# HeartMate 3™ LVAD

## Patient Education Handbook







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* 

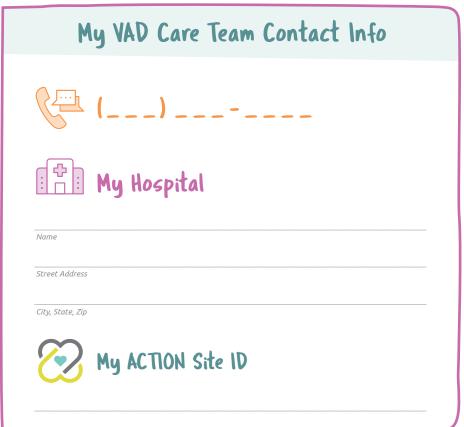


Hi, my name is:

| ()               |
|------------------|
|                  |
| My caregiver is: |

## **Quick References**

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



| – My Heart Disease – | I am Allergic to:                |
|----------------------|----------------------------------|
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| Surgeries |  |
| 96        |  |
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| My Past   |  |
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| My VAD Surgery                  | Date:                       |  |
|---------------------------------|-----------------------------|--|
| Notes:                          |                             |  |
|                                 |                             |  |
| My driveline is on the:         | l am listed for transplant: |  |
| Left Right                      | No Yes                      |  |
| My pump parameters:             |                             |  |
| RPM: Power:                     | Flow:PI:                    |  |
| I can feel my pulse: Yes No     |                             |  |
| Take my blood pressure using a: |                             |  |
| My blood pressure goal:         |                             |  |
| Blood thinner medicine(s)       | l take: My INR goal:        |  |
|                                 |                             |  |
|                                 |                             |  |

#### **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  $3^{\text{TM}}$  LVAD, please refer to your *HeartMate*  $3^{\text{TM}}$  *Left Ventricular Assist System Patient Handbook.* 

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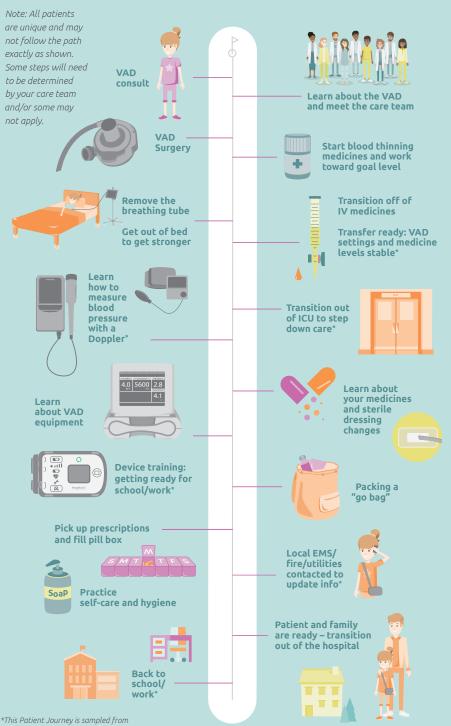
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# Introduction to Your HeartMate 3™ LVAD

- HeartMate 3<sup>™</sup> 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?



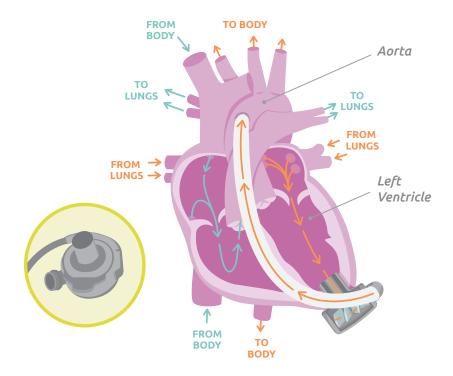
# Heart Mate 3™ LVAD Patient Journey



the full ACTION VAD Patient Journey

#### What is a VAD?

#### How does it work?

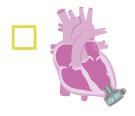


VAD stands for "Ventricular Assist Device". It helps a weak or really sick heart to pump blood to the body. The type of VAD that we are talking with you about is a continuous flow VAD, called the **HeartMate 3™ Left Ventricular Assist Device (LVAD).** 

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 will you hope the VAD will help you do? Use the space below to note any concerns or reasons you think a VAD will be right for you.

