Working together to improve critical outcomes for all pediatric and congenital heart failure patients.

The Advanced Cardiac Therapies Improving Outcomes Network (ACTION), was established to improve the care of patients with heart failure. ACTION unites all stakeholders (providers, patients/families and researchers), to share experiences, improve education and search for best practices to drive improvement in areas that are often untouched by clinical trials alone.

The learning network approach allows for critical improvements to be made faster across a collaborative system.

Visit our online education site myactioneducation.org to learn more about:

- understanding your heart failure diagnosis
- medicine treatment options
- knowing your device and surgery options
- maintaining your health and wellness

For more information about the learning network approach or the work ACTION is doing, visit actionlearningnetwork.org.
This is MY VAD Journey

Hi, my name is:

(_____) ___-____

My caregiver is:

----------------
Quick References

It's important to keep some basic information about your diagnosis and surgeries available for quick reference.

My VAD Care Team Contact Info

My Hospital

Name

Street Address

City, State, Zip

My ACTION Site ID

My Heart Disease

I am Allergic to:

information above completed on ____/____/____
### My VAD Surgery

<table>
<thead>
<tr>
<th>Notes:</th>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### My driveline is on the:
- [ ] Left
- [ ] Right

#### I am listed for transplant:
- [ ] No
- [ ] Yes

#### My pump parameters:

<table>
<thead>
<tr>
<th>RPM:</th>
<th>Power:</th>
<th>Flow:</th>
<th>PI:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range</td>
<td>Range</td>
<td></td>
</tr>
</tbody>
</table>

#### I can feel my pulse:
- [ ] Yes
- [ ] No

#### Take my blood pressure using a:

#### My blood pressure goal:

#### Blood thinner medicine(s) I take:

#### My INR goal:

---

**My Past Surgeries**

<table>
<thead>
<tr>
<th>Notes:</th>
<th>Range:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**My VAD Surgery**

- Date:

---

**My driveline is on the:**
- Right

**I am listed for transplant:**
- Yes

**My pump parameters:**

<table>
<thead>
<tr>
<th>RPM:</th>
<th>Power:</th>
<th>Flow:</th>
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<td>Range</td>
<td>Range</td>
<td></td>
</tr>
</tbody>
</table>

**I can feel my pulse:**
- Yes

**Take my blood pressure using a:**

**My blood pressure goal:**

**Blood thinner medicine(s) I take:**

**My INR goal:**

---

**My Past Surgeries**

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</table>

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Using this Handbook

This is a quick educational reference guide and scrapbook to keep track of topics that may come up during your journey. There are times when your care team may ask you to follow different instructions, make sure to write down these important pieces of information.

Additional education will be provided by your care team. If you need more information or clarification on certain topics or questions, please ask your care team.

For complete instructions regarding the HeartMate 3™ LVAD, please refer to your HeartMate 3™ Left Ventricular Assist System Patient Handbook.

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   How will a VAD help me?
   Why do I want a VAD?
   Who will be my care team?

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   Intensive Care
   Transfer Ready
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   HeartMate 3™ LVAD System Components
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   Nutrition & Hydration
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Introduction to Your HeartMate 3™ LVAD

- HeartMate 3™ LVAD Patient Journey
- What is a VAD?
- How will a VAD help me?
- Why do I want a VAD?
- Who will be my care team?
Note: All patients are unique and may not follow the path exactly as shown. Some steps will need to be determined by your care team and/or some may not apply.

- **VAD consult**
- **VAD Surgery**
- **Learn about the VAD and meet the care team**
- **Start blood thinning medicines and work toward goal level**
- **Transition off of IV medicines**
- **Transfer ready: VAD settings and medicine levels stable**
- **Transition out of ICU to step down care**
- **Learn about your medicines and sterile dressing changes**
- **Device training: getting ready for school/work**
- **Packing a ‘go bag’**
- **Learn about VAD equipment**
- **Remove the breathing tube**
- **Get out of bed to get stronger**
- **Learn how to measure blood pressure with a Doppler**
- **Pick up prescriptions and fill pill box**
- **Practice self-care and hygiene**
- **Back to school/work**

*This Patient Journey is sampled from the full ACTION VAD Patient Journey*
What is a VAD?

How does it work?

VAD stands for “Ventricular Assist Device”. It helps a weak or really sick heart to pump blood to the body. The type of VAD that we are talking with you about is a continuous flow VAD, called the **HeartMate 3™ Left Ventricular Assist Device (LVAD)**.

Your HeartMate 3™ LVAD will work by continuously spinning blood from the weak part of the heart, through the device, out to the **aorta**, and the rest of the body. There is a small rotor located inside the VAD that helps with this spinning motion. The pump is always connected to a controller and requires a power source to keep the VAD spinning. Because the continuous flow device bypasses the weakened heart chamber, you may not be able to feel your pulse.
Where is the VAD implanted?

The VAD can be implanted in any chamber of the heart but usually is placed in the left ventricle. The location of the device determines what your VAD may be called. With your care team, check the box next to the kind of VAD that is right for you.

☐ **LVAD:** A left ventricular device implant, or LVAD, is implanted in the left ventricle of the heart. It improves blood flow to the entire body.  
*Note: This is the only U.S. Food & Drug Administration (FDA) approved use for medical device implantation.*

☐ **SVAD:** A systemic assist device is for patients who were born with only one working ventricle. A VAD is implanted into the “systemic” ventricle that pumps blood to the body.

☐ **BiVAD:** A biventricular assist device, or BiVAD, is implanted in both ventricles of the heart.
How will a VAD help me?

VADs are placed for different reasons. Check the boxes below that apply for why you need a VAD.

☐ The VAD will help my body prepare for transplant while I wait for the best heart to be available.

☐ The VAD will make me feel better and allow me to spend more time with my family and friends even if a transplant is not right for me.

☐ The VAD will give more blood flow to my body and make me feel better but my future journey is still unknown.
Why do I want a VAD?

What are your biggest worries about a VAD? What do you hope the VAD will help you do? Use the space below to note the reasons you think a VAD will be right for you and any concerns you may have.
Who will be my care team?

