ADVANCED CARDIAC THERAPIES IMPROVING OUTCOMES NETWORK

Heart ~~Failure~~ Success

Patient & Family Education Handbook

action

action

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*
Heart ~~Failure~~ Success Journey

Hi, my name is:

(___) ___-____

_____

My caregiver is:

_____

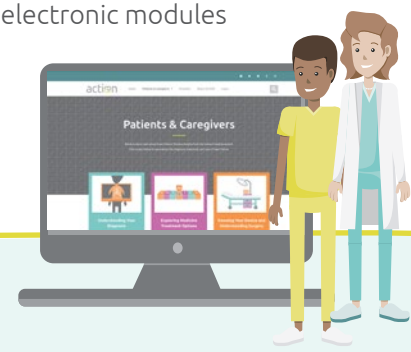
Using this Handbook

This handbook is like a helpful friend on your heart journey. It's here to teach you, as well as keep your memories safe. Make sure to **use a pencil** in this handbook to record the important things your doctors and nurses may tell you, as well as take note of your own thoughts. Always ask questions to learn more and work with your care team to keep your information up to date.

QR Codes: This booklet incorporates various QR (Quick Response) codes. These QR codes will lead you to webpages with other ACTION educational materials, including informative handouts and electronic modules. Use your phone/camera to scan the code, and once the link appears, click on it to take you to the webpage. You can also access the information by entering the URLs provided below the QR codes.

QR code example

Online Education: Learning about your diagnosis 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 prepare you for your journey. To get personalized content, create a login and write it below to remember it!



MyActionEducation.org

Username: _____

Password: _____

Quick References

It's important to keep some basic information available for quick reference. This handbook will also serve as a great resource to record all the memories and milestones experienced throughout your journey.

Use a **pencil** to fill in your information below.

My Care Team Contact Info

My Hospital

_____
Name

_____
Street Address

_____
City, State, Zip

– My Heart Disease –

- ☐ Congenital Heart Disease (CHD)
- ☐ Cardiomyopathy
  - ☐ *Dilated*
  - ☐ *Restrictive*
  - ☐ *Hypertrophic*
  - ☐ *Other:* _____
- ☐ Myocarditis
- ☐ Other: _____

I am allergic to:

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

information above completed on ____/____/____

My Past Surgeries

I have a Pacemaker/ICD: ☐ Yes ☐ No

My blood pressure goal: _____

My target weight (lbs): _____

I am on the following types of heart medicines:

- ☐ ACE/ARB/ARNI: _____
- ☐ Beta Blocker: _____
- ☐ Aldosterone Antagonist: _____
- ☐ SGLT2 Inhibitor: _____
- ☐ Diuretic: _____
- ☐ Heart Rhythm: _____
- ☐ Other: _____

Activity

☐ I can participate in all activities.

☐ I have activity limitations. My limitations are:

_____

_____

information above completed on ____/____/____

Table of Contents

1

Introduction to Heart Failure

- Definition
- Causes
- Complications

Definition

The heart is one of the most important parts of your body. But what happens when it doesn't work like it should?

Video Resource: *This video explains heart failure and its potential causes.*

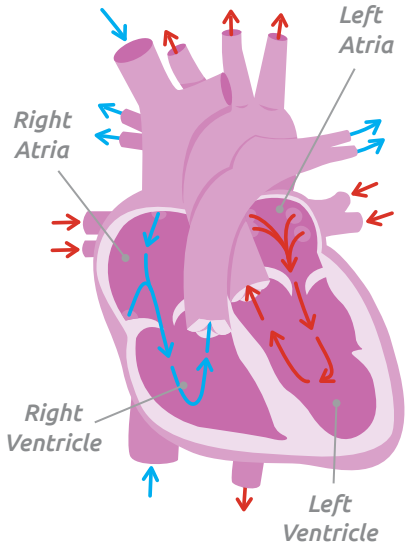
tinyurl.com/bdc4nbdb

Normal Heart Structure and Function

The heart is a pump in your chest. It has four parts, or chambers: two ***atria*** at the top and two ***ventricles*** at the bottom.

The right side of the heart takes **blue** blood that has been used throughout your body and sends it to the lungs to be cleaned and oxygenated. The **blue** blood turns to **red** blood.

Now the left side of the heart takes the clean oxygenated **red** blood from the lungs and pumps it to the rest of your body.



The right side

*of the heart takes used **(blue)** blood from your body and sends it to the lungs to get clean and oxygenated.*

The left side

*of the heart takes the clean oxygenated **(red)** blood from the lungs and pumps it to the rest of your body.*

The heart has two functions: it squeezes (***systole***) and it relaxes (***diastole***). When it relaxes, the ventricles fill up with blood. When it squeezes, it pushes the blood out to the rest of your body.

What is the heart made of?

The heart is a special muscle, like the muscles you use in your arms and legs. This muscle has to squeeze, just like when you make a fist and then open your hand. The heart muscle is made up of lots of tiny cells called ***myocytes***.

What happens when heart muscle is not working well?

When the heart does not work properly, you may not feel the effects right away. You may experience unusual sensations, known as symptoms. These symptoms may not always seem to be due to your heart. For example, having difficulty catching your breath may seem like a lung issue, but because the lungs and heart are connected, this feeling may be due to your heart not working correctly. Another example is feeling nauseous, having less appetite, or throwing up after eating. This may seem like a ***gastrointestinal*** issue, but it may also be a symptom of the heart not working properly.

What does the term heart failure mean?

It might sound a bit scary, but don't worry, it doesn't mean your heart is giving up. Your heart is still trying its best! Sometimes, when your heart doesn't work perfectly, it can cause sensations or symptoms that make it a little harder to do everyday things. People use the word "heart failure" to talk about these heart problems, even though it sounds serious. But remember, your heart is strong, and we're here to help you feel better!

What are the symptoms of heart failure?