## 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 Doctor |
| VAD Coordinator      |
| Nurse Practitioner   |

| ICU Doctor                        |
|-----------------------------------|
| Nurse(s)                          |
|                                   |
| Physical Therapist(PT)/           |
| Occupational Therapist(OT)        |
| Psychologist                      |
| Cardiac Rehabilitation Specialist |
| Nutrition Specialist              |
| Pharmacist                        |
| Child Life Specialist             |
| Social Worker                     |

## Who will be my care team?

Other people from my journey I want to remember are:

| Name | Why are they special? |
|------|-----------------------|
|      |                       |
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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



#### **Expectations**

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.

# Surgery

| Questions I have                                   | e about my surgery   |
|--|--|
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |
|  |  |
| How is the VAD placed i                            | n my chest?  |
| an incision in the chest bone), and ir             | Your surgeon performs a <i>sternotomy</i> mplants the VAD into your heart. This urgery requires a heart and lung bypass body during the operation. |
| After the surgery your heart and VAI<br>your body. | D work together to send blood to   |
| My surgery took                                    | hours.   |
|  |  |
| Things to know and how                             | u I am feeling after surgery.  |
|  |  |
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#### **Intensive Care**

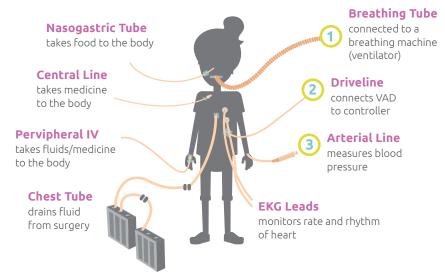
After the operation, you will recover in the ICU. You will have a breathing tube that's connected to a ventilator (breathing machine) and you will be connected to many lines, tubes, and medical equipment (see illustration below).

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 # \_\_\_\_



#### **Intensive Care**

#### **Unplanned Events**



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.



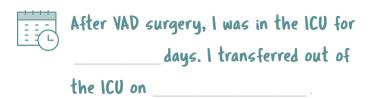


**Doppler** 



## **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.



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<sup>TM</sup> 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.

# A Lot to Learn: Device Education

- Online Resources
- HeartMate 3<sup>™</sup> LVAD System Components
- Mathematics & Mechanics
- HeartMate 3<sup>™</sup> LVAD Quiz

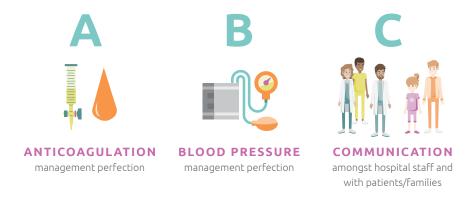


#### **Online Resources**

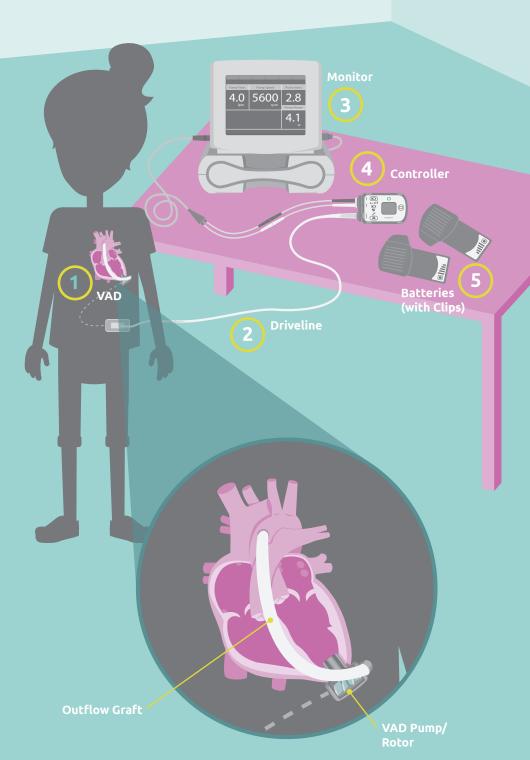
Learning about your HeartMate 3™ LVAD is an important part of getting you ready to be discharged and keeping you safe. Your care team and our online educational platform: *myactioneducation.org* will provide more in depth training with electronic modules and videos to help prepare you for the HeartMate 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:



| myactioneducation.org |
|-----------------------|
| My Login Information  |
| Username:             |
| Password:             |
|                       |



## HeartMate 3™ LVAD System Components

Your HeartMate 3<sup>™</sup> 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.



The HeartMate  $3^{TM}$  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  $3^{\text{TM}}$  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  $3^{\text{TM}}$  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  $3^{\text{TM}}$  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  $3^{\text{TM}}$  LVAD to make the pump spin. If the driveline is ever disconnected from the system controller your HeartMate  $3^{\text{TM}}$  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.



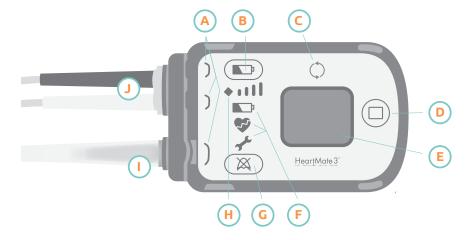
The modular cable is the section that connects the pump cable to the system controller through a metal connection. If the modular cable is damaged, it can be replaced without having to exchange the pump.

#### HeartMate 3<sup>™</sup> 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<sup>™</sup> 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 represent 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.



Batteries with Clips



Battery Charger

#### 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 listed below.

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** 

| ALARM TYPE                           | SYSTEM CONTROLLER MESSAGE/SYMBOLS   | REASON  | ACTION TO TAKE  |  |  |
|--------------------------------------|---|---|---|--|--|
| CRITICAL ALARMS Contant Tone Sounded |   |   |   |  |  |
| Pump Off                             | "Call Hospital Contact"  AND "Low Flow" alternate  AND  flashing red  solid black | Pump has stopped running, possibly because power has been disconnected or failed. | 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. |  |  |

тоге >

## HeartMate 3<sup>™</sup> LVAD System Components

| ALARM TYPE                               | SYSTEM CONTROLLER MESSAGE/SYMBOLS   | REASON   | ACTION TO TAKE   |
|--|---|--|--|
| No External<br>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<br>AND<br>No External<br>Power | "Connect Power Immediately"  AND "Backup Battery" alternate AND  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<br>Disconnected                | "Connect Driveline" flashes flashing red flashing red next to driveline connector solid black   | Driveline is<br>disconnected from<br>the Controller or<br>the connector is<br>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  flashing red  | Pump flow is less<br>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<br>(less than<br>5 min)      | "Low Battery" AND "Replace Power Immediately" alternate AND  Flashing red   | Less than 5 minutes of battery power remains.  | Immediately connect to a<br>working power source (Mobile<br>Power Unit or two charged<br>batteries.  |

| ALARM TYPE                   | SYSTEM CONTROLLER MESSAGE/SYMBOLS   | REASON   | ACTION TO TAKE   |
|------------------------------|---|--|--|
| Controller<br>Hardware Fault | "Call Hospital Contact;<br>Controller Fault" AND<br>All Symbols are off AND<br>All Controller buttons are<br>non-functional | Controller is not functioning. Pump will operate as long as power is applied to the Controller and no other malfunction occurs. All alarms are not functional. | Call care team immediately for diagnosis and instructions.  Switch to backup Controller if instructed. |

#### System Controller Change Out

The HeartMate 3<sup>™</sup> LVAD cannot run without the system controller. If the system controller is not working, the HeartMate 3<sup>™</sup> 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:

- 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).
- 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.