There are many people that will care for you during your journey. You and your family are a very important part of the team and will always help to make decisions about your care.

Fill in your care team member’s names under their titles.

Cardiac Surgeon
Heart Failure/Transplant Doctor
VAD Coordinator
Nurse Practitioner/APRN
ICU Doctor

Nurse(s)

Physical Therapist(PT)/Occupational Therapist(OT)

Psychologist

Cardiac Rehabilitation Specialist

Nutrition Specialist

Pharmacist

Child Life Specialist

Social Worker
Other people from my journey I want to remember are:

<table>
<thead>
<tr>
<th>Name</th>
<th>Why are they special?</th>
</tr>
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**Send Thanks!**

Send a thank you note to anyone who has made an impact in your journey. Let them know how they are doing or why they are special to you.
What to Expect: Surgery

- Expectations
- Surgery
- Intensive Care
- Transfer Ready
- Preparing to Go Home
Many patients that have VAD surgery notice an improvement in symptoms while they are in the hospital, but it can take months for you to get stronger and recover. As you recover, you may feel sad, have pain and be anxious. This is normal. Be honest about how you’re feeling and share your feelings with your care team. Here are some other things to keep in mind:

♥ You will have to work hard on your exercises, both in and out of the hospital, in order to get strong (it can take 3–6 months to recover).
♥ Medicines and time will help lessen the pain.
♥ Sometimes things may not go as planned and there will be bumps in the road. Ask questions if you feel like things are not going as planned.
♥ The **Intensive Care Unit (ICU)** can be loud and it may be hard to sleep at times. If you are having trouble sleeping, talk with your team about options to decrease the noise and interruptions.
♥ What you eat is really important. Your care team will help you make proper food choices.
♥ Your care team will help keep you comfortable and teach you a lot of information in order to keep you safe after surgery.

**Changes in Your Journey**

There are times when a plan may not go as expected, causing your journey to take a different path. Sometimes patients receiving a VAD as a bridge to transplant experience **complications**. Those complications could remove you from being a candidate for transplant. If this happens, your care team will talk to you and your family about the options.

Additionally, if you experience any complications that cause the VAD to not work properly, it may need to be turned off. Your care team will be there with you throughout your journey.
How is the VAD placed in my chest?

The surgery can take an entire day. Your surgeon performs a **sternotomy** (an incision in the chest bone), and implants the VAD into your heart. This will leave a scar on your chest. The surgery requires a heart and lung bypass machine to circulate blood to your body during the operation.

After the surgery your heart and VAD work together to send blood to your body.

My surgery took ________ hours.

---

**Questions I have about my surgery...**

---

**Things to know and how I am feeling after surgery.**
After the operation, you will recover in the ICU. You will have a breathing tube that’s connected to a ventilator (breathing machine) and you will be connected to many lines, tubes, and medical equipment (see illustration below).

This equipment is necessary to monitor your body and give medicine needed for recovery. The equipment and lines can be scary, but are completely normal. Day by day, your care team will work towards removing lines and tubes. The breathing tube is one of the first to be removed. It is also important to get out of bed as soon as possible to help with the recovery process.

1. My breathing tube was removed on ________________.

2. My 1st driveline dressing change was on ________________.

3. My arterial line was removed on ________________.

I got out of bed post-surgery day# ________________.
Your care team watches closely for bumps in the road or issues that may arise. Some of the issues that can occur during your hospital stay include:

**Stroke:** With all VADs there is a risk of stroke, which is caused by bleeding or a blood clot in your brain. Both may cause injury to your brain. Your care team manages your medicines carefully to prevent strokes, however sometimes strokes may occur.

**Chest Bleeding:** After the operation there will be some bleeding from the chest that is captured and removed by the chest tube. Over time the bleeding will slow and the fluid will become clear. This is when **anticoagulation** medicines (blood thinners) will be started to prevent the pump from getting a clot inside of it.

**Infection:** When you come out of the operating room you will be on **antibiotics** to prevent infection. Everything will be kept as clean as possible. Your care team will perform frequent **dressing** changes to prevent germs from causing an infection at your surgical site and driveline site.
**Right Heart Function:** *(for patients with LVADs and two ventricles only)*

For the LVAD to work, the right side of the heart has to be able to move blood to the left side of the heart. When it doesn’t, this is called “right heart failure.” It’s difficult to predict how the right heart will handle surgery. In some instances, you may need to remain on IV medicines or even need a second VAD to help the right side of the heart move blood to the left side of the heart.

**Fluid Management:** The pump needs **preload**, or blood volume, in order for the pump to send fluid to the rest of the body. It can be difficult to determine if you have too much water in your body or if you are **dehydrated**. To make sure there is a perfect fluid balance, medicines (**diuretics**) are given to help get rid of extra fluid.

**High or Low Blood Pressure:** When your blood pressure is too high, the device will have trouble getting blood to the body. When your blood pressure is too low, the blood may have trouble traveling back to the pump. Your care team will determine a target blood pressure goal and adjust medicines to meet the goal.
Transfer Ready

If available at your care center, the Cardiac Floor or Step Down Unit is where you would be transferred after the ICU. These areas of care centers are for patients who are not as critically ill but are still recovering after surgery.

After VAD surgery, I was in the ICU for ________ days. I transferred out of the ICU on ________________.

Your focus will be on getting stronger. In addition, this is the time that education becomes even more important so that you can be discharged out of the hospital.

Preparing to Go Home

There are specific goals that must be met in order to be discharged, or leave the hospital to go home. Use the HeartMate 3™ LVAD Patient Journey in Chapter 1 to follow along and note your specific goals.

NOTE: All patients are unique and may not follow the path exactly as shown. Some steps will need to be determined by your care team and/or some may not apply.

I was discharged on ____________________.
A Lot to Learn: Device Education

- Online Resources
- HeartMate 3™ LVAD System Components
- Mathematics & Mechanics
- HeartMate 3™ LVAD Quiz
Learning about your HeartMate 3™ LVAD is an important part of getting you ready to be discharged and keeping you safe. Your care team and our online educational platform: myactioneducation.org will provide more in depth training with electronic modules and videos to help prepare you for the HeartMate 3™ LVAD quiz you and your caregivers must complete before leaving the hospital.

