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Better conversations, better decisions

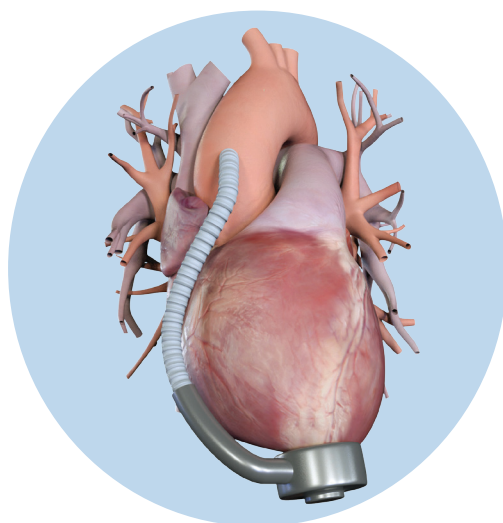
A decision aid for

Left Ventricular Assist Device (LVAD)

A device for patients with advanced heart failure



Exploring Options



You are being considered for an LVAD. This booklet should help you understand what an LVAD is and help you and your family think about what is best for you. Your values and goals are the most important factors in making a decision.

What are your current feelings?

- How do you want to live the rest of your life?
- What are your hopes and fears?
- What are your biggest questions?

To view a video about this decision or for an online version of this booklet, visit patientdecisionaid.org.

Now that you've thought about your feelings, let's talk about the details of this **DECISION**.

You have severe heart failure.

Heart failure is when the heart is too weak to pump enough blood for the body. This causes shortness of breath, tiredness, and swelling. For most people, heart failure gets worse over time. Severe heart failure can lead to death.



You are in a tough spot.

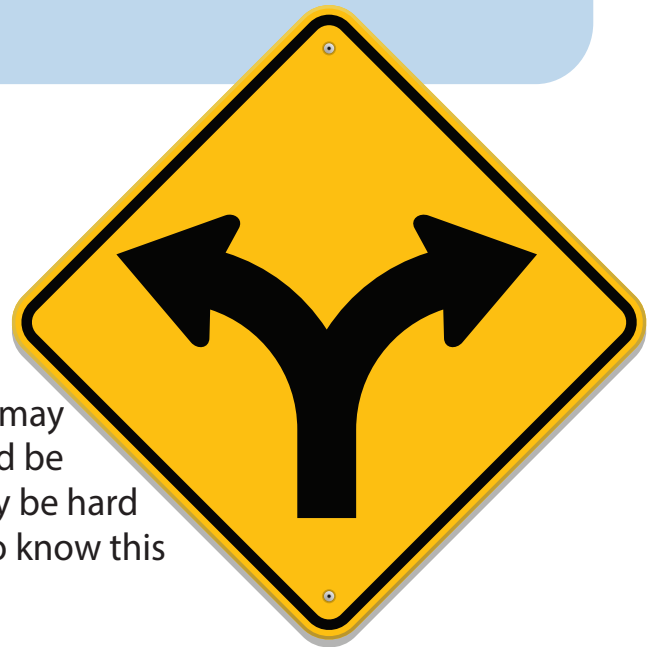
Your medicines are not working. Without a major heart surgery, you may die soon. Even if you can get a heart transplant, you may have to wait a long time. Therefore, you are being considered for an LVAD (partial mechanical heart).

Many find this scary or confusing. Some patients feel pressured to make a decision.

These emotions are normal.

This is a major decision.

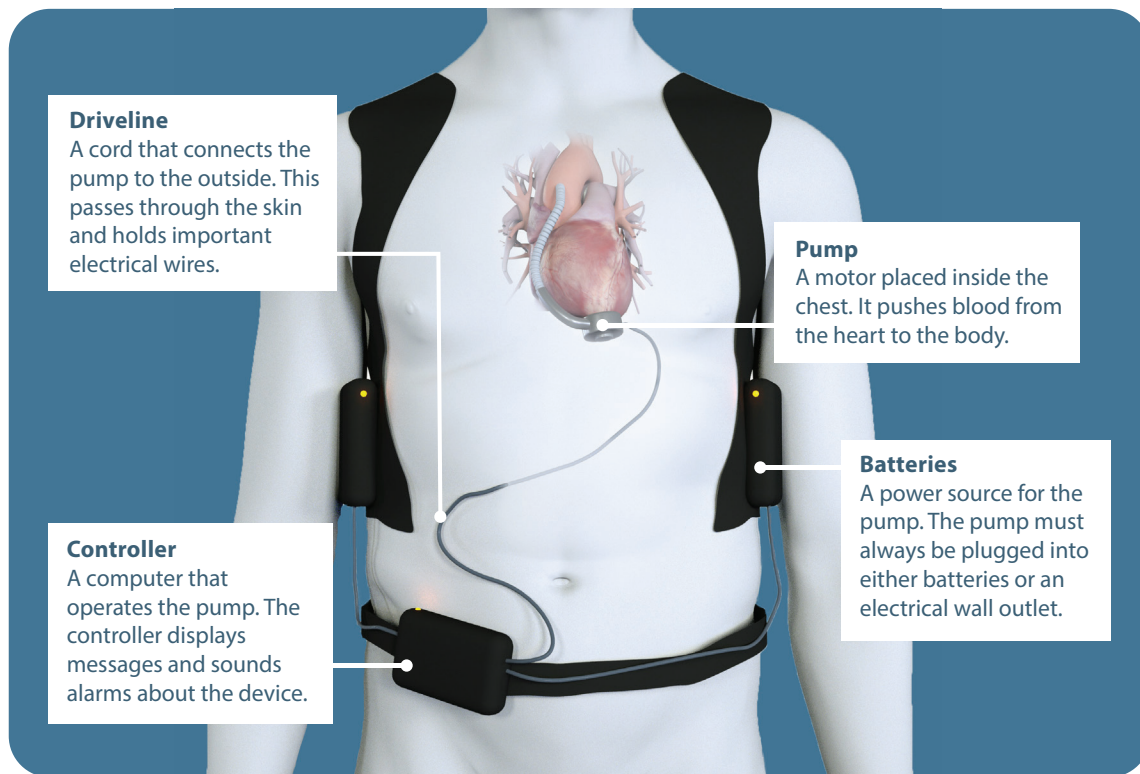
If your doctors feel you are eligible for an LVAD, you are facing a major decision. Such a decision may make some people feel uncomfortable. While no one can predict the future, understanding what could happen may help you to feel more at peace about your decision and be better prepared for what happens after. While this may be hard to think about, people in your position have wanted to know this information.



