

ADVANCED CARDIAC THERAPIES IMPROVING OUTCOMES NETWORK

HVAD™ System

Patient Education Handbook



action n



ADVANCED CARDIAC THERAPIES
IMPROVING OUTCOMES NETWORK

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:

- ♥ _____
- ♥ _____
- ♥ _____
- ♥ _____
- ♥ _____

My Past Surgeries

My VAD Surgery

Date: _____

Notes: _____

My driveline is on the:

☐

Left

☐

Right

I am listed for transplant:

☐

No

☐

Yes

Listing Date _____

My pump parameters: _____

RPM: _____ Power: _____ Flow: _____
Range Range

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:



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 HVAD™ System, please refer to your **HeartWare™ HVAD™ System Patient Manual**.

HVAD and HEARTWARE are trademarks of Heartware, Inc.

©2021 Cincinnati Children's Hospital Medical Center. All Rights Reserved.

The contents of this VAD book, including text, graphics and other materials ("Contents") is offered solely for educational and informational purposes. The information should in no way be considered as offering medical advice for a particular patient or as constituting medical consultation services, either formal or informal. The Contents do not constitute either an explicit or implicit consent or contract by any physician or other employee of Cincinnati Children's Hospital Medical Center or other member of the ACTION Network (collectively, "Network") to create a physician-patient relationship and such information in no way creates, substitutes or in any way consists of examination, diagnosis, treatment or the prescription of treatment for any patient. Content users must use their independent judgment in determining the value and use of the information contained herein and its application to a situation. The Network expressly disclaims any decision-making authority or supervisory control over the Content users. No information provided herein shall create a warranty of any type nor shall any person rely on any such information or advice. Views expressed or implied in the Contents are not the official positions or views of the Network. The Network makes no representations or warranties of any kind, express or implied, about the completeness, accuracy, or reliability of the information contained in the Contents.

IN NO EVENT WILL ANY MEMBER OF THE NETWORK OR THEIR RESPECTIVE TRUSTEES, OFFICERS, EMPLOYEES, AGENTS, VOLUNTEERS, OR REPRESENTATIVES BE LIABLE TO YOU OR ANY OTHER PARTY FOR ANY DIRECT, INDIRECT, CONSEQUENTIAL, EXEMPLARY, INCIDENTAL, SPECIAL OR PUNITIVE DAMAGES OR CLAIMS OF ANY KIND.

Table of Contents



1. Introduction to Your HVAD™ System 09

HVAD™ System Patient Journey

What is a VAD?

How will a VAD help me?

Why do I want a VAD?

Who will be my care team?



2. What to Expect: Surgery..... 19

Expectations

Surgery

Intensive Care

Transfer Ready

Preparing to Go Home



3. A Lot to Learn: Device Education 27

Online Resources

HVAD™ System Components

Mathematics & Mechanics

HVAD™ System Quiz



4. A Lot to Learn: Self Care..... 41

Labs

Tests

Medicines

Blood Pressure

Nutrition & Hydration

Weight

Emotional Wellbeing

Driveline Care

Table of Contents



5. Life Outside the Hospital: Potential Challenges 53

Infections

Strokes

Bleeding

Hemolysis

Pump Clots



6. Daily Life and Safety 59

Your “Go Bag”