The VAD equipment is life-saving and while managing it may feel overwhelming, learning how each of the pieces work together will help you feel more comfortable in your daily journey.

Below are some examples of topics covered:

A
ANTICOAGULATION
management perfection

B
BLOOD PRESSURE
management perfection

C
COMMUNICATION
amongst hospital staff and with patients/families

myactioneducation.org

My Login Information

Username: _________________________

Password: _________________________
HeartMate 3™ LVAD System Components

Your HeartMate 3™ LVAD should always be connected to the system controller and will require two power sources to work. It is important to always have backup equipment with you wherever you go.

1 VAD

The HeartMate 3™ LVAD is placed inside your chest. During the surgery, a small hole is cut into your heart muscle and the pump holder (called the apical sewing ring) is attached to the heart muscle. The HeartMate 3™ pump is then inserted through the sewing ring and locked into place. The outflow graft is a flexible tube that connects the outflow of the HeartMate 3™ LVAD to the aorta. It helps carry the blood from the pump to the rest of the body. The inside of the pump has a rotor that spins continuously and can distribute up to 10 liters of blood per minute (L/min).

2 Driveline

The driveline is made of electrical wires that connect the HeartMate 3™ LVAD to the system controller. The driveline has two important functions in order to make the device work properly. First, the driveline brings power to the HeartMate 3™ LVAD to make the pump spin. If the driveline is ever disconnected from the system controller your HeartMate 3™ LVAD will stop working. Secondly, the driveline sends important information back and forth between the LVAD (inside the heart) and the system controller.

There are two parts of the driveline, the pump cable and the modular cable. The pump cable is the section that is mostly inside the body. The modular cable is the section that connects the pump cable to the system controller through a metal connection. If the modular cable is damaged, it can be replaced without having to exchange the pump.
HeartMate 3™ LVAD System Components

3 System Monitor

You will only be plugged into the monitor when you are in the hospital or in clinic. The monitor tells your care team how your device is working so they can make any adjustments needed.

4 System Controller

(A) **Cable Disconnect Symbols**: light up if a power cable or driveline has been disconnected

(B) **Battery Button**: shows how much battery power remains

(C) **Pump Running Symbol**: stays on (and green) to show that the pump is working

(D) **Display Button**: allows the user to advance through settings and alarms

(E) **User Interface Screen**: displays the VAD settings and other important information

(F) **Alarm Symbols**: the red broken heart and wrench symbols notify when there is a problem with the controller or pump, and the battery symbol notifies when the batteries are disconnected or have less than 5 minutes of power remaining
(G) **Silence Alarm Button:** silences active red alarms and power cable disconnected alarm for 2 minutes, low battery yellow diamond alarms for 5 minutes and yellow wrench alarms for 4 hours

(H) **Battery Status Symbol:** displays how much battery power remains when the battery status button is pressed

(I) **Driveline Connector:** the port that attaches the driveline to the controller

(J) **Power Cable Connectors:** attach to the power module, mobile power monitor module or batteries and provide power to the controller

The driveline connects to the controller through the **driveline port (I).** The system controller has **two power cables (J)** that connect to a power source. There is a backup battery in the system controller that powers the controller for approximately 15 minutes in the event that the power becomes disconnected. You will have a primary controller and a backup system controller. Always carry the backup system controller and spare batteries in the event that you need to change them quickly.

The system controller has a display screen (E) that provides VAD settings: Speed (RPM), Flow (L/min), Power (watts) and Pulsatility Index (**See Math & Mechanics section for more information**). You can see each setting by pressing the display button. If there is an active alarm, the screen will provide information and the system controller will have lights to alert you.

**Reminder:** complete a self-test daily by holding the battery button for 5 seconds. All the lights turn on and alarms will sound for 15 seconds and then they will turn off. If this does not occur, follow directions from your care team.
HeartMate 3™ LVAD System Components

5 Batteries (with Clips)

A pair of batteries can last 10–17 hours. The battery indicator on the system controller (H) will show how much power a battery has remaining. The battery indicator has four bars. Each bar represents 25% of the battery life remaining. If the battery is less than 15 minutes, the diamond indicator will turn yellow. The battery indicator will turn red if there is less than 5 minutes remaining.

After checking for full charge, connect the batteries to the clip by lining up the red arrows and inserting the battery into the clip until you hear a click.

To connect a power cable to the clip, align the prongs to make a complete connection. Firmly push the power cable directly to the battery clip. Twist the connector clockwise to tighten the connection. When disconnecting the battery, untwist the connector and pull directly out from the clip.

Battery Charger

The battery charger is a charging station for up to four batteries. It takes 4 hours to completely charge each battery. The status symbol will turn green when a battery is fully charged. Check the symbol before connecting a battery to the controller. If the status symbol is flashing red, the battery must be replaced.
Mobile Power Unit

The Mobile Power Unit (MPU) plugs into the wall and can be used to power the controller while you are sleeping. The MPU has a black cord that plugs into a standard wall power outlet. Make sure that this connection is always tight. The power cables connect to the patient cable the same way that the battery clips are connected. Always connect black-to-black and white-to-white. In the event of a power outage, quickly connect to battery power or a different power source.