# HeartMate 3™ LVAD System Components

# My Heart Mate 3™ LVAD Checklist

#### Daily

- Perform a system controller test—hold battery button until alarm rings and symbols light up
- When removing batteries from charger check battery power before connecting to system controller
- Check that the arrows on the system controller are green
- Scroll through VAD numbers and write them down
- Check for the green light on the mobile power unit before plugging in at nighttime
- Check to make sure the safety lock is covering the red release button

#### Weekly

- Complete driveline dressing care as instructed
- Check the modular connection and driveline for any damage
- Check the battery charger is free of dust and debris
- Rotate the unused batteries in the charger slots

#### Monthly

- Inspect and clean the battery and battery clip contacts with a cotton swab dampened with alcohol
- Check for any damage to connections
- Check the shower bag for any damage

#### 6 Months - Yearly

- Replace the AAA batteries in the mobile power unit
- Inspect both system controllers for damage
- Recalibrate all batteries. Check battery expiration date—if it has been used for more than 3 years, contact your care team
- 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.

# **Mathematics & Mechanics**

## What Can Your Care Team Change on the Device?



#### Pump Speed or Revolutions Per Minute (RPM):

How fast the rotor spins is measured in RPMs. 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 (L/Min):** The amount of blood that flows through the device and is pumped to the body is measured in "liters per minute (L/min)."



**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  $3^{\text{TM}}$  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



# Labs

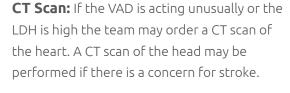
You will have laboratory testing (labs), including blood draws, both at scheduled times and whenever your team feels they need to follow you closer. Requested labs may include the the following:

| ANTICOAGUL                  | ATION  |
|-----------------------------|--|
| Heparin Level<br>or Anti-Xa | measures how thick the blood is when on Heparin  |
| PT/INR                      | measures how thick the blood is when on Warfarin   |
| PTT                         | <ul> <li>test performed as frequently as every 6 hours when<br/>on IV medications</li> </ul>               |
| PII                         | <ul> <li>measures how thick the blood is when on Heparin<br/>or Bivalirudin</li> </ul>                     |
| LDH                         | <ul> <li>shows if red blood cells are breaking, signaling<br/>there may be a clot in the device</li> </ul> |
| CARDIAC                     |  |
| BNP                         | <ul> <li>helps monitor fluid status and how well the heart<br/>and VAD are working together</li> </ul>     |
| HEMATOLOG                   | Y  |
| СВС                         | <ul> <li>measures red blood cells, white blood cells and<br/>platelets in the blood</li> </ul>             |
| KIDNEY                      |  |
| Renal                       | <ul> <li>monitors kidney function and measures fluid status<br/>and electrolytes</li> </ul>                |
| LIVER FUNCT                 | ION  |
| Hepatic Profile             | measures how well the <i>liver</i> is functioning  |
| INFECTION &                 | INFLAMATION  |
| CRP                         | <ul> <li>measures if there is any infection or inflammation<br/>within the body</li> </ul>                 |

#### **Tests**

You will have tests at scheduled times and additional ones can be requested whenever your care team thinks you need closer surveillance. Tests include:



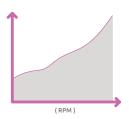




**Echocardiogram:** An "Echo" is an ultrasound that uses nonradioactive, high-frequency sound waves to view the heart. An Echo is a non-invasive test to help the VAD team diagnose any heart or VAD problems.



**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.

# **Medicines**

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

## **Medicines**

#### **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.

| 1 mg | 2 mg     | 2.5 mg | 3 mg | 4 mg | 5 mg                  | 6 mg               | 7.5 mg | 10 mg |
|------|----------|--------|------|------|-----------------------|--------------------|--------|-------|
|      |          |        |      |      |                       |                    |        |       |
| Pink | Lavender | Green  | Tan  | Blue | Peach<br>light orange | Teal<br>blue-green | Yellow | White |

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.