Dental Visits

Colds & Non-VAD Infections

Over the Counter Medicines

Travel

School & Work

Exercise



7. Your Journey Continues: Resources 67

The Waitlist

Reasons to Call Your Care Team

Keeping You Safe

Emergency Services & Medical Safety Card



8. Glossary 73

Glossary

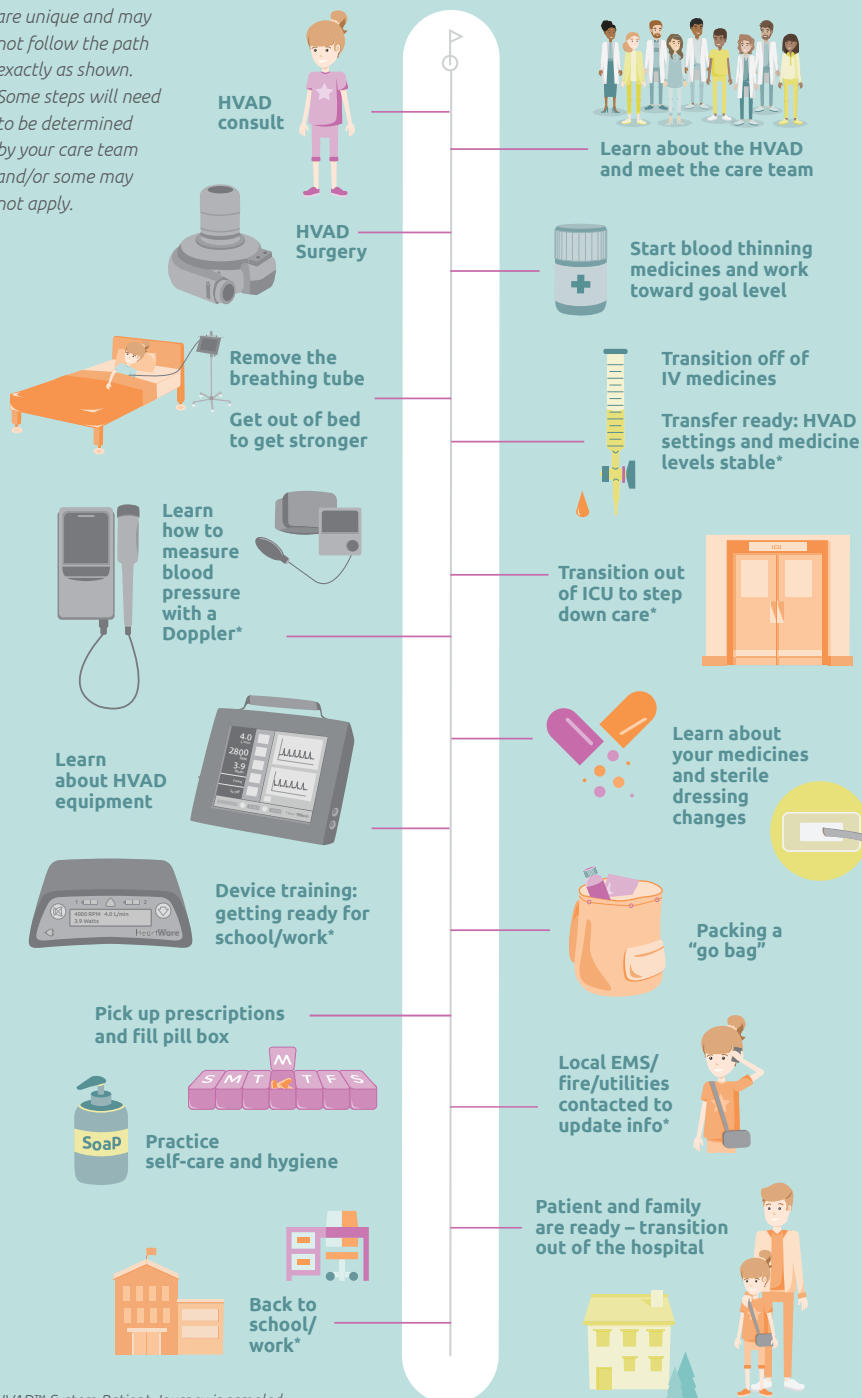
Word Search

Introduction to Your HVAD™ System

- ♥ HVAD™ System Patient Journey
- ♥ What is a VAD?
- ♥ How will a VAD help me?
- ♥ Why do I want a VAD?
- ♥ Who will be my care team?

HVAD™ System Patient Journey*

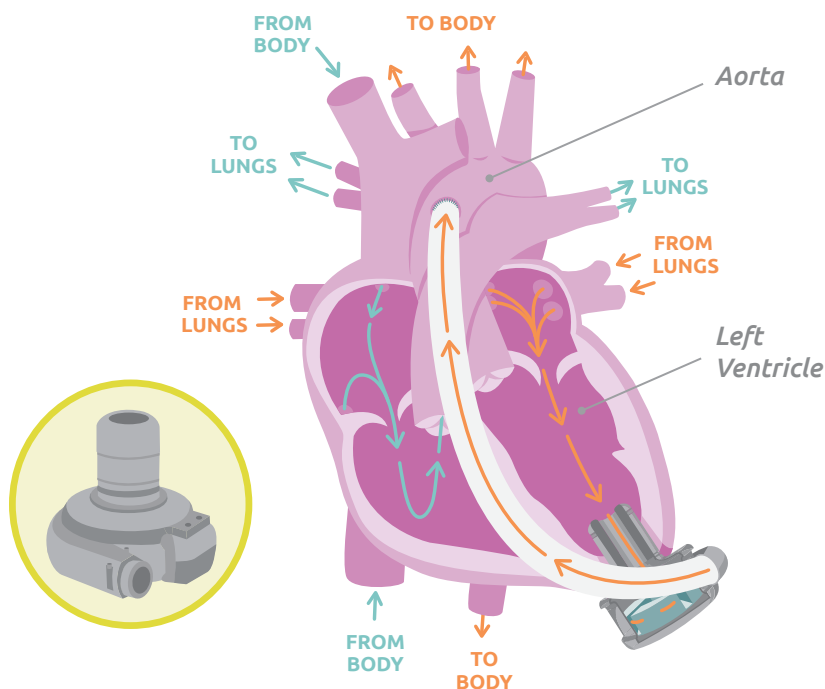
Note: All patients are unique and may not follow the path exactly as shown. Some steps will need to be determined by your care team and/or some may not apply.



*HVAD™ System Patient Journey is sampled from the full ACTION VAD Patient Journey

What is a VAD?

How does it work?

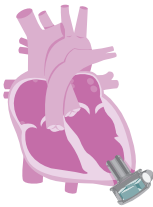


VAD stands for “Ventricular Assist Device”. It helps a weak or really sick heart to pump blood to the body. The type of VAD that we are talking with you about is a continuous flow VAD, called the **HVAD™ System**.

Your continuous flow VAD 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 impeller located inside the VAD that helps with this spinning motion. The pump is always connected to a controller and a power source that keeps the VAD spinning. Because the continuous flow device bypasses the weakened heart chamber, you may not be able to feel your pulse.

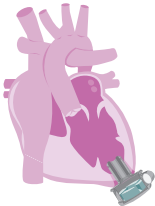
Where is the VAD implanted?

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.

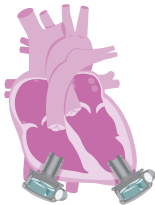


LVAD: A left ventricular device implant, or LVAD, is implanted in the left ventricle of the heart. It improves blood flow to the entire body.

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.