Alarms

Alarms can be loud and scary but they are meant to let us know when your LVAD and/or the system controller is not working properly. There is no need to panic when you hear an alarm because there are several steps that you can take to correct the problem. When you hear an alarm, check the display screen to determine what is wrong. Use the troubleshooting guide below or refer to the HeartMate 3™ LVAD alarm guide for more information on alarms. **Notify your care team immediately if you experience any of the critical alarms listed below.**

<table>
<thead>
<tr>
<th>ALARM TYPE</th>
<th>SYSTEM CONTROLLER MESSAGE/SYMBOLS</th>
<th>REASON</th>
<th>ACTION TO TAKE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pump Off</strong></td>
<td>&quot;Call Hospital Contact&quot; AND &quot;Low Flow&quot; alternate AND ![flashing red](solid black)</td>
<td>Pump has stopped running, possibly because power has been disconnected or failed.</td>
<td>Immediately connect to a power source (if disconnected/failed). If restoring power does not resolve, press any button on the Controller to attempt pump start, and immediately call care team.</td>
</tr>
</tbody>
</table>
### HeartMate 3™ LVAD System Components

<table>
<thead>
<tr>
<th>ALARM TYPE</th>
<th>SYSTEM CONTROLLER MESSAGE/SYMBOLS</th>
<th>REASON</th>
<th>ACTION TO TAKE</th>
</tr>
</thead>
</table>
| No External Power | “Connect Power Immediately” and Backup Battery graphic alternate AND
- flashing red
- flashing yellow (next to power cables) | The Controller is not receiving power from either power cable. The pump is being powered by the Controller's backup battery. | Immediately connect to a working power source (Mobile Power Unit or two charged batteries) to ensure pump does not stop. |
| Pump Stop AND No External Power | “Connect Power Immediately” AND “Backup Battery” alternate AND
- heart icon flashing red
- solid black
- flashing yellow (next to power cables)
- flashing red | Pump has stopped running and mobile power unit has failed, possibly due to static electricity. | Immediately connect to charged batteries. If restoring power does not resolve, press any button on the Controller to attempt pump start. |
| Driveline Disconnected | “Connect Driveline” flashes
- flashing red
- flashing red next to driveline connector
- solid black | Driveline is disconnected from the Controller or the connector is broken. | Reconnect the Driveline to the Controller. Move Driveline Safety Lock on the Controller to the locked position. Make sure Modular inline Connector is secure.
- If alarm persists after reconnection, press any button on the Controller to attempt pump start.
- If Driveline alarm still persists, replace Controller with backup.
- If alarm still persists, call care team. |
| Low Flow | “Call Hospital Contact” AND “Low Flow” alternate AND
- heart icon flashing red | Pump flow is less than 2.5 lpm | Make sure the Driveline is connected to the Controller and a power source is connected to the Controller. Call care team for diagnosis. |
| Low Battery (less than 5 min) | “Low Battery” AND “Replace Power Immediately” alternate AND
- flashing red | Less than 5 minutes of battery power remains. | Immediately connect to a working power source (Mobile Power Unit or two charged batteries). |
<table>
<thead>
<tr>
<th>ALARM TYPE</th>
<th>SYSTEM CONTROLLER MESSAGE/SYMBOLS</th>
<th>REASON</th>
<th>ACTION TO TAKE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Controller</td>
<td>Hardware Fault</td>
<td>“Call Hospital Contact; Controller Fault” <strong>AND</strong> All Symbols are off <strong>AND</strong> All Controller buttons are non-functional</td>
<td><strong>Call care team immediately for diagnosis and instructions.</strong> Switch to backup Controller if instructed.</td>
</tr>
</tbody>
</table>

**System Controller Change Out**

The HeartMate 3™ LVAD cannot run without the system controller. If the system controller is not working, the HeartMate 3™ LVAD will stop spinning and may make you feel dizzy, or may even cause you to faint. Stay calm, sit or lay down and contact your care team. Have someone quickly get your backup controller to perform a system controller change out. Once the backup controller is located, place it in front of the faulty controller and follow these steps:

1. Connect the backup batteries to the clips (skip this step if using the mobile power unit).
2. Connect the backup controller to a power source (batteries or mobile power unit).
3. Open the safety lock on the damaged controller and press the red button to release the driveline. While pressing the red button, pull the driveline out of the damaged controller.
4. Line the driveline arrow to the controller arrow and insert the driveline into the new controller until you hear a “click.” Check that the double arrow symbol is green indicating the pump is turned on.
<table>
<thead>
<tr>
<th><strong>Daily</strong></th>
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<tbody>
<tr>
<td>✦ Perform a system controller test—hold battery button until alarm rings and symbols light up</td>
</tr>
<tr>
<td>✦ When removing batteries from charger check battery power before connecting to system controller</td>
</tr>
<tr>
<td>✦ Check that the arrows on the system controller are green</td>
</tr>
<tr>
<td>✦ Scroll through VAD numbers and write them down</td>
</tr>
<tr>
<td>✦ Check for the green light on the mobile power unit before plugging in at nighttime</td>
</tr>
<tr>
<td>✦ Check to make sure the safety lock is covering the red release button</td>
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<table>
<thead>
<tr>
<th><strong>Weekly</strong></th>
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<tbody>
<tr>
<td>✦ Complete driveline dressing care as instructed</td>
</tr>
<tr>
<td>✦ Check the modular connection and driveline for any damage</td>
</tr>
<tr>
<td>✦ Check the battery charger is free of dust and debris</td>
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<tr>
<td>✦ Rotate the unused batteries in the charger slots</td>
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<tr>
<th><strong>Monthly</strong></th>
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<tbody>
<tr>
<td>✦ Inspect and clean the battery and battery clip contacts with a cotton swab dampened with alcohol</td>
</tr>
<tr>
<td>✦ Check for any damage to connections</td>
</tr>
<tr>
<td>✦ Check the shower bag for any damage</td>
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<table>
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<tr>
<th><strong>6 Months – Yearly</strong></th>
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<tbody>
<tr>
<td>✦ Replace the AAA batteries in the mobile power unit</td>
</tr>
<tr>
<td>✦ Inspect both system controllers for damage</td>
</tr>
<tr>
<td>✦ Recalibrate all batteries. Check battery expiration date—if it has been used for more than 3 years, contact your care team</td>
</tr>
<tr>
<td>✦ Have your equipment serviced by your care team. Connect the back up controller to a power source and allow it to charge completely. Afterward, perform a self test on that controller.</td>
</tr>
</tbody>
</table>
What Can Your Care Team Change on the Device?

**Pump Speed or Revolutions Per Minute (RPM):**
How fast the rotor spins is measured in RPM. This is important because the speed determines how much blood can flow through the device to the body. The speed is the only setting your care team can change.