Check the boxes below for any signs or symptoms you are experiencing:*

- ☐ Trouble breathing
- ☐ Chronic cough and chest congestion
- ☐ Swelling in your legs, face, and sometimes belly
- ☐ Excessive sweating
- ☐ Rapid heart rate or palpitations
- ☐ Feeling like you need to take breaks during physical activities
- ☐ Fatigue (tiredness)
- ☐ Nausea or vomiting*
- ☐ Belly pain
- ☐ Loss of appetite
- ☐ Not able to lie flat when sleeping or waking up gasping for air

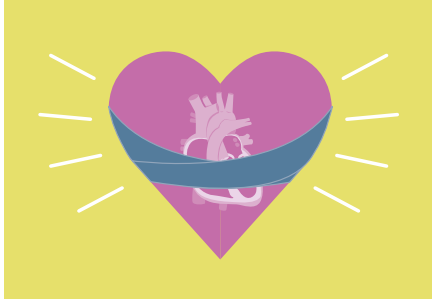
* *For infants, trouble feeding, difficulty gaining weight, falling asleep while eating, sweating while eating, and rapid breathing are most common.*

What are the different types of heart failure?

Types of heart failure are based on whether the ventricle has a hard time squeezing or a hard time relaxing. Talk to your care team and check the box below for your type of heart failure (sometimes you can have both):

☐ **Systolic Heart Failure**

If the ventricle can't squeeze (or contract) well enough to pump blood to all parts of the body (including your brain, muscles, and other important organs), we call it systolic heart failure.

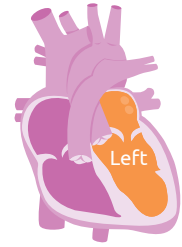


☐ **Diastolic Heart Failure**

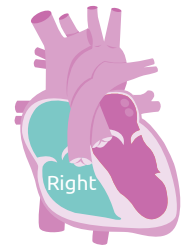
If the ventricle can't relax well enough to fill properly, we call it diastolic heart failure. This can happen if your heart muscle becomes stiff or thick.

Heart failure can involve the left ventricle (left-sided heart failure), right ventricle (right-sided heart failure), or both (biventricular).

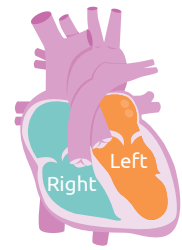
- **Left-sided Heart Failure:** The left ventricle is the heart's main pumping chamber. With left-sided heart failure, the left ventricle loses some of its pumping power and may not get enough blood to the rest of the body. This can lead to fluid building up in your lungs, causing you trouble when breathing, coughing, and feeling more tired, especially if you're doing activities like exercising or playing.



- **Right-sided Heart Failure:** Right-sided heart failure often happens as a result of left-sided heart failure. With right-sided heart failure, the right ventricle loses some of its pumping power, and it becomes too weak to pump enough blood to your lungs. When the right ventricle struggles to pump, blood builds up in your liver and veins. This can cause swelling in your legs, belly, and feet.



- **Biventricular Heart Failure:** Biventricular heart failure happens when both sides of your heart are affected. Your symptoms can be a combination of left- and right-sided failure.



Causes

1 in 100 people are born with heart defects in the U.S. alone.

Let's explore some of the most common causes of heart failure in children and young adults.

Congenital Heart Disease

Congenital heart disease (CHD) occurs when a person is born with a heart defect, meaning somewhere in

the heart something did not form correctly. CHD is more common than most people realize. In some cases, the defects will make it harder for the heart to pump blood and deliver oxygen to the body. In select cases, a child or adult with CHD may develop signs and symptoms of heart failure.

Additional Resources: *See various handouts for children and adults with congenital heart disease on MyACTIONeducation.org.*

tinyurl.com/5fzvdkfw

There are many different types of CHD, but if you have single ventricle CHD you may be more likely to have signs and symptoms of heart failure. When a heart forms with only one ventricle, doctors may perform a surgery to create a special pathway called a ***Fontan circulation.*** It's like making a shortcut for the blood, so it can go directly to the lungs to get more oxygen, without needing to go through the ventricle. This way, one strong ventricle does all the hard work to send the blood to the rest of your body. Most of the time, the Fontan works really well and makes you feel better. Sometimes, that one ventricle starts to get tired and may still need a little help.

Additional Resource: *Download the 'Fontan Circulation Patient Handbook' created by the Heart Institute at Cincinnati Children's.*

tinyurl.com/nhfjdh87

If you are a patient with a Fontan circulation and have symptoms of heart failure (that can't be managed with medicines), you may need advanced cardiac therapy. *See chapter 6.*

Note: ACTION is actively collaborating, sharing, and innovating to figure out how best to provide life-saving therapies to help patients with a Fontan circulation.

Video Resource: *See how patients like Brooklyn are living longer and healthier.*

tinyurl.com/3k5acrc6

Cardiomyopathy

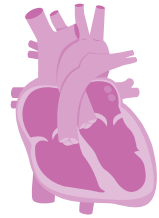
The word "cardiomyopathy" means "heart muscle disease." If you have cardiomyopathy, it means the heart muscle is not feeling its best and can find it hard to relax and send blood to the rest of your body. Depending on how your heart feels, your care team may suggest treatments as simple as taking special medicine. In more serious cases, they might talk about other options like a Ventricular Assist Device (VAD) or even a heart transplant.

Different types of cardiomyopathy include:

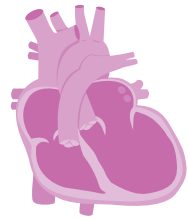
Dilated (DCM): DCM is the most common form of cardiomyopathy. It occurs when the heart muscle becomes thin and stretched out making it harder to pump blood to the body.

Hypertrophic (HCM): HCM occurs when the heart muscle is too thick, making it hard for the ventricle to fill normally, which can lead to less blood being pumped to the rest of the body.

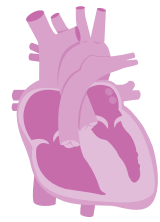
Restrictive (RCM): RCM occurs when the heart muscle is too stiff and does not relax, making it hard for the ventricle to fill normally, which can lead to less blood being pumped to the rest of the body.