A large, rounded rectangular box with a yellow border, containing horizontal lines for writing. The box is positioned in the center of the page, below the text prompt. The lines are evenly spaced and extend across the width of the box. The box is set against a background of teal geometric shapes.

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 _____



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 HVAD 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 about my surgery...

How is the HVAD 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 HVAD 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 HVAD work together to send blood to your body.



My surgery took _____ hours.

Things to know and how I am feeling after surgery.

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.

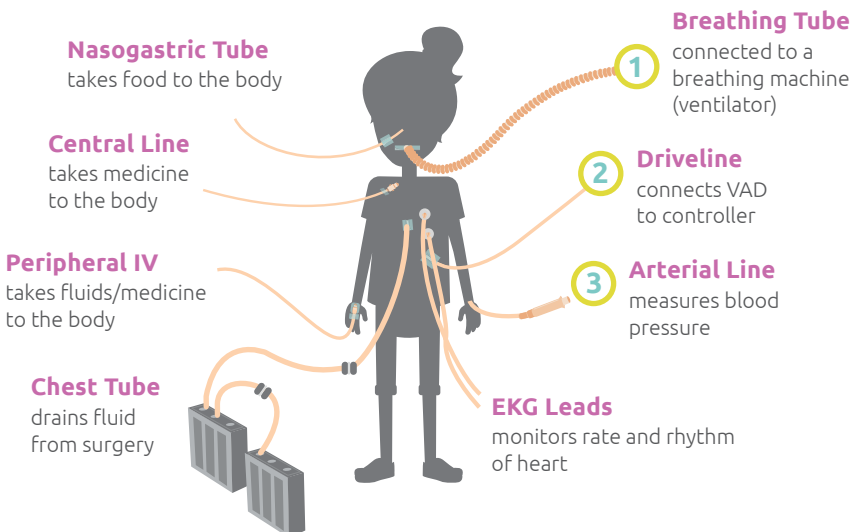
1 My breathing tube was removed on _____.

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 HVADs 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. It will slow and the fluid will become clear. When the bleeding has slowed, **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.

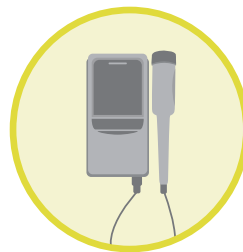
Fluid Management: The pump needs ***preload***, or blood volume, in order for the pump to send fluid to the rest of the body. It can be difficult to determine if you have too much water in your body or if you are ***dehydrated***. To make sure there is a perfect fluid balance, medicines (***diuretics***)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

Blood Pressure Cuff



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.



After HVAD 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 **HVAD™ System Patient Journey map 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
- ♥ HVAD™ System Components
- ♥ Mathematics & Mechanics
- ♥ HVAD™ System Quiz

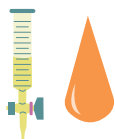
Online Resources

Learning about your HVAD is an important part of getting you ready to be discharged and keeping you safe. Your care team and our online learning site: myactioneducation.org will provide more in depth training with electronic modules and videos to help prepare you for the HVAD™ System quiz you and your caregivers must complete before leaving the hospital.

The HVAD 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:

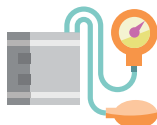
A



ANTICOAGULATION

management perfection

B



BLOOD PRESSURE

management perfection

C



COMMUNICATION

amongst hospital staff and
with patients/families

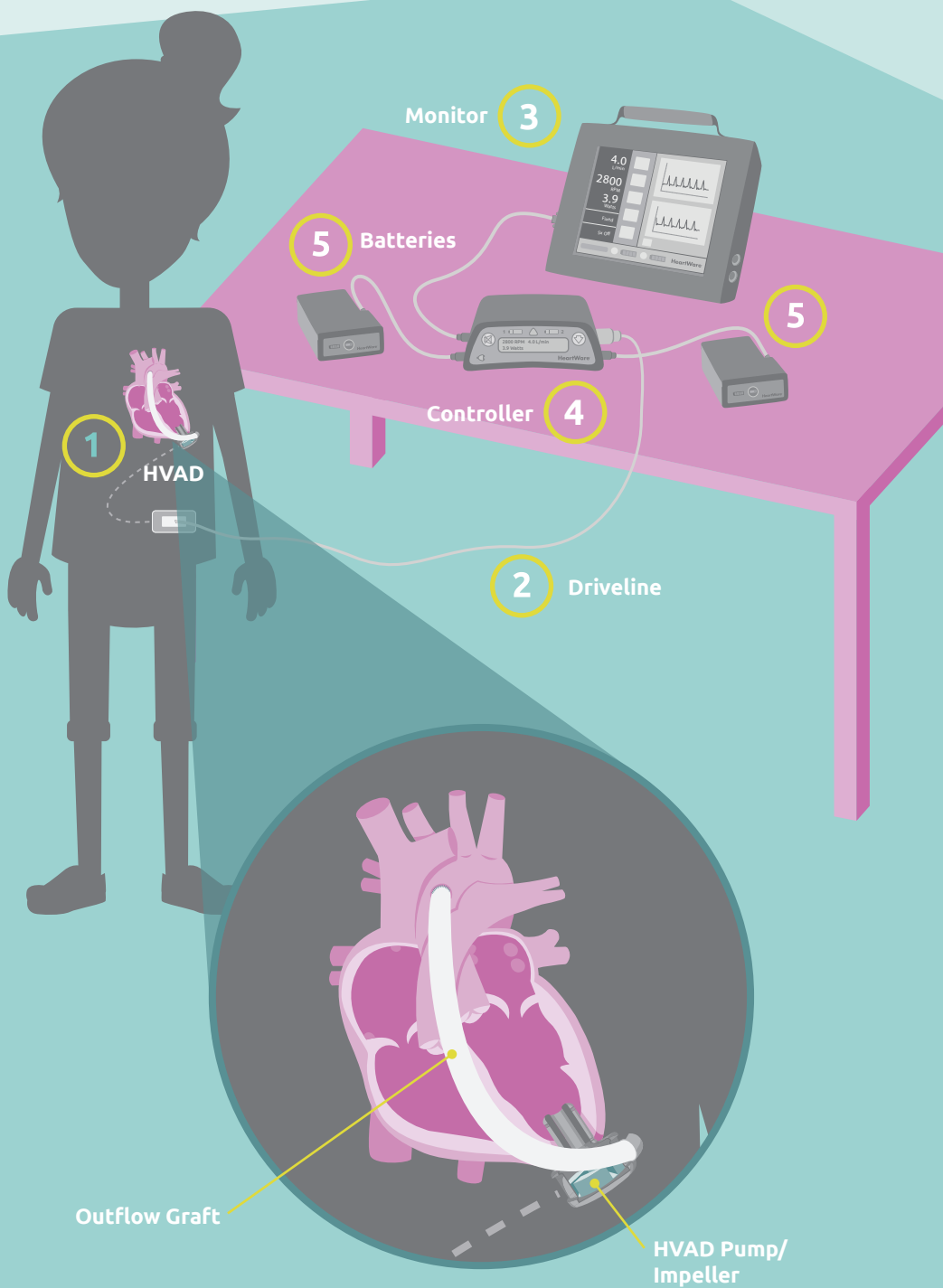


myactioneducation.org

My Login Information

Username: _____

Password: _____

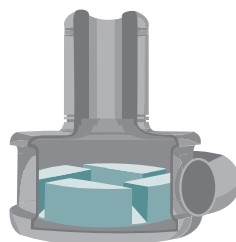


HVAD™ System Components

Your HVAD 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 HVAD

The HVAD is implanted inside of your chest. During the surgery, a small hole is cut through the muscle of the heart and carefully removed to fit the inflow of the pump. The sewing ring is sewn to the outside of the heart. The pump inflow is inserted through the sewing ring and locked into place. The outflow graft is a flexible tube that connects the outflow of the pump to the aorta. It helps carry the blood from the pump to the rest of the body. The inside of the pump has an impeller that spins continuously and can distribute up to 10 liters of blood per minute (L/min).



2 Driveline

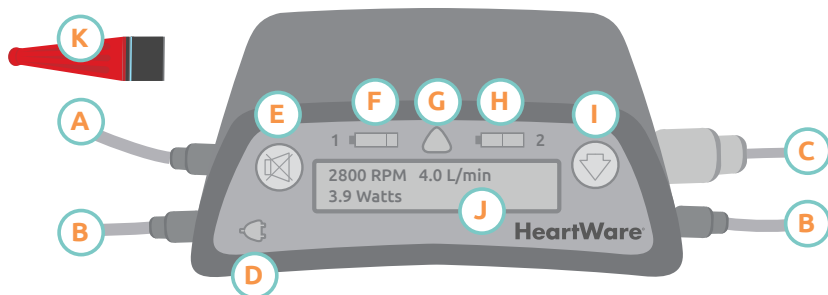
The driveline cord is filled with electrical wires that connect the HVAD to the controller (the brains of the HVAD). This cord performs two functions to help the device work properly. The HVAD (inside the heart) transfers important information to the controller through the driveline. The driveline also brings power back to the pump to make the HVAD spin. Never disconnect your driveline because this would make your pump stop.

3 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.

HVAD™ System Components

4 Controller



The driveline connects to a port located on the controller. The controller provides power to the pump and the pump sends vital information back about how the pump is working. There are 4 ports: **the monitor connection (A)**, **two power connections (B)**, and **the driveline connection (C)**.

The controller has a display **(J)** with information on it, buttons that control alarms and lights that alert you to what is going on. The display provides HVAD settings: Speed (RPM), Flow (L/min), and Power (watts) (*See Math & Mechanics section for more information*). If there is an alarm, the screen will provide information about the alarm.

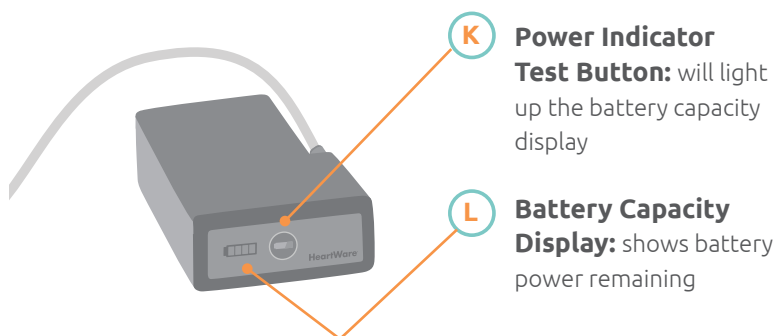
- (D) AC/DC Indicator:** shows if the controller is connected to wall power
- (E) Silence Button:** will mute a low or medium alarm
- (F) Battery Power Indicator 1:** shows battery power remaining
- (G) Alarm Indicator:** small triangle that lights up yellow or red when an alarm occurs
- (H) Battery Power Indicator 2:** shows battery power remaining
- (I) Scroll Button:** the scroll button allows the user to advance through the settings and alarms
- (J) Controller Display**

(K) Red Alarm Adapter (Pacifier): When both power sources have been disconnected, the red alarm adapter silences the high alarm. Note: Should only be inserted on a non-active controller.

