid.com

LVAD AND YOUR VALUES

Some people have found that thinking about the following values helps them decide whether to get an LVAD. Being clear about what you value can also help you when you talk with your healthcare team. This tool helps everyone understand what's most important to you.

Look at each value in the first column and decide how much it matters in your LVAD decision.

Then circle the number in the second column that reflects how important that value is to you. **The numbers range from 0 (for a value that isn't important at all to you) to 5 (for a value that is extremely important to you).**

You can use the ruled line to write down your thoughts about each value.

When you are finished, talk about your answers with your doctor.

BENEFITS OF LVAD

HOW MUCH DOES THIS MATTER FOR YOUR DECISION?

Please circle a number 0 (none) to 5 (a lot)

Extending your life for a few more years

0 1 2 3 4 5

Why does this matter? _____

Bridging to a transplant

0 1 2 3 4 5

Why does this matter? _____

**Improving heart failure symptoms such as shortness of breath, weakness,
and swelling so that you feel better**

0 1 2 3 4 5

Why does this matter? _____

**Increasing your mobility for simple activities such as cleaning house,
preparing meals, and going to the grocery store**

0 1 2 3 4 5

Why does this matter? _____

**Increasing your mobility for more involved activities such as taking
longer trips, going on a cruise, and participating in non-contact sports**

0 1 2 3 4 5

Why does this matter? _____

RISKS OF LVAD

HOW MUCH DOES THIS MATTER FOR YOUR DECISION?

Please circle a number 0 (none) – 5 (a lot)

Spending a long time in the hospital or rehabilitation center after surgery

0 1 2 3 4 5

Why does this matter? _____

Having to go back into the hospital for problems such as driveline infections or internal bleeding throughout life with an LVAD

0 1 2 3 4 5

Why does this matter? _____

Having a disabling stroke

0 1 2 3 4 5

Why does this matter? _____

DAILY CHALLENGES

HOW MUCH DOES THIS MATTER FOR YOUR DECISION?

Please circle a number 0 (none) – 5 (a lot)

Dealing with daily lifestyle changes such as cleaning the driveline, making special preparations for showering, and carrying the device and batteries

0 1 2 3 4 5

Why does this matter? _____

Increasing dependence on others

0 1 2 3 4 5

Why does this matter? _____

Affecting your caregiver's life because of the time and energy needed for your care

0 1 2 3 4 5

Why does this matter? _____

Dealing with expenses for LVAD maintenance such as medicines, co-pays, dressings, and gas for traveling to appointments

0 1 2 3 4 5

Why does this matter? _____

MORE INFORMATION ONLINE

For videos of patients and additional information about this kit, visit the LVAD Decision Aid website at **lvaddecisionaid.com**