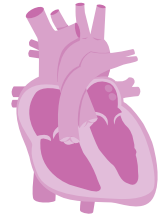
Healthy



Dilated



Hypertrophic



Restrictive

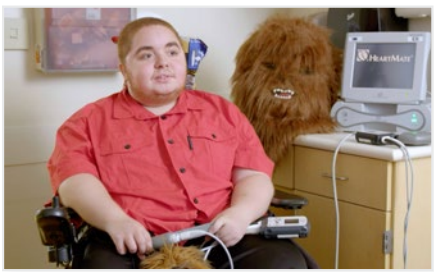
Arrhythmogenic (ARVC): ARVC is more rare. It occurs when the heart muscle is replaced with fat and scarring, which changes the heart's electrical activity. This can lead to dangerous heart arrhythmias (irregular heart rhythm), and makes it difficult for the heart to squeeze.

Left ventricular non-compaction (LVNC): LVNC occurs when the muscle of the heart's left ventricle does not fully develop, and instead appears spongy and has deep ***trabeculations***. While many patients with LVNC have normal heart function and no evidence of heart failure, some can develop a weak heart.

The cause of cardiomyopathy is often unknown, but possible causes include:

- Genetics
- Chemotherapy
- Metabolic disorders
- Certain nutritional deficiencies
- Autoimmune problems
- Muscle diseases (Muscular Dystrophy)

Video Resource: *See how patients like Ricky are living with their Muscular Dystrophy diagnosis.*



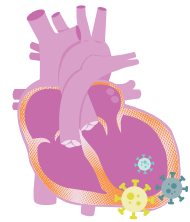
tinyurl.com/3haad6hp

Other Causes

Transplant Graft Failure: When you receive a heart transplant, the new donor heart is called a "graft." Transplanted hearts, or grafts, can develop heart failure over time.

Myocarditis: Myocarditis happens when the wall of the heart gets irritated and inflamed. It's rare, but this can happen when you catch a cold, or because

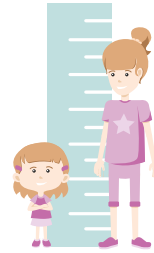
of a virus, like the flu or Coronavirus. Scientists have found other reasons too, like tiny bacteria, parasites, or even special molds. Even allergies to medicines or things we're not supposed to eat can sometimes make our hearts act and can feel a bit funny.



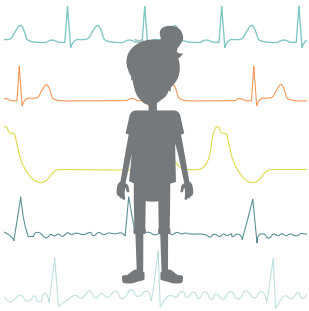
Additional Resource:
See the 'An Introduction to Myocarditis' handout found in the Understanding Your Diagnosis section of MyACTIONEducation.org.

tinyurl.com/mrjevtk8

Complications



Complications can happen when you have heart trouble, but your care team is here to keep an eye on things and help you stay strong. Complications are like challenges that might show up because of your condition. Some examples include:

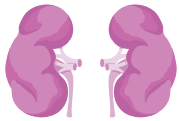


Slowed growth: Sometimes, when your heart isn't feeling its best, it can slow down your growth. But don't worry, your care team will make sure your nutrition, medicines, etc., are used properly to help your growth.

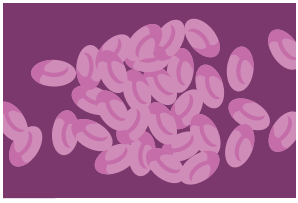
Arrhythmias: Your heart is like a drum, and sometimes when you have heart trouble, it might play too fast or too slow. This is called an "arrhythmia." There are special tools like medicine and even a device called a defibrillator to help your heart's rhythm dance to the right beat!

Heart Valve Issues: Think of your heart like a house with doors. Sometimes, when your heart is tired it can stretch, which doesn't let the doors (valves) close properly and the blood can flow the wrong way.

Kidney Problems: Your ***kidneys*** are like magical filters in your body, but when your heart is a little unwell, they might have trouble doing their job.



Liver Disease: Your ***liver*** is a busy bee in your body that helps to process toxins. When your heart has too much fluid, it can irritate your liver and cause it to not work as well.



Clots: When your heart isn't pumping as well as it should, little blood cell blobs called ***"clots"*** can sneak inside your heart. If these clots travel to other parts of your body, like your brain, it can cause issues.

Anemia: Red blood cells are needed to carry oxygen around your body. If your heart is having trouble, you may not have enough red blood cells. This is called anemia, which means you may feel tired and have trouble breathing. If you have anemia, you may need a blood transfusion to add healthy red blood cells into your blood.

2

Diagnosis

- Vital Signs & Physical Exam
- Laboratory Tests
- Special Heart Tests

Your care team uses different tests and exams to understand how your heart is doing and how best to help you feel better.

Video Resource: *Learn more about how your doctor checks your health.*

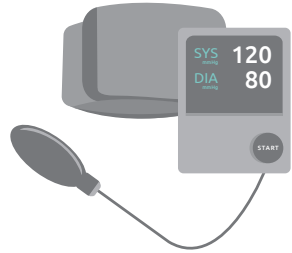
tinyurl.com/34awp48s

Vital Signs & Physical Exam

Your body has special ways of talking to your care team. It tells your care team important things about your health, which are called ***"vital signs".***

Heart Rate: The heart rate helps us count how many times your heart beats per minute. The heart makes a sound like a "thump-thump" from a drum when it's working. This sound is the squeezing of your heart to pump blood to the rest of the body.

Blood Pressure: Blood pressure tells us how strong your blood is pushing through your body. It's like checking if the water in a hose is flowing just right. There is an upper (systolic) and lower (diastolic) blood pressure number that is measured and recorded.



Body Temperature: This measurement tells your care team how warm your body is and signals if it is too hot or too cold. Its like making sure your house is just the right temperature.

Breaths per Minute: When you breathe, we count how many breaths you take in a minute. This helps us see if your body is getting enough air.