What Does the Device Calculate and Display?

**Cardiac Output (LPM):** The amount of blood that flows through the device and is pumped to the body is measured in “liters per minute (LPM).”

**Power (Watts):** Amount of “work” the pump is doing to get blood to move through the body. How much power the pump is using is measured in “watts.” The controller and power source provides power to the pump to keep it spinning.

**Pulsatility Index:** Provide details on how the pump is functioning – these numbers help guide fluid and blood pressure management.

What Does Your Care Team Calculate?

**Cardiac Index** (L/Min/m2): Amount of blood flow moving through the body in relation to the size of the patient, also known as body surface area (BSA)*

*Body Surface Area (BSA) = takes into account weight & height
HeartMate 3™ LVAD Quiz

Once your education is complete, you and your caregiver will need to complete a quiz about your equipment. The quiz is to make sure everyone is comfortable with the equipment.

Ask your care team for the web link to complete the HeartMate 3™ LVAD quiz.

myactioneducation.org

My quiz is available at:

________________________

________________________

________________________
A Lot to Learn: Self Care

- Labs
- Tests
- Medicines
- Blood Pressure
- Nutrition & Hydration
- Weight
- Emotional Wellbeing
- Driveline Care
You will have laboratory testing (labs), including blood draws, both at scheduled times and whenever your team feels they need to follow you closer. Requested labs may include the following:

<table>
<thead>
<tr>
<th><strong>ANTICOAGULATION</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Heparin Level or Anti-Xa</strong></td>
<td>◼ measures how thick the blood is when on Heparin</td>
</tr>
<tr>
<td><strong>PT/INR</strong></td>
<td>◼ measures how thick the blood is when on Warfarin</td>
</tr>
<tr>
<td><strong>PTT</strong></td>
<td>◼ test performed as frequently as every 6 hours when on IV medications ◼ measures how thick the blood is when on Heparin or Bivalirudin</td>
</tr>
<tr>
<td><strong>LDH</strong></td>
<td>◼ shows if red blood cells are breaking, signaling there may be a clot in the device</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>CARDIAC</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BNP</strong></td>
<td>◼ helps monitor fluid status and how well the heart and VAD are working together</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>HEMATOLOGY</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CBC</strong></td>
<td>◼ measures red blood cells, white blood cells and platelets in the blood</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>KIDNEY</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Renal (BUN/Creatinine)</strong></td>
<td>◼ monitors <em>kidney</em> function and measures fluid status and electrolytes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>LIVER FUNCTION</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hepatic Profile</strong></td>
<td>◼ measures how well the <em>liver</em> is functioning</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>INFECTION &amp; INFLAMATION</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CRP</strong></td>
<td>◼ measures if there is any infection or inflammation within the body</td>
</tr>
</tbody>
</table>
You will have tests at scheduled times and additional ones can be requested whenever your care team thinks you need closer surveillance. Tests include:

**CT Scan:** If the VAD is acting unusually or the LDH is high the team may order a CT scan of the heart. A CT scan of the head may be performed if there is a concern for stroke.

**Echocardiogram:** An “Echo” is an ultrasound that uses nonradioactive, high-frequency sound waves to view the heart. An Echo is a non-invasive test to help the VAD team diagnose any heart or VAD problems.

**Exercise Test:** To determine how well you are doing on the VAD, your care team may order an exercise test. An exercise test may be performed on a stationary bike, a treadmill or as a six minute walk.

**Ramp Study:** A ramp study is performed to determine the best speed (RPM) for your VAD device to be set to. Your care team will watch how your heart reacts as the speed of the device is changed. The ramp study can also be performed if there is concern for a blood clot in the device.

**IMPORTANT** Once you have a VAD, **DO NOT have an MRI test.** A MRI uses strong magnets that attract metal objects and would damage your VAD.
In the hospital, medicine will be given through an IV. Your care team will change those medicines to be given by mouth when preparing for discharge. It’s important the medicines are taken at the same time every day. By the time you are ready to go home, medicines will likely be taken twice a day. Use a pill box to keep your medicines organized. Inform your care team if you take any additional medicines NOT prescribed by them.

Below is a list of medicines you may be taking when discharged. Check off the medicines you are taking and write in any additional ones that are not listed below.

- Aspirin
- Warfarin (Coumadin)
- Enalapril/Lisinopril
- Hydralazine
- Clonidine
- Amlodipine
- Antibiotics
- Omeprazole/Pantoprazole (Protonix)
- Furosemide (Lasix)
- Chlorothiazide (Diuril)
- Spironolactone (Aldactone)
- Sildenafil (Revatio)
Blood Thinners

When you are on a VAD, you will usually be on blood thinner medicine. Your care team will increase and decrease the medicine based on your lab results.

**Aspirin:** You will usually take aspirin to prevent platelets from sticking together and forming a clot in your VAD.

**Warfarin (Coumadin):** Once your care team determines the time is right, you may take warfarin pills by mouth. Warfarin is the most important medicine you will take, but it can be difficult to get your dose (the amount you take) correct. The dose needed will go up and down frequently depending on your INR and it can take a number of days to get it right. Once your dose is correct, your IV blood thinner medicine will be turned off.

Warfarin is what makes your INR (blood levels for anticoagulation or how thick or thin your blood is) increase. Below are causes for:

### High INR (thin blood)
- New medicines
- Prolonged vomiting/diarrhea*
- Prolonged inability to eat*
- An increase in alcohol consumption
- A decreased intake of food or drink containing vitamin K
  *
  
  *Discuss with your care team

### Low INR (thick blood)
- Missed doses of warfarin
- An increased intake of food or drink containing vitamin K
- Large increase in exercise
My goal INR is: ____________________________________.

All warfarin tablets (no matter the brand name) have a color and shape that indicate their strength, or how many milligrams (mg) are in each tablet. There may be frequent changes in your warfarin dosing, please be familiar with your dose’s tablet color and shape. Contact your care team ahead of time if you need refills on medicine so you don’t miss taking any of your doses.