5 Batteries

A pair of batteries will power your device when it is not connected through the AC or DC adapter. A single battery can last **4–7 hours**. When the controller is connected to 2 batteries, it drains one battery at a time providing **a maximum of 14 hours**. Throughout the day you will need to check battery power levels and change batteries when needed.

The battery indicators on the controller **(F & H)** show how much power each battery has remaining. The battery indicator has four bars. Each bar represent 25% of the battery life remaining. When the battery reaches 50%, the indicator will turn yellow. With less than 25%, the indicator will turn red and the controller will draw power from the second battery. When both batteries reach less than 25%, a low battery alarm will sound. For safety, be sure to change the batteries before both reach the low battery stage.



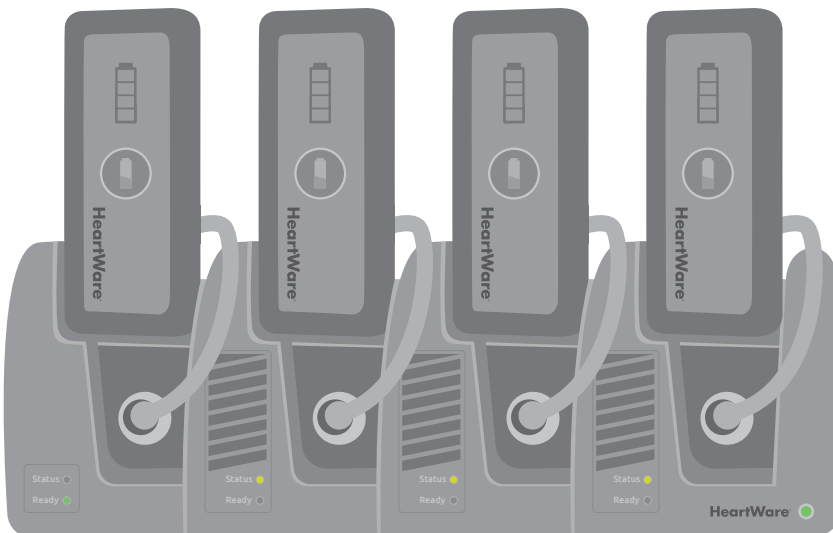
There is also a power indicator **(L)** on the battery itself. Prior to connecting the battery to the controller, always press the power indicator test button **(K)** to make sure the battery is fully charged.

HVAD™ System Components

After checking for full charge, connect the batteries to the controller by lining up the solid white arrow on the cable connector with the dot on the controller. Insert the cable directly to the power connection port. A good connection will result in an audible click. When disconnecting a battery, rotate the connector counterclockwise, and pull the power cable straight out from the controller. If the controller does not have power connected within 20 seconds, it will beep with a power disconnect low alarm. Replace the battery connection as soon as possible.

Battery Charger

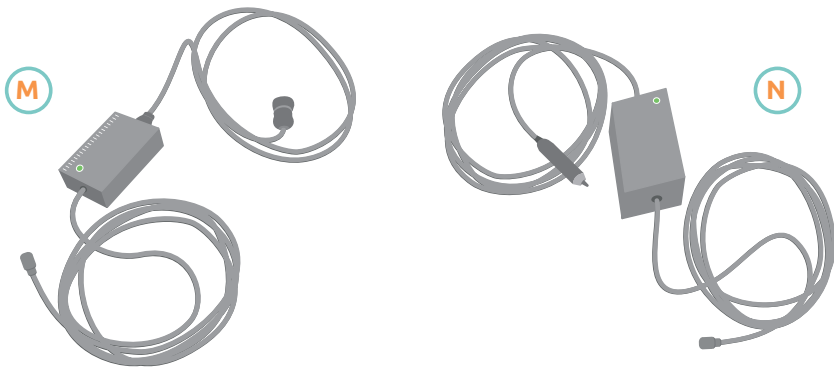
The battery charger dock is a charging station for up to four batteries. It takes **5–6 hours** to completely charge each empty battery. The status symbol will turn green when a battery is fully charged. Check the symbol before connecting a battery to the controller. If the status symbol is flashing red, the battery must be replaced. Rotate the use of your batteries and charge them nightly to ensure the best battery function.



Electrical Power (AC/DC Adapters)

The AC adapter **(M)** connects from the wall to the controller. When using the AC adapter, the controller only pulls power from the wall. A battery should always stay connected to the controller when using an AC adapter. The DC adapter **(N)** connects to a car charger port and can be used when power is needed during long road trips.

You will always need to have two power sources connected. You must avoid being away from electricity for a long period of time, and always keep spare batteries with you. Always check your controller to determine how much battery you have. Never disconnect from both power sources because it will lead to your pump stopping.