Weight: Your care team will measure your weight on a scale at every visit to determine if you have too much or too little fluid in your body. This also helps to monitor your growth.

Physical Exam

Your doctor will perform a physical exam to look for signs of heart trouble. They will listen to your heart for unusual sounds or leaky valves. They'll also check your lungs, and look for swelling by feeling your legs, feet, and pushing on your belly to check your liver.

Laboratory Tests

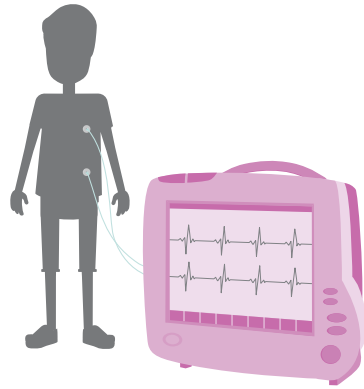
You will have lab tests, which include blood draws, either at scheduled times, or whenever your care team feels you need them. These tests may include:

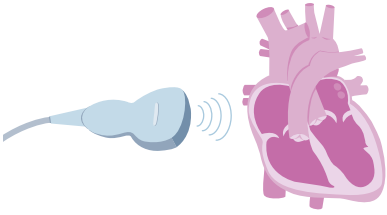
CARDIAC	
BNP (B-Type Natriuretic Peptide)	• is a special chemical your heart releases into your blood stream • can show if your heart is stressed or if you are holding on to too much fluid
KIDNEY FUNCTION	
Renal Panel (BUN/ Creatinine & Electrolytes)	• monitors kidney function and measures fluid status and electrolytes • will signal if your electrolyte levels are not normal and/or if your kidneys are being affected by your medicines or by your heart function
LIVER FUNCTION	
Hepatic Profile	• monitors how well the liver is functioning • will alert if your liver is being affected by your medicines or by your heart function

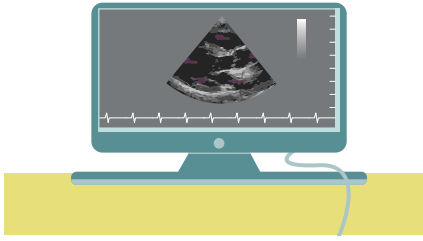
Special Heart Tests

You will have special tests to check on your heart when your care team thinks they are needed. These tests include:

EKG and Holter Monitor: An ***EKG*** measures the electrical signals in your heart. Changes in your EKG results can signal that your heart function is changing. Your care team may request you wear a ***Holter monitor*** or a Zio patch, similar to a portable EKG, to check for heart rhythm issues (arrhythmia).



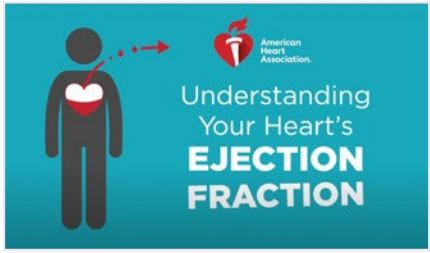




Echocardiogram (and Ejection Fraction): Heart failure is often diagnosed using an ***echocardiogram*** (or echo). It uses sound waves or ultrasound to take a video, which shows the structure of the heart and how well it's working.

An important number to determine the function of the heart is called an ***ejection fraction*** (or EF%). EF is a calculation of the amount of blood pumped out from the left ventricle divided by the total amount of blood that is in the heart. A normal EF is >55%. The lower the percent, the more difficult it is for the heart to pump blood to the rest of the body.

Video Resource: *The American Heart Association explains more about Ejection Fraction.*



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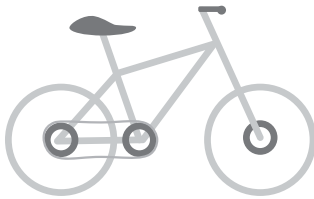
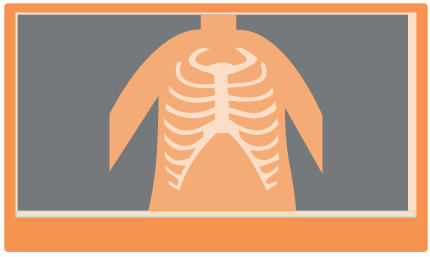
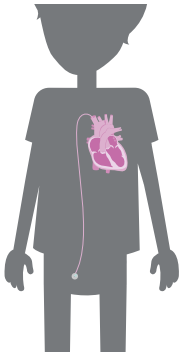


Exercise Stress Test: Think of this test as a way for your care team to see how well you can play and move around. You might be asked to take a walk on a special machine like a treadmill, or even ride an exercise bike. During your exercise test, they will keep a close eye on your heart rate (how fast your heart beats) and rhythm (heart beat pattern) and how well you breathe.

Six Minute Walk Test: This is a challenge to see how far you can walk in just six minutes, and it also helps your doctor understand how well you can move and play.

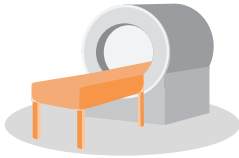


Chest X-Ray: These images can show if you have extra fluid in your lungs due to your heart condition. These X-rays can also show changes in the size and shape of your heart.

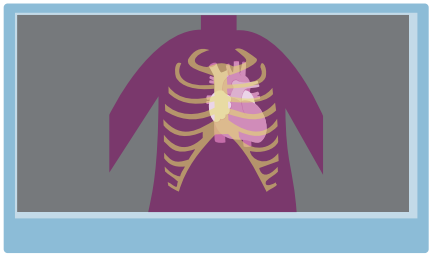


Cardiac Catheterization: If necessary, your doctor may perform a catheterization while you're asleep. A long IV tube is used to measure pressures inside your heart and lungs, providing important information about your blood flow. This helps your care team determine the best treatment for you.

Cardiac CT: A cardiac CT (computed tomography) uses a powerful camera to take detailed pictures of your heart. It helps your doctors see the blood vessels and structures in your heart.