A consistent diet is very important while taking warfarin. Warfarin blocks the ability for the body to activate vitamin K, which helps the body produce blood clots. When vitamin K interacts with warfarin, it can cause changes in your INR level. If you eat foods rich in vitamin K, such as leafy green vegetables, you will need more warfarin to keep your blood thin. Note: Other medicines can also affect how well the warfarin works. Below are some examples of vitamin K rich foods from high to low to be mindful of while on the medicine. Foods with high to medium amounts of Vitamin K will interact with Warfarin the most.

<table>
<thead>
<tr>
<th>Vitamin K Content</th>
<th>Foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Kale, Spinach, Turnip Greens, Collard Greens</td>
</tr>
<tr>
<td>Medium</td>
<td>Cabbage, Coleslaw, Brussel Sprouts, Broccoli, Green Onions, Lettuce, Parsley, Protein Shakes</td>
</tr>
<tr>
<td>Low</td>
<td>Pork Chops, Bacon, Chicken, Green Beans, Edamame, Soybeans, Asparagus, Pinenuts, Cashews, Kidney Beans, Kiwi, Avocado, Cheese</td>
</tr>
<tr>
<td>Very Low</td>
<td>Ground Beef, Green Peas, Prunes, Blueberries, Blackberries, Blackberries, Pomegranate</td>
</tr>
</tbody>
</table>

information above completed on ____/____/_____.

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High Blood Pressure
At times, on a VAD you may have high blood pressure, which will prevent the VAD from pumping well and can increase your risk of stroke. Blood pressure medicine examples include:

- Enalapril
- Clonidine
- Amlodipine
- Other blood pressure medicines

Preventing Infection
Antibiotics are given in the operating room and ICU to prevent infection. They are also given if your driveline gets infected. You may need antibiotics indefinitely to prevent infection. Antibiotics can make your INR high or low. **Immediately notify your care team if you start taking an antibiotic.**

Stomach Ulcers & Acid Reflux
Medicines to prevent “heartburn” are used to decrease the acid in the stomach. This may help with decreasing your stomach discomfort. Examples include:

- Omeprazole/Pantoprazole (Protonix)
- Lansoprazol (Prevacid)

Extra Body Water (Diuretics)
Diuretics were important when you were in heart failure. When you are on a VAD you should require less, but you still may need a small amount to get the fluids in your body just right. Examples include:

- Furosemide (Lasix)
- Chlorothiazide (Diuril)
- Spironolactone (Aldactone)
Blood Pressure

Controlling your blood pressure is important. Your care team will determine a target blood pressure goal and adjust medicines to meet it. Blood pressure can be monitored using a blood pressure cuff and/or a Doppler. This depends on if you can feel a pulse. If you go to an outside hospital you may need to tell them the best way to take your blood pressure.

My blood pressure goal is: __________________________.

The best way to take my blood pressure is using a: (Check one)

- Blood Pressure Cuff
- Doppler

Nutrition & Hydration

Once you have your VAD you must stay on a stable diet. Eating a healthy diet will help you heal and get stronger.

Fluids

To function properly, the VAD needs a certain amount of fluid flowing through it. Preload is the amount of fluid in your body, or how “full” the heart is. Dehydration from not drinking enough, or increased fluid losses
(vomiting, diarrhea, sweating) will lead to low preload. High preload is usually caused by drinking too much or not peeing enough.

If you have **low pre-load** (dehydration) you may experience:

♥ lightheadedness, tiredness, falls
♥ alarms from your VAD

If you have **high preload** (fluid-overload) you may experience:

♥ swollen face, hands, or legs
♥ poor appetite
♥ shortness of breath

VAD speed and flow may need to be changed over time as your fluid balance changes. It’s important to track your weight and fluid intake, so your care team knows if your fluid balance is off.

**My goal is to drink** ______________ of water per day.

---

**Weight**

**My weight at discharge is** _____________ lbs/kgs.

**I will weigh myself at home every** ___________ day(s).
Contact my care team if my weight is:

☐ above ________ lbs/kg

☐ below ________ lbs/kg

Emotional Wellbeing

For some patients, having a VAD and needing lots of medical care can be hard. You or your caregiver may feel sad, worried, or even angry at times. Taking care of your emotional and mental health is a very important part of your care. Be sure to talk with your care team if you have these feelings or any changes in behavior. Your care team will be able to connect you with the right support services.

Things that make me feel better when worried or upset:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

information above completed on ___/___/____
Driveline Care

The driveline connects the VAD on the inside of the body to the system controller on the outside of the body. If an infection develops on or around your driveline site, it can be very serious. Depending on how bad it is, the infection may need to be treated with IV or long-term antibiotics taken by mouth, or it may require being admitted into the hospital.

It’s important to properly care for the driveline site to prevent infection. Germs that collect at the driveline site could travel to the heart if left untreated. Frequent movement of the driveline can cause damage above and underneath the skin and increase the risk of infection. Using anchors to keep the driveline in place is important to keep the driveline site healthy.

**Dressing Changes:** Your driveline site will need to have dressing changes using *sterile* technique. Everyone should use sterile gloves and wear masks during dressing changes. How often you change your dressings will be determined by your care team.

My dressing should be changed every _________ day(s).
Life Outside the Hospital: Potential Challenges

• Infections
• Strokes
• Bleeding
• Hemolysis
• Pump Clots
If an infection develops on or around your driveline, it can be very serious. Most infections can be treated with antibiotics and changes to your dressing care.

If the infection becomes more severe and spreads to your blood it is called *sepsis* or bacteremia. This will need to be treated with antibiotics through an IV and you will potentially need to be hospitalized. While it is rare, if the infection can’t be cleared from the blood with the VAD in place, the device may need to be taken out and a new one put in place, which would require another surgery.

If you notice any changes in your driveline or if your driveline gets pulled, tell your care team right away so it can be treated quickly. Signs and symptoms of a driveline infection include:

- Redness
- Pain or tenderness
- Drainage (new or increased)
- Swelling and warmth
- Fever
With all VADs there is a risk of stroke, which is caused by bleeding or a blood clot in your brain. Both may cause injury to your brain. Your care team manages your medicines carefully to prevent strokes, however sometimes strokes may occur.