# **Medicines**

#### 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)









# **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

# **Nutrition & Hydration**

(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 tear | n if my weight is: |  |
|----------------------|--------------------|--|
| above                | lbs/kgs            |  |
| below                | _lbs/kgs           |  |
|                      |                    |  |

# **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 | be | feel | better | when | worried | or ups | et: |
|---|--------|------|------|----|------|--------|------|---------|--------|-----|
|   |        |      |      |    |      |        |      |         |        |     |
| _ |        |      |      |    |      |        |      |         |        |     |
| - |        |      |      |    |      |        |      |         |        |     |
| _ |        |      |      |    |      |        |      |         |        |     |
|   |        |      |      |    |      |        |      |         |        |     |

# **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

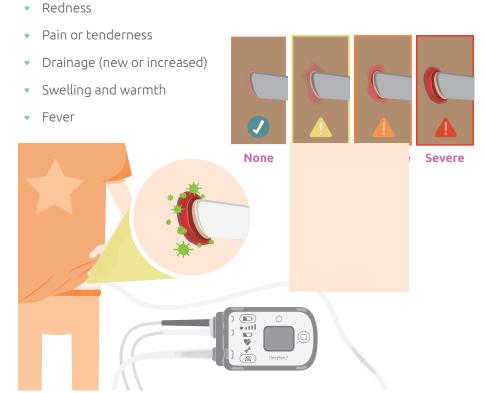


# **Infections**

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:



# **Strokes**

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



# Your "Go Bag"

Always have backup equipment with you in case something happens to one of your VAD components. The following items should always be with you:



#### **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.



# **Over the Counter Medicines**

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



(Tylenol) for pain

| Safe over the counte | r medicines for me to take include: |
|----------------------|-------------------------------------|
|                      |                                     |
|                      |                                     |
|                      |                                     |
|                      |                                     |

# Travel

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.



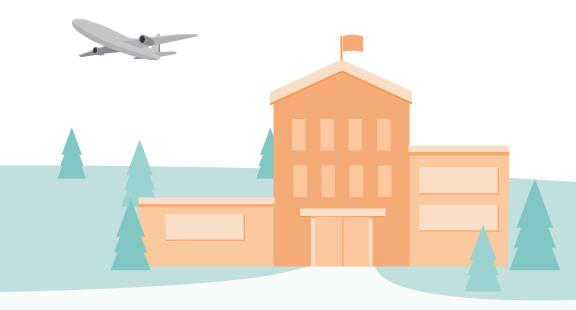
# **School & Work**

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, 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.



## Exercise

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:



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 |
|----------|------|------|----|-------|
|          |      | J    |    |       |

# Your Journey Continues: Resources

- The Waitlist
- Reasons to Call Your Care Team
- Keeping You Safe
- Emergency Services & Medical Safety Card



## The Waitlist

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* or the *ACTION YouTube channel* to watch our waitlist video.

# **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.

# **Emergency Services & Medical Safety Card**



**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.



| First Name MRN: |  |
|-----------------|--|
| DIAGNOSIS:      |  |
| NOTES:          |  |
|                 |  |
|                 |  |
|                 |  |
|                 |  |
|                 |  |

# 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.

# **Word Search**

```
WZXA
                             NACV
       NLWNNL
                                 O V D
               S
                 G U
                         H N
                             M F
                                       O V
   O W B
             D
               R
                 MNEBCYYT
                                 P
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| Antibiotics     | Diagnosis  | Kidney     |
|-----------------|------------|------------|
| Anticoagulation | Discharged | Liver      |
| Aorta           | Diuretics  | Preload    |
| Clot            | Dressing   | Sepsis     |
| Complications   | Hygiene    | Sterile    |
| Consistent Diet | ☐ Implant  | Sternotomy |
| Dehydrated      | □ ICU      | Stroke     |



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#### Rx Only

**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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