HVAD™ System Components

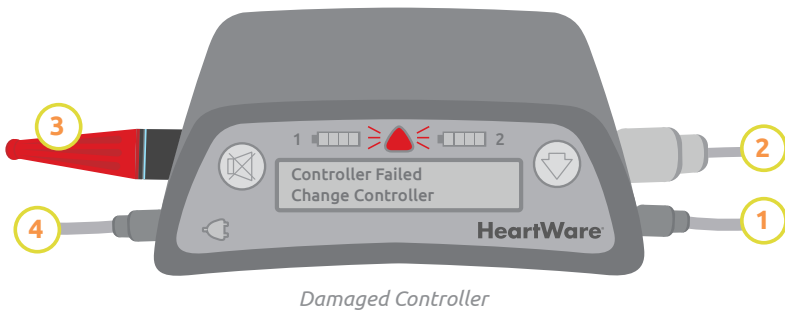
Alarms

Alarms can be loud and scary but they are designed to let us know when your HVAD and/or the controller are 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 the alarm, check the display screen to determine what is wrong. Use the troubleshooting guide below and refer to the HVAD alarm guide for more information on alarms. **Notify your care team immediately if you experience high or medium alarms.**

ALARM TYPE	CONTROLLER MESSAGE	REASON	ACTION TO TAKE
LOW ALARM <i>(low pitched intermittent beeping sound & solid yellow light)</i>			
Low Battery	Replace Battery 1 or 2	Alarm sounds when both batteries have 10–25% remaining	<i>Change to a fully charged battery</i>
Battery Disconnect	Reconnect Battery 1 or 2	Alarm sounds when only one power source is connected	<i>Connect additional power source</i>
MEDIUM ALARM <i>(three tone sounds & yellow flashing light)</i>			
Low Flow	Low Flow Call	Pump flow decreased below set limit	<i>Call care team</i>
Suction	Suction Call	Pump inflow is blocked, preventing flow through the pump.	<i>Call care team</i>
High Watts	High Watts Call	Pump power is higher than the set limit	<i>Call care team</i>
HIGH ALARM <i>(loud continuous high pitched sound or two tone beeping sounds & RED flashing light)</i>			
Driveline Disconnect	VAD Stopped Connect Driveline	Driveline is disconnected from the controller or the connector is broken	<i>Reconnect driveline to the driveline port</i>
Power Disconnect	(blank screen)	Two power sources are removed from the controller at one time	<i>Reconnect power immediately</i>
Critical Low Battery 1 Or 2	Critical Battery 1 or 2 —or— Replace Battery 1 or 2	Battery power is critically low	<i>Change battery immediately</i>
Controller Failure	Change Controller	The controller may have a critical error and may stop working	<i>Change controller</i>

Controller Change Out

If the controller fails, the pump will stop spinning which may cause dizziness, palpitations, or may even cause you to faint. Stay calm and contact your care team. Make sure you are sitting down, and have someone quickly find a backup controller to perform a controller change out. Once the backup controller is located, place it in front of the faulty controller and follow these steps:



- 1** Remove **power cable #1** from the damaged controller and connect it to the new controller in the same port location (right front).
- 2** Disconnect the **driveline** from the damaged controller and connect it to the new controller in the driveline port. This should immediately restart the pump.
- 3** Insert the **red alarm adapter** into the damaged controller's monitor connection port (left back) to prevent the high alarm from continuously sounding in the next step.
- 4** Remove **power cable #2** from damaged controller and connect it to the new controller in the same port location (left front).

HVAD™ System Components

HVAD Checklist

Daily

- ♥ Check the batteries for full charge before connecting to the controller
 - ♥ Scroll through HVAD numbers and write them down
-

Weekly

- ♥ Complete driveline dressing care as instructed
 - ♥ Check controller and driveline for any damage
 - ♥ Rotate the unused batteries in the charger slots
 - ♥ Ensure the red alarm adapter is close to the backup controller
-

Monthly

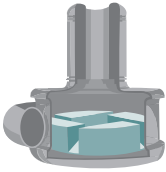
- ♥ Inspect the battery contacts and clean with a dry cotton swab
 - ♥ Check the batteries and battery charger for any damage to the connections
 - ♥ Check the shower bag for any damage
-

6 Months – Yearly

- ♥ Inspect both controllers for damage
- ♥ Have your equipment serviced by your care team

Mathematics & Mechanics

What Can Your Care Team Change on the Device?



Pump Speed or Revolutions Per Minute (RPM):

How fast the pump 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).”

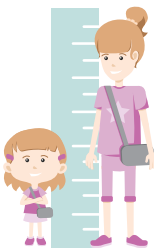


Power (Watts): Amount of “work” the pump is doing to get blood to move through the body. How much power the pump is using is measured in “watts.” The controller and power source provides power to the pump to keep it spinning.



Pump Waveforms: 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*

HVAD™ System 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 HVAD™ System 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

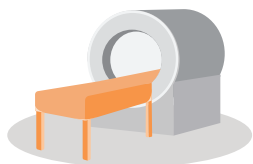
Labs

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 following:

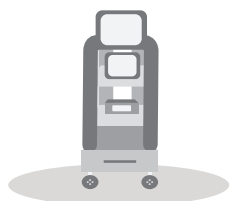
ANTICOAGULATION	
Heparin Level or Anti-Xa	♥ measures how thick the blood is when on Heparin
PT/INR	♥ measures how thick the blood is when on Warfarin
PTT	♥ test performed as frequently as every 6 hours when on IV medications ♥ measures how thick the blood is when on Heparin or Bivalirudin
LDH	♥ shows if red blood cells are breaking, signaling there may be a clot in the device
CARDIAC	
BNP	♥ helps monitor fluid status and how well the heart and HVAD are working together
HEMATOLOGY	
CBC	♥ measures red blood cells, white blood cells and platelets in the blood
KIDNEY	
Renal	♥ monitors <i>kidney</i> function and measures fluid status and electrolytes
LIVER FUNCTION	
Hepatic Profile	♥ measures how well the <i>liver</i> is functioning
INFECTION & INFLAMMATION	
CRP	♥ measures if there is any infection or inflammation within the body

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:



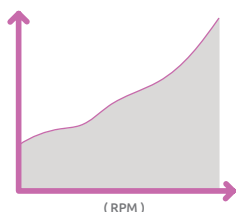
CT Scan: If the HVAD is acting unusually or the LDH is high the team may order a CT scan of the heart. A CT scan of the head may be performed if there is a concern for stroke.