Some patients choose to get an LVAD. Other patients decide not to get an LVAD. The right choice really depends on how you hope to live the rest of your life.

What is an LVAD (Left Ventricular Assist Device)?

An LVAD is a mechanical device that helps your heart pump blood.



LVADs are used for different reasons.

- Sometimes an LVAD helps treat people until they can get a heart transplant. This is called **“bridge to transplant”** (or BTT).
- At some centres, LVADs are used to treat people who have severe heart failure and cannot get a transplant. This is called **“destination therapy”** (or DT). Those who are DT will live with the LVAD for the rest of their lives until death.

For both BTT and DT, the surgery, types of device, and recovery are the same.

What is the process of getting an LVAD?

- Getting an LVAD requires open-heart surgery
- The surgery can be dangerous, and recovery can be long and hard
- Most patients stay in the hospital for a couple of weeks – some stay longer
- Patients and their caregivers need to attend education sessions to learn how to use the device equipment

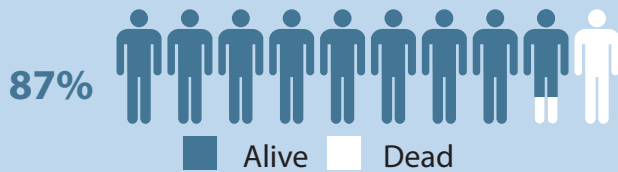
What might my life look like with each OPTION?

The numbers below are from recent medical studies. However, no one can know what will happen to any one person.

Life *with* an LVAD

How long might I live?

Patients usually live longer with an LVAD. Slightly less than 9 out of 10 patients who got an **LVAD** are still alive after 1 year.¹⁻⁴



How might I feel?

Of those patients who get through surgery, many feel big improvements in heart failure symptoms – less shortness of breath, less swelling, and more energy.¹ Most patients say they can do more.

What complication might occur?

1 year after surgery, about:¹⁻⁴

- 5 to 6 patients out of 10 are readmitted to the hospital



- 1 in 10 have a stroke



- 2 in 10 develop a device-related infection



- 2 in 10 have a serious bleed that requires medical attention



- Nearly 2 in 10 have ongoing heart failure



Life *without* an LVAD

How long might I live?

Patients usually do not live as long without an LVAD or transplant.

Among the **sickest** patients, less than 2 out of 10 who did not get an LVAD are still alive after 1 year.¹



For **less sick** patients able to live at home, nearly 7 out of 10 who did not get an LVAD are still alive after 1 year.⁵



*Most patients are somewhere in between these two numbers. **Ask your doctor how sick you are.***

How might I feel?

Nearly all patients without an LVAD or transplant continue to have severe heart failure. Symptoms, like anxiety and shortness of breath, may be helped with medicines.

What might occur if I don't get an LVAD or transplant?

Many patients will not be alive at 1 year.^{1,5}

- Patients will not have to be dependent on a machine to live
- Patients can often leave the hospital earlier and spend their remaining time at home
- Palliative care and hospice may be needed sooner - see next page

With or without an LVAD, there are services to help with your **SYMPTOMS** and suffering.

What is palliative care?

Palliative care is medical care for people with serious illnesses. It helps give relief from symptoms, pain, and stress. It also provides emotional and spiritual support. The goal of palliative care is to improve quality of life for patients and their caregivers. Palliative care usually occurs at a patient's home. It can also occur in other places, such as a nursing home or hospice facility.