Cardiac MRI: A cardiac MRI (magnetic resonance imaging) is a safe and painless test using strong magnets and radio waves to create detailed images of your heart. Like a CT, it helps doctors look inside your heart to see how well it's working. The cardiac MRI is unique because it can detect scar tissue in the muscle of your heart.



3

Treatment

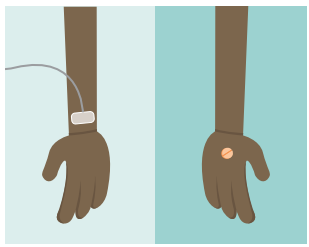
- Medicines
- Cardiac Rehabilitation

Your care team may prescribe different medicines to keep you healthy. These medicines work to help the heart's pumping strength, lower the pressure inside your heart, and get rid of any excess fluid that may lead to heart failure. Taking these medicines is important because they may help to improve the way your heart works and tries to keep it from getting weaker.

Video Resource: *Explore a variety of possible medicine treatment options on MyACTIONEducation.org.*

tinyurl.com/2pef3c26

Medicines



If you need to be admitted to the hospital, your medicines may be given to you orally (by mouth) or through an IV.

When preparing for your discharge (to leave the hospital), or if you are at home, medicines will be taken by mouth. It's very important to take your medicines at the same time each day and using a pillbox can help you stay organized. Be sure to inform your care team if you are taking any additional medicines that were NOT prescribed by them.

People with decreased heart function often have elevated levels of ***neurohormones.*** Neurohormones are proteins that are released from your cells into your blood and can be harmful to the heart, blood vessels, and

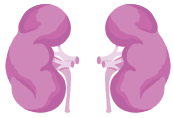
circulation system. This may lead to worsening symptoms of heart failure. The following medicines, **often used in combination,** help by blocking or lowering the effect of the neurohormones on your heart. They help improve your heart's function and prevent it from getting worse by slowing down harmful changes in your heart. These medicines are an important part of your journey to better heart health.

Additional Resources: *See the 'Heart Success Medicines' handout under the By Mouth Therapy topic of the Exploring Medicine Treatment Options section of MyACTIONEducation.org.*

tinyurl.com/mrb8mz2x

Angiotensin

Angiotensin is a chemical produced by your body that tightens up your arteries. ACE (angiotensin-converting enzyme) inhibitors and angiotensin receptor blockers (ARBs), help the blood vessels relax (easier for the heart to pump, allowing blood to circulate freely throughout your body), and help preserve or potentially improve heart function. They also can help decrease salt and water in the body.



Possible side effects may include: Lower blood pressure (light-headedness, headache, or dizziness), elevated levels of potassium, a dry cough, swelling of the lips, and change in kidney function

ACE inhibitors

Common ACE inhibitor medicines end in "-pril" :

- Enalapril (Vasotec)
- Captopril (Capoten)
- Lisinopril (Prinivil)

Angiotensin Receptor Blockers (ARBs)

Common ARB medicines end in "-artan":

- Losartan (Cozaar)
- Valsartan (Diovan)

Angiotensin Receptor Blocker Neprolysin Inhibitor (ARNIs)

- Sacubitril + Valsartan (Entresto®)

Mineralocorticoid Inhibitors (MRAs)

These medicines, also known as "potassium sparing diuretics," do much more than help your body get rid of excess water and salt. By reducing swelling, they make it easier for your heart to pump blood efficiently. They also help preserve or potentially improve heart function.

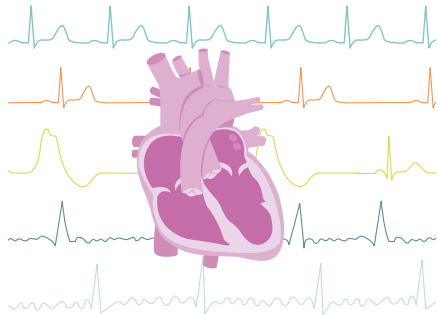
Possible side effects may include: elevated levels of potassium, stomach cramps, dry mouth, excessive thirst, dizziness, headache, enlarged breast tissue, breast pain and irregular menstrual periods (women)

Common MRAs end in "-one":

- Spironolactone (Aldactone)
- Eplerenone (Inspra)

Beta Blocker

These medicines help slow the heart rate (relax the heart), help the blood vessels relax making it easier for the heart to pump, and help preserve or potentially improve heart function. They can also be used to treat arrhythmias, or abnormal heart rhythms. They are prescribed to aid in heart healing or remodeling.



Possible side effects may include: Lower blood pressure (light-headedness or dizziness), lower heart rate (light-headedness or dizziness), feeling tired or drowsy, decreased energy, insomnia, slow heartbeat, cold hands and feet, dry mouth, skin, or eyes, headache, and upset stomach.

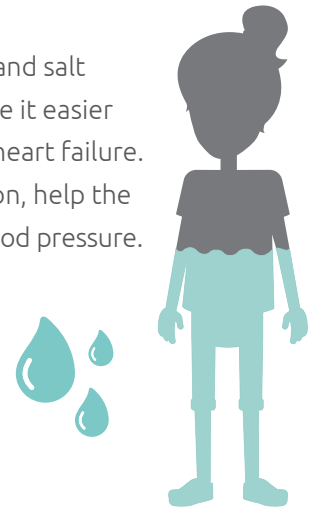
Common Beta blocker medicines end in "-lol":

- Atenolol (Tenormin)
- Carvedilol (Coreg)
- Metoprolol XL (Toprol)

You may also be prescribed additional heart remodeling medicines including:

- **Digoxin (Lanoxin)**
  Digoxin helps the heart beat stronger and slower. It's a little helper for hearts that need an extra boost to squeeze.
- **Ivadabrine (Procoralan)**
  Ivabradine is used to slow down the heart rate in patients with certain heart conditions. The slower heart rate can help the heart pump blood better.

Diuretics



Diuretics help your kidneys remove excess water and salt from your body. Getting rid of extra fluid can make it easier for your heart to pump and reduce symptoms of heart failure. These medicines, which can be used in combination, help the body make more urine, and can also help lower blood pressure.