Notify your care team or call 911 if you have any of the following symptoms:

- Headaches that are different than usual
- Numbness and/or tingling on one side of the body
- Weakness on one side of the body
- Losing feeling and/or movement in the legs or arms
- Slurring words or trouble when talking
- Facial expressions and movements don’t match (or mirror) on each side of the face
- Pupil (the dark circle in the middle of the eye) sizes don’t match
Bleeding

When on blood thinners, you are always at risk of bleeding. You may experience bleeding from your gums when brushing your teeth and your cuts may bleed more than normal.

Girls may experience heavier bleeding during menstrual periods and may need to seek additional treatment.

If you are involved in a traumatic accident, such as a car accident, it can be harder to stop the bleeding. Your care team will need to help.

Nose Bleeds: Blood thinners often can lead to nose bleeds. To prevent nose bleeds, use petroleum jelly or saline nose spray in your nasal passages during cold, dry weather. Do not pick your nose as this may start a nosebleed.

If you have a nose bleed:

♥ Stay calm. Look forward. Do not tilt your head back.
♥ Hold pressure at the bridge of your nose for 10 minutes without letting go.
♥ If pressure doesn’t stop the bleeding, your care team may advise you to use Afrin® or saline nasal spray.
♥ Let your care team know if you can’t stop the bleeding, or if you have frequent nose bleeds.
♥ Your care team may need to decrease your blood thinner medicine, or you may need to see a special Ear, Nose, and Throat (ENT) doctor.

Gastrointestinal (GI) Bleeds: Rarely, you may have a more serious bleed in your belly. Signs and symptoms of a GI bleed include:

♥ Belly pain and no appetite
♥ Vomit with blood in it
♥ Black, tarry, or sticky stools
Hemolysis

Red blood cells are a type of cell that circulate in your blood, bringing oxygen to your tissues and organs. When your red blood cells break down, it’s called hemolysis. Hemolysis may occur for multiple reasons, the most concerning being a mechanical problem with the VAD. If a clot develops in the VAD it can affect the flow, causing red blood cells to break down as they pass through it. In return, this causes an elevation in your LDH (a marker in your blood of broken red cells) blood test.

Notify your care team if you have any of the following symptoms:

♥ Pink, red, cola, or tea colored urine
♥ Increased pump power/flow that is out of your range
♥ Decreased pump power that is out of your range

Pump Clots

Your VAD could develop a clot inside of it, causing it not to work properly. If this happens, and changes to your blood thinner medicine doesn’t fix the problem, you may need to get a new VAD. The following symptoms should be discussed with your care team:

♥ Pink, red, cola, or tea colored urine
♥ Increased pump power/flow that is out of your range
♥ Heart failure symptoms such as shortness of breath, exhaustion, or abdominal pain/vomiting
Daily Life & Safety

- Your “Go Bag”
- Dental Visits
- Colds & Non-VAD Infections
- Over the Counter Medicines
- Travel
- School & Work
- Exercise
Always have backup equipment with you in case something happens to one of your VAD components. The following items should always be with you:

- Emergency VAD contact information
- Extra controller
- Extra batteries and clips
- Water bottle
- Medicines (needed while away)
Dental Visits

Good dental hygiene is very important. If you get an infection in your mouth it could lead to an infection in your VAD. Before you go to the dentist for a cleaning or other dental work you will need to take antibiotics, called an antibiotic prophylaxis.

My care team wants me to take:

___________________________________________________________________
___________________________________________________________________

Colds & Non-VAD Infections

When you have a VAD you can still get common colds or other infections. Do everything you can to avoid getting sick. Wash your hands frequently, avoid contact with others who are sick, and get a flu shot every year.

Always let your care team know if you get sick. They may direct you to your primary care doctor or ask to see you themselves. What you think may be a common illness could be something more serious for you. Being sick will affect your INR and your care team may need to make changes to your blood thinner medicine.
Always check with your care team before starting any new prescription, over the counter medicine, or any other medicines or remedies.

When on a VAD, you may have pain, especially after your surgery.

You CAN’T take NSAIDS (Motrin, Advil, Ibuprofen) because it changes how your blood clots

You CAN take Acetaminophen (Tylenol) for pain

Safe over the counter medicines for me to take include:

- 
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-
As a precaution, always carry your VAD emergency information with you.

Driving Precautions

Every state has different rules about driving with a VAD, discuss this with your care team. If you are a licensed driver, use caution within the first 90 days after surgery because you may still be taking medication that may affect your concentration. Some medications will cause side effects that you won’t have adjusted to yet.

When you start driving again, take short supervised trips to get used to driving with the new equipment. If you feel dizzy, short of breath, or have blurred vision, pull over to the side of the road immediately and call for help.

Long Distance and Air Travel

You will be able to travel, even on a plane but it takes some extra planning with your care team to make sure you’re safe. You will need a travel plan and an emergency action plan for long-distance trips. Your care team will make this plan and contact other ACTION hospitals to discuss your care.

When traveling by plane, you will not go through standard security. You will need to tell the airline agents you have a medical device and they will take you through a separate security lane.
It will vary from hospital to hospital, but once your care team decides it's safe for you to return home and go to school or work, multiple steps will occur to ensure your safety.

When you do leave the hospital, make sure to:

♥ Have a trained person available to help with alarms and emergencies
♥ Notify the local EMS department (fire station, police, etc.)
♥ Have backup batteries, a backup controller, and any additional information your team gives you to prepare for leaving the hospital

If your care team feels you must stay in the hospital for a longer period of time, you may be able to get school services in the hospital. In-hospital school staff can work with your school to make sure you get the right learning materials.
Once you’ve recovered from surgery you should be exercising to get stronger. **You will not be able to swim or play contact sports.** You may be instructed to do special exercises at home or you may be asked to come to the hospital frequently to exercise in the clinic. Your care team will help you choose exercises that you can do safely. With your care team, check off the activities that you can do:

- Ride a bike (wear a helmet)
- Shoot hoops
- Throw a football
- Kick a soccer ball
- Walk or Jog
- Bowling
- Tennis
- Yoga

If you have a wearable tracking device, talk to your care team about coming up with a step goal to keep you moving daily.