Even with an LVAD, some patients will continue to feel worse or get sicker due to other health problems. Near the end of life, patients will have the option of turning off the pump. It can be difficult to know when the right time for that is. It is important to talk with your loved ones and doctors ahead of time about your wishes for end of life.

Whether we like it or not, everybody eventually dies.

However, you have some control over how you will live the rest of your life.

Patient Perspectives:

Patients who got an LVAD

"It wasn't an easy choice for me to make. But then I started focusing on my life. On myself."

"I was willing to do anything they told me I had to do to feel better."

Patients who chose not to get an LVAD or transplant

"I don't know if the pump would keep me alive. And even if it does, I'm not sure it would be worth living. Because I'm not going to claw and hold on to the wall to stay alive."

"I'm tired of being in pain and suffering. I'm not scared of death."



If I get an LVAD, how will my life CHANGE?

There are many life-changing aspects of the LVAD. Some details may be different depending on your hospital.



Power Source: You must be plugged into a power source at all times – loss of power to the pump can result in death. When you are sleeping, you will plug into an electrical outlet. During the day you can switch over to batteries, which last up to 17 hours.



Carrying Equipment: Along with batteries, you will have to carry the controller. Equipment can be carried in a bag, vest or on a belt. Battery packs and equipment weigh about 2 to 3 kilograms. Carrying extra battery packs and an extra controller is also important, in case they need to be changed.



Driveline Care: The driveline site (where the electrical cord exits the skin) must be cared for carefully. Dressings must be changed and the site should be cleaned daily or several times a week. Lack of care could cause a serious infection.



Medicine: With an LVAD, you will have to take blood thinners for the rest of your life. You may need to continue some medicine to help with your heart, but most patients take less medicine after getting an LVAD. You also will have to go to the doctor's office for check-ups.



Driveline Site



Water Precautions: Due to the equipment and driveline site, you cannot go into water. This means you can't swim or bathe. There is water protection equipment in order to shower with your device.



Driving: You will not be able to drive a car for 3 months after the implant surgery. After 3 months you may be able to drive if your treating medical team feel it is safe to do so on a conditional license.



Sex: Some patients and their partners report a change in their sex life. However, for most LVAD patients, sex is safe after recovery from surgery.



Emotions: The LVAD may cause emotional effects for both patients and caregivers. Some people are very grateful for the LVAD and get used to these lifestyle changes. Others worry often about their equipment failing or feel overwhelmed with taking care of the device. This stress can lead to depression and anxiety. Seeking mental health care may be helpful.

An LVAD is a major decision for CAREGIVERS, too.

Caring for a patient with severe heart failure often requires lifestyle changes. When a patient gets an LVAD, the caregiver's lifestyle can change even more. The caregiver's responsibilities are different for every patient and change over time.

Some LVAD caregivers feel happy that they can help their loved one. However, some caregivers feel stressed with responsibilities, finances, or the health of the patient.

Caregivers of patients who choose not to get an LVAD may also experience the same feelings.

The LVAD caregiver may help with:

- Driveline site dressing changes and checking for infection
- Equipment care
- Managing medicines
- Arranging follow-up appointments
- Extra care during recovery, usually the first couple months after surgery:
 - Personal hygiene
 - Cooking
 - Running errands
 - Driving the patient

Things to consider:

- Most hospital programs recommend LVAD patients have a caregiver – some programs require a caregiver for up to 3 months after hospital discharge, while other programs may require a longer commitment
- Caregivers must be committed to help the patient every day – this usually lessens over time
- The primary caregiver usually attends training to learn how to operate the LVAD and care for the patient
- Some LVAD programs offer support for caregivers
 - check with your local program to see what is available for caregivers and families



Caregiver Perspectives:

Caregivers of patients with an LVAD

"I am so thankful for the LVAD. You learn to deal with those little things."

"I've never regretted this decision. It's just that sometimes you get to the point where you want to be at the house and not have someone there that you need to constantly take care of."

Caregivers of patients without an LVAD or transplant

"My husband would have been through a lot more stress if he had the LVAD. He died the way he wanted to. He died at home and he died very peacefully. He wasn't in pain and that's brought a lot of peace to me."

"My worries after we made the decision to not get the LVAD were how much worse he was going to get and how long I would be able to keep him at home and look after him."

Take some time to **CONSIDER** what you have learned about LVADs and think about how you want to live the rest of your life.

On a Scale...

How do you want to live out the rest of your life? (check one box)

Favours LVAD

Do everything I can to live longer, even if that means having major surgery and being dependent on a machine.

Favours Medical Therapy

Live with whatever time I have left, without going through major surgery or being dependent on a machine.

Reflection...	With an LVAD?	Without an LVAD?
What do you hope for with or without an LVAD?		
What frightens you about living with or without a LVAD?		

What are your biggest questions...

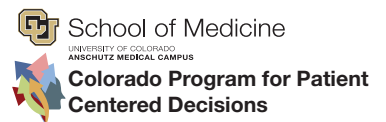
...for your treating medical team? _____

...for your caregiver or family? _____

...for patients who currently have an LVAD? _____

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