Possible side effects of all diuretics include:
dizziness, vertigo (feeling like you're spinning), increased thirst, numbness, and tingling

Common diuretic classes are:

Loop Diuretics
These medicines work by helping your kidneys remove extra water and may increase urination. These drugs can be taken orally or administered continuously through an IV while in the hospital.

Common loop diuretics end in "-ide":

- Furosemide (Lasix)
- Bumetanide (Bumex)
- Torsemide (Demadex)

Thiazide Diuretics

You may be prescribed hydrochlorothiazide tablets or chlorothiazide solution. These medicines help your body eliminate excess water and salt and can also lower blood pressure.

Common thiazide and thiazide-like diuretics are:

- Hydrochlorothiazide (Hydrodiuril)
- Chlorothiazide (Diuril)
- Metolazone (Zaroxolyn)

Sodium-Glucose Cotransporter 2 (SGLT2) Inhibitors

SGLT2 inhibitors are medicines that help remove excess fluid caused by heart failure, improve kidney function, address anemia and iron levels, and reduce stress and inflammation in the heart muscle, risk of hospitalization or heart failure-related death.

Possible side effects may include: lower blood sugar, increased chance of urinary tract infection

Common SGLT2 inhibitors end in "-ozin":

- Dapagliflozin (Farxiga, Forxiga)
- Empagliflozin (Jardiance)

Additional Resources: *Review the 'Heart Success SGLT2 Inhibitors' handout under the By Mouth Therapy topic of the Exploring Medicine Treatment Options section of MyACTIONEducation.org.*

tinyurl.com/mrb8mz2x

Blood Thinners

Blood thinners are used to prevent blood clots and keep them from getting bigger. A blood clot is a clump of gel-like blood that can get stuck in the lungs, brain or kidneys. They can be dangerous if they block blood flow to important parts of your body.

There are two primary types of blood thinners: anti-coagulants, which slow down your body's blood clotting process, and anti-platelet medicines, which prevent platelets from sticking together and forming blood clots.

Anti-coagulants

These blood thinners help prevent or treat blood clots.

Possible side effects may include: Easy bleeding and bruising, reactions at the injection site (including swelling, pain, redness, and bruising)

Common anti-coagulants:

- Warfarin (Coumadin)
- Apixaban (Eliquis)

Anti-platelets

These blood thinners prevent your platelets from sticking together and forming clots in your body.

Possible side effects may include: Easy bleeding and bruising, upset stomach

Common anti-platelet drugs:

- Dipyridamole (Persantine)
- Clopidogrel (Plavix)
- Aspirin

If your blood thinner medicines are changed from oral medicines, the following medicines may be given by IV or other routes:

- **Lovenox (Enoxaparin)** *given by injection*
  Enoxaparin is an anticoagulant which keeps your blood flowing smoothly in order to treat and prevent blood clots. This medicine is given one or two times a day as an injection in your stomach, back of arms or thigh.

  Possible side effects may include:
  easy bleeding and bruising, reactions at the injection site (including swelling, pain, redness, and bruising)

- **Heparin**
  Heparin is another type of anticoagulant that helps treat and prevent blood clots.
  This medicine is also given in the hospital through your IV continuously. Heparin is sometimes used together with aspirin. While you are on Heparin, you will need frequent labs to monitor the thickness of your blood, and your dose will be adjusted based on those lab results.

  Possible side effects may include: easy bleeding and bruising

- **Bivalirudin (Angiomax)**
  Bivalirudin is an anticoagulant that helps treat and prevent blood clots. This medicine will be given in the hospital through your IV. Bivalirudin is sometimes used together with aspirin. While you are on bivalirudin, you will need frequent labs to monitor the thickness of your blood and your dose will be adjusted based on those labs.

  Possible side effects may include: easy bleeding and bruising

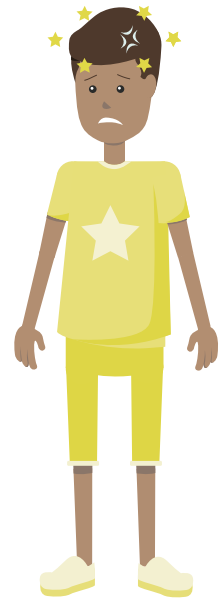
Inotropes

Inotropes are used for heart failure to help your heart pump, or squeeze, easier. These medicines are only given through IV.

Possible side effects may include: redness (flushing), nausea, tingling feelings or shakiness, headache, change in heart rate, change in blood pressure

Common inotropes are:

- **Milrinone:** Used for heart failure, it helps the heart pump more blood and relaxes blood vessels. This can improve symptoms like trouble breathing and fatigue.
- **Epinephrine:** Used for heart failure, it enhances the heart's pumping action and may relieve symptoms.
- **Dobutamine:** Given for heart failure, it boosts the heart's pumping capacity and relaxes blood vessels.
- **Calcium Chloride:** Some hospitals use this IV medicine to improve the heart squeeze and blood flow.



Cardiac Rehabilitation

Staying active is an important part of staying healthy. Your care team will help create an exercise plan and activity recommendations that work best for your heart. This team (which may include occupational therapy, physical therapy, and/or a cardiac rehabilitation) is made up of people who specialize in exercise and heart care. They may do some measurements and tests in the beginning to better understand your body. They will monitor you while working with them to make sure the activities and exercises you do work well and don't make your heart work too hard. Cardiac rehabilitation can occur inside the hospital, or while you are at home.

To find out if exercise therapy or cardiac rehabilitation is right for you, and if you have any restrictions on your activities, be sure to ask your care team.