My daily step goal is _____________ steps.
Your Journey Continues: Resources

- The Waitlist
- Reasons to Call Your Care Team
- Keeping You Safe
- Emergency Services & Medical Safety Card
With heart failure, patients often feel uncomfortable, sad, frustrated and even angry. Our goal is to help you feel better and get back to doing the things you enjoy. A VAD should help to relieve the symptoms of heart failure, although it may take a while to see the benefit. Always discuss how you feel with your care team so they can help you achieve the best quality of life possible.

**Waitlist Video:** If you are on the waitlist for transplant and want more information about how ACTION can help with your journey, visit [actionlearningnetwork.org](http://actionlearningnetwork.org) or the [ACTION YouTube channel](https://www.youtube.com/) to watch our waitlist video.

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**Reasons to Call Your Care Team**

If you are discharged to go home, you will have a detailed communication plan. The plan will include a phone number to call. Your care team will want to hear about most everything. Examples include:

- Change in pump parameters, equipment issues, and alarms
- Blood pressure outside your goal ranges
- Changes in your diet
- New medicines
- Pain or Bleeding
- Fever
- Changes to driveline site
- Red, pink, cola, or tea colored urine
- Changes in your mood or anything else you feel uneasy about
Keeping You Safe

When on a VAD you will feel better and you will want to be active. Your care team will talk with you about what is safe and what is not safe.

You CAN’T

take a bath, swim, vacuum or play contact sports.

You CAN

shower (with a shower kit), play, dance, jog, travel and drive (if old enough).
Prevent exposure to static electricity when possible. If you are concerned about exposure, make sure to use battery power. Use dryer sheets when doing laundry, wear rubber sole shoes/slippers indoors, be careful on outdoor slides.

Protect your controller and batteries when it is raining outside or around large amount of water.

Always wear a seatbelt in the car.

Never disconnect your driveline. Your pump will stop. Never disconnect from both power sources.

Wash your hands before doing a dressing change.

Always bring your backup equipment when leaving the house. Check the battery charge level before connecting to batteries.

If there is a power outage, switch to battery power. Notify your care team if the power is out for more than 24 hours.

For bleeding cuts, firmly press on the cut for 5–10 minutes, or until the bleeding stops. Call your care team if the bleeding does not stop.
Local Emergency Services (Medical/Fire/Utilities): Either you or your care team members should notify your local emergency medical department when you are discharged. It is nice for them to know you are at home with life-saving equipment. If you lose power you must relocate to a new location or contact your care team if you have questions about what to do.

Medical Safety Card: Always carry your medical safety card with you in case of an emergency. If you don’t have a medical safety card, ask your care team to provide the ACTION medical safety card (sample below) for you.
Glossary

- Glossary
- Word Search
Glossary

**Antibiotics:** Medicines to treat bacteria and germs.

**Anticoagulation:** Medicines to make your blood thinner so your VAD pump does not clot.

**Aorta:** The large artery that brings blood from the heart to the rest of the body.

**Clot:** When red blood cells stick together to form a ‘glob’ in one of your blood vessels. Similar to a scab.

**Complications:** A disease or problem that happens in addition to the first disease.

**Consistent Diet:** Always eating the same kind of foods.

**Dehydrated:** When you do not drink enough water, or you have diarrhea, the volume of fluid in your body goes down. This can make your pump not work as well.

**Diagnosis:** Determining the cause of the disease or problem.

**Discharged:** When you leave the hospital and go home, or go to a local place such as the Ronald McDonald house or a hotel.

**Diuretics:** Medicine to make you pee more.

**Dressing:** A bandage around the driveline that is coming out of your belly.

**Hygiene:** Keeping yourself clean to prevent infection.

**Implant/Implanted:** During surgery your VAD is placed in your heart.

**Intensive Care Unit (ICU):** A place in the hospital where patients recover after surgery when they leave the operating room.
**Kidney:** The organs in your body that remove waste and make pee.

**Liver:** The organ in your body that cleans the blood.

**Preload:** The amount of fluid that travels through your blood vessels to your heart.

**Sepsis:** An infection in your blood which can make you very sick.

**Sterile:** Keeping a wound clean. Using a procedure that includes clean gloves and masks to make sure germs do not get near the driveline.

**Sternotomy:** An incision in the chest bone that is made by the surgeon to get to your heart.

**Stroke:** When a blood clot travels to your brain through a blood vessel.
**Brief Summary:** Prior to using these devices, please review the Instructions for Use for a complete listing of indications, contraindications, warnings, precautions, potential adverse events and directions for use.

**HeartMate 3™ LVAS Indications:** The HeartMate 3™ Left Ventricular Assist System is indicated for providing short- and long-term mechanical circulatory support (e.g., as bridge to transplant or myocardial recovery, or destination therapy) in adults and pediatrics with advanced refractory left ventricular heart failure and with an appropriate body surface area.

**HeartMate 3™ LVAS Contraindications:** The HeartMate 3™ Left Ventricular Assist System is contraindicated for patients who cannot tolerate, or who are allergic to, anticoagulation therapy.

**HeartMate 3™ LVAS Adverse Events:** Adverse events that may be associated with the use of the HeartMate 3™ Left Ventricular Assist System are: death, bleeding, cardiac arrhythmia, localized infection, right heart failure, respiratory failure, device malfunctions, driveline infection, renal dysfunction, sepsis, stroke, other neurological event (not stroke-related), hepatic dysfunction, psychiatric episode, venous thromboembolism, hypertension, arterial non-central nervous system (CNS) thromboembolism, pericardial fluid collection, pump pocket or pseudo pocket infection, myocardial infarction, wound dehiscence, hemolysis (not associated with suspected device thrombosis) or pump thrombosis.

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