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 HVAD team diagnose any heart or HVAD problems.



Exercise Test: To determine how well you are doing on the HVAD, 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 HVAD 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 HVAD, **DO NOT have an MRI test.** A MRI uses strong magnets that attract metal objects and would damage your HVAD.

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.

- | | |
|---|---|
| <input type="checkbox"/> Aspirin | <input type="checkbox"/> Chlorothiazide (Diuril) |
| <input type="checkbox"/> Warfarin (Coumadin) | <input type="checkbox"/> Spironolactone (Aldactone) |
| <input type="checkbox"/> Enalapril/Lisinopril | <input type="checkbox"/> Sildenafil (Revatio) |
| <input type="checkbox"/> Hydralazine | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Clonidine | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Amlodipine | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Antibiotics | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Omeprazole/Pantoprazole (Protonix) | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Furosemide (Lasix) | <input type="checkbox"/> _____ |

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.

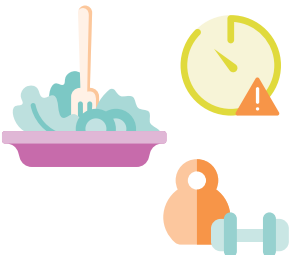
Warfarin is what makes your INR (blood levels for anticoagulation or how thick or thin your blood is) increase. Below are causes for:



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 light purple	Green	Tan	Blue	Peach light orange	Teal 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.

High 400–800+ mcg per 100 grams	Medium 80–400+ mcg per 100 grams	Low 25–80 mcg per 100 grams	Very Low <25 mcg per 100 grams
Kale Spinach Turnip Greens Collard Greens	Cabbage Coleslaw Brussel Sprouts Broccoli Green Onions Lettuce Parsley Protein Shakes	Pork Chops Bacon Chicken Green Beans Edamame Soybeans Asparagus Pinenuts	Cashews Kidney Beans Kiwi Avocado Cheese Ground Beef Green Peas Prunes Blueberries Blackberries Pomegranate

information above completed on ____/____/____

Medicines

High Blood Pressure

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

- ♥ Enalapril
- ♥ Amlodipine
- ♥ Clonidine
- ♥ 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 HVAD 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 HVAD you must stay on a stable diet. Eating a healthy diet will help you heal and get stronger.



Fluids

To function properly, the HVAD 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 HVAD

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

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

HVAD 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.



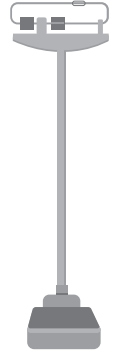
I will weigh myself at home every _____ day(s).



Contact my care team if my weight is:

☐ above _____ lbs/kgs

☐ below _____ lbs/kgs



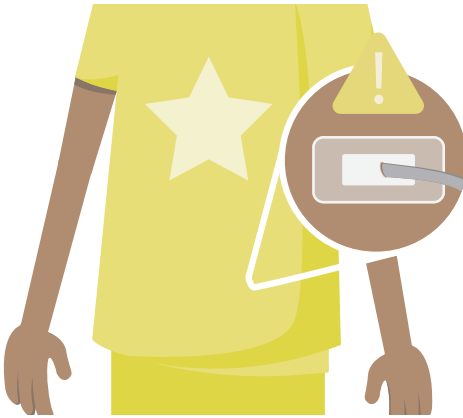
Emotional Wellbeing

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 me feel better when worried or upset:

Driveline Care

The driveline connects the HVAD on the inside of the body to a 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, the infection may 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

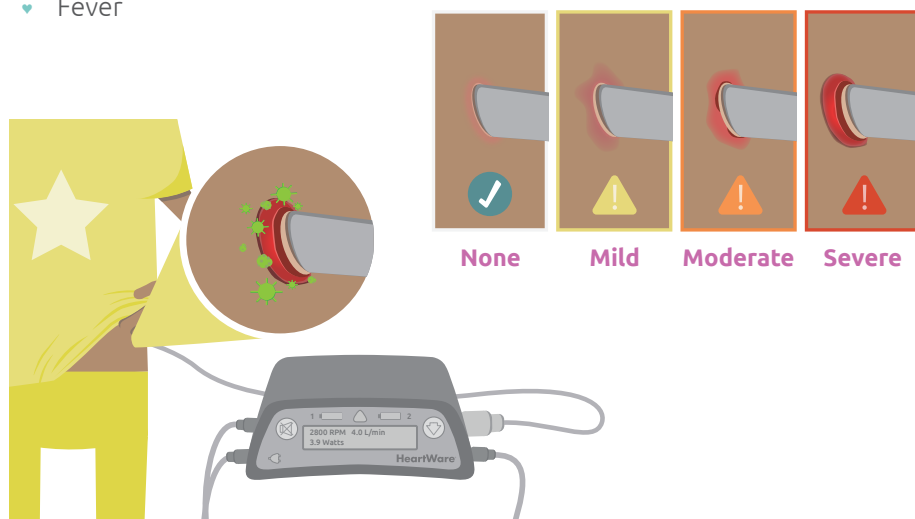
Infections

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 HVAD 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