Additional Resources: *Check with your care team to see if these ACTION exercise videos are recommended for you.*

tinyurl.com/66t5tt6t

Notes

4

Hospital Admission

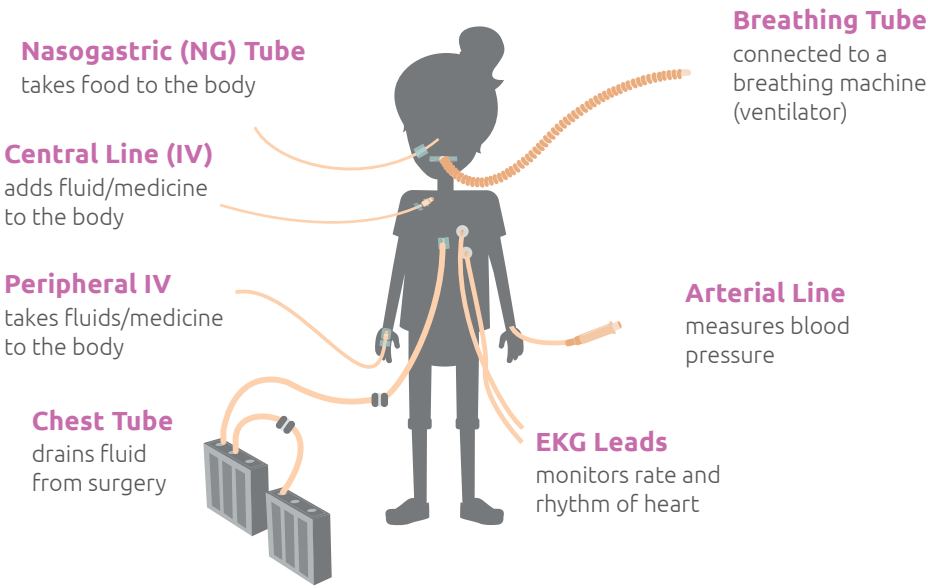
- Expectations
- Discharge
- Resources

Expectations

Sometimes you may need care in the hospital instead of in the clinic. Being in the hospital for heart failure allows your care team to closely monitor your heart and overall health to provide you with the best specialized care. They will adjust your medicines and treatments as needed to help you feel better and get back to your daily activities as soon as possible.

Intensive Care Unit (ICU)

Sometimes you might get sick and need to be cared for in the ICU. You may require a ventilator (breathing machine) and need to be connected to many lines, tubes, and medical equipment as you recover *(see illustration below)*. The medical equipment is necessary for monitoring the body and giving the medicine needed to help you recover. All the equipment and lines can be scary to look at, but they are necessary to help you feel better. Day by day, your care team will work towards getting you closer to going home.



Cardiac Step-Down Unit

You may need to be on the Cardiac Step-Down Unit or cardiac floor, where patients go if their heart failure is less severe, or if they are recovering after being in the ICU. In the cardiac step-down unit, you will focus on getting stronger. This is the time that education becomes more important so that you can be safely discharged out of the hospital.

Discharge

Once your care team feels you are ready to be discharged from the hospital, several steps will be taken to make sure you stay safe. There are specific goals that must be met before you can be discharged.

I was discharged on _____.
DATE

My next follow up visit is on _____
DATE

at _____ with _____
TIME CARE PROVIDER

at _____
LOCATION

My care team can be reached at:

_____ - _____ - _____

At discharge, I am on the following types of heart medicine:*

- ☐ ACE/ARB/ARNI: _____
- ☐ Beta Blocker: _____
- ☐ Aldosterone Antagonist: _____
- ☐ SGLT2: _____
- ☐ Diuretic: _____
- ☐ Heart Rhythm: _____
- ☐ Other: _____

Your heart medicines may change often. At your next check up visit, ask your care team if any of your medicine doses need to change. Please see your* ***discharge summary* *for exact dose of each heart failure medicine to take.*

At discharge, my vital signs are:

Blood Pressure: _____

Oxygen Saturation: _____ Heart Rate: _____

Weight: _____ *lbs* _____ *kg*

Diet

☐ I can eat my normal diet.

☐ I have a limited diet. My diet limitations are:

_____

_____

I am on a low sodium diet: ☐ Yes ☐ No

Fluids

☐ I can drink my normal amount of fluids daily.

☐ My daily fluid amount is set by my care team:

I need to drink at least : _____ *oz, but not more than:* _____ *oz.*

Activity

☐ I can participate in all activities.

☐ I have activity limitations.
My activity limitations are:

_____

_____

School / Work

I can return to school/work on:

_____
DATE

Resources

My Clinic Visit Checklist

It is important to keep all scheduled clinic appointments, and bring your medicines and any food logs/records with you. Some appointments will be faster than others, depending on what tests are ordered. **Use a pencil** to fill out the checklist below when preparing for your clinic visit.

Things to bring to my visit:

- ☐ Food logs
- ☐ Weight logs
- ☐ Symptoms logs
- ☐ Remember to bring an activity to do while waiting! *(e.g. coloring book, games, books)*

Questions for my visit:

- ☐ Medicines – *Do I need a different dose? Do I need refills?*
- ☐ Activity and exercise – *Do I have any restrictions or changes?*
- ☐ Vaccines – *Do I need any?*
- ☐ Other questions:

Notes

5

Staying Healthy

- Nutrition & Hydration
- Fitness
- Lifestyle
- Emotional Wellbeing
- Neurodevelopmental Considerations
- Vaccinations

Nutrition & Hydration

As a patient with heart disease, it's important you stay active and keep a healthy diet throughout your journey. A balanced diet is important to maintain a healthy weight, potentially improve your symptoms, and keep your heart condition from getting worse. Certain foods and the amount you drink may affect your condition or interact with your medicines. It's really important to make these changes to your diet in order to keep you and your heart as healthy as possible.

Your care team is following your growth and weight gain to keep your heart as healthy as possible. They may have a target weight they aim for, and may ask you to regularly check your weight at home.

My target weight is _____ lbs/kgs.

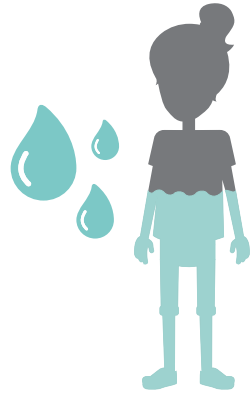
Fluids

Your care team will track your weight and fluid intake to know if the amount of fluid in your body is balanced. To make sure there is the right fluid balance, you may be given medicines (diuretics or SLGT2i) to help get rid of extra fluid when needed. In some cases, your care team may also need to put limits on how much fluid you are able to drink as well.