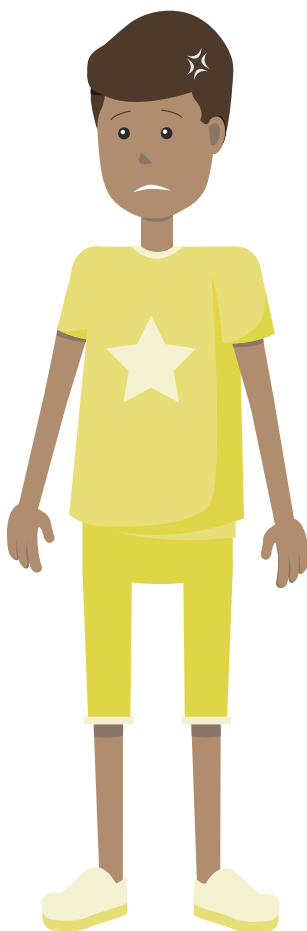


Strokes

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:

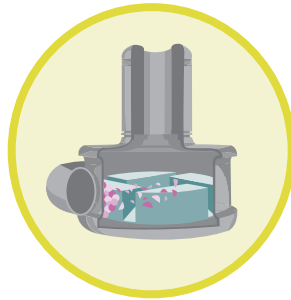
- ♥ Belly pain and no appetite
- ♥ Vomit with blood in it
- ♥ Black, tarry, or sticky stools

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 HVAD. If a clot develops in the HVAD 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:

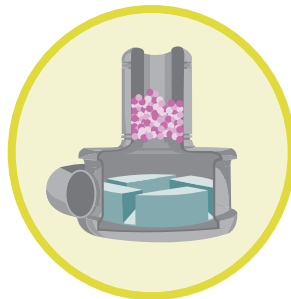
- ♥ Pink, red, cola, or tea colored urine
- ♥ Increased pump power/flow that is out of your range
- ♥ Decreased pump power that is out of your range



Pump Clots

Your HVAD 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 HVAD. 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 HVAD components. The following items should always be with you:



- ♥ Emergency VAD contact information
- ♥ Extra controller
- ♥ Extra batteries
- ♥ 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 HVAD. 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 HVAD 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 HVAD, 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:



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, a back up 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:

☐ Ride a bike (wear a helmet)

☐ Shoot hoops

☐ Throw a football

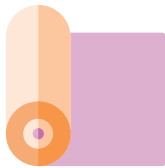
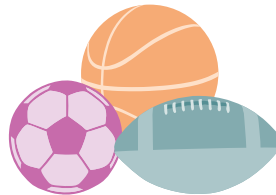
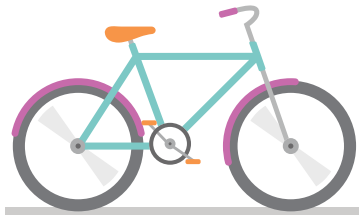
☐ Kick a soccer ball

☐ Walk or Jog

☐ Bowling

☐ Tennis

☐ Yoga



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

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 HVAD 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 HVAD 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.

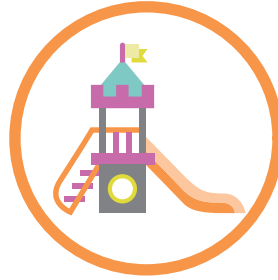
You CAN'T

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.

VAD Emergency Contact:	
PHONE	 actionlearningnetwork.org
HOSPITAL NAME	
STREET ADDRESS	
CITY, STATE, ZIP	

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

W Z X A N A C V
 N L W N N L V M L O V D
 G L O T W S G U H N M F M T A T
 Q W B J I D R M N E B C Y Y T P V O O V
 D E T E I D T N E T S I S N O C L R L L Q E
 C E R Y F F V G A D V D V H J I P I C E C M J Z
 C L S E A H Q O T L I I N S E N L C E R G G T I
 R I T V S B U Z G A U I L C K B S A U P T V Z F
 N R R A P S Z B G N A G M I T U R T L A Q H E E
 X E O X T N I N M D K A A P E N E I G Y H W P D
 E T K Y G R O N T V Q A T O L J O O N A C I E L
 S E R G S O V G C C J Q R C A C N K W K T P
 Z E Q I Y I A W S N T O U R I N S A A A Z B
 X S P D I S C H A R G E D R T T X R J F
 W A N T I B I O T I C S O Z N D C E
 S S U C I L Q Q K X E Y E Y A Z
 I W X G P W B I L I W H W V
 S H F G U G D U X E J T
 P F J M D N I D Q Y
 E Q A P E C V S
 S K B Y Q K
 S T N B
 F U

☐ Antibiotics

☐ Anticoagulation

☐ Aorta

☐ Clot

☐ Complications

☐ Consistent Diet

☐ Dehydrated

☐ Diagnosis

☐ Discharged

☐ Diuretics

☐ Dressing

☐ Hygiene

☐ Implant

☐ ICU

☐ Kidney

☐ Liver

☐ Preload

☐ Sepsis

☐ Sterile

☐ Sternotomy

☐ Stroke



actionlearningnetwork.org | myactioneducation.org



@actionlearningnetwork



@Action4HF