My daily fluid amount:

I need to drink at least : _____oz,

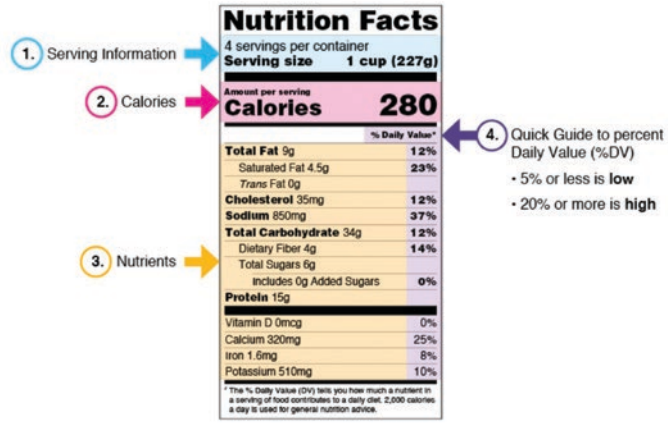
but not more than: _____oz.



Nutrition

Mindful eating involves knowing what you're eating and how much. Here are some ways to help you practice mindful eating:

- **Read Nutrition Facts:** The nutrition labels on your food can tell you a lot about what you're eating. Learning how to read these labels can help you in avoiding too much sugar, fat, salt, and calories in your diet. The example nutrition label *(below)* shows you more about what you can learn when you take a closer look.



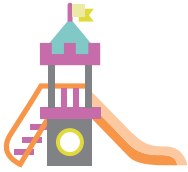
- **Choose healthier foods:** Did you know the more natural, unprocessed foods are typically found around the outside edge of the grocery store? The processed foods are often located in the center aisles. Consider spending more time shopping around the outside edge of the store, since this can help you get more natural grains, fruits, and vegetables in your diet.
- **Select healthier beverages:** Choose water, skim milk/milk alternative, or sparkling water instead of sugary drinks.
- **Reduce sugar intake:** Eat food with 5 grams or less of added sugar per serving. Lowering your sugar intake can contribute to better health and reduced calorie consumption.

- **Avoid trans fats:** Steer clear of foods with trans fat, like hydrogenated or partially hydrogenated oil. When cooking, consider using healthier alternatives like canola oil or olive oil.
- **Plan meals ahead:** Planning your meals ahead of time can help you make better choices. You can even try using an app or website for ideas and shopping lists.

- **Limit dining out:** If you eat at restaurants, consider taking some of your meal home. Restaurant portion sizes are often larger than what is recommended for a healthy meal. This can result in eating too much sugar, salt, fat, and calories than you should in a single meal.

Fitness

Maintaining an exercise routine that is safe for your condition is important to learning how to live with heart failure. Your doctor will prescribe specific exercises to keep you and your heart healthy. Some exercises will be used to test how strong your heart is and how well it's working. Other exercises will help keep your heart strong before and after surgery.



Activity

If approved by your care team, it's important to get physical activity every day. Activity can be exercise, sports, or daily tasks like walking up the stairs. Ask your doctor which activities are safe for you:

- **Moving and playing at home:** Taking the stairs, playing outside, and helping with chores are great ways to get small amounts of activity throughout the day.

- **Steps and walking:** Counting your steps with a wearable monitor (like an Apple watch or Fitbit) is a great way to check your progress.

My daily step goal is _____ steps.

- **Low impact sports:** Participating in low-pressure sports where you can easily take breaks if needed is another great way to stay active. Walking, jogging, biking, shooting hoops, yoga, golf, and bowling are all safe.
- **Competitive sports:** Playing on a team, training and performing at a high level may also be possible if your care team clears you for these activities.

Exercises

There are two different forms of exercise you can include in your daily routines: ***aerobic*** and strengthening. Ask your care team which type of exercise is right for you.

Aerobic exercises: Aerobic exercise makes you breathe fast and sweat. Because your heart is a muscle, it's important that your heart gets a workout. Aerobic exercises are a great way to do that. There are three main levels of aerobic exercises.

My care team recommends the following exercise intensity:

- [ ] **Low intensity:** During these exercises you can still sing while you exercise. Walking is a great low intensity exercise.
- [ ] **Moderate intensity:** During these exercises you can talk in sentences without feeling too out of breath. Jogging is a typical moderate intensity exercise.
- [ ] **High intensity:** If you're exercising at a high intensity level, you should have trouble talking in full sentences. Running often falls into the high intensity level of exercise.

Strengthening exercises: Strengthening exercises involve using muscles to push or pull. Keeping a strong, healthy body is important during your journey and strengthening exercises can help you do that. There are two ways you can perform strengthening exercises.

My care team recommends the following strengthening exercise:

- ☐ **Body weight:** Exercises that use your own body weight for resistance and may include activities like jumping, push-ups, and sit-ups.
- ☐ **Heavier weight:** Exercises that would require you to use additional resistance, such as handheld weights. Some examples include squats and bench presses. Your care team can help you find the appropriate strength exercises for your needs.

Talk to your care team to determine the best exercise routine for your specific health condition to make sure you are exercising safely and effectively.

Additional Resources: *Review the 'Moving toward a Heart-Healthy Life' handout under the Fitness topic in the Health & Wellness section of MyACTIONEducation.org.*

tinyurl.com/3mbenz6h

Do's & Don'ts

It's important that no matter what exercises you do, you do them safely. Here are a few things to keep in mind while you exercise:

- **It's okay to:** sweat, feel a little breathless, and have mild soreness.
- **It's important to:** drink water, avoid excessive heat, and take breaks as needed.
- **You should NEVER:** feel squeezing chest pain or dizziness.

Questions for my care team about exercise and activity

Lifestyle

In addition to regular exercise and healthy eating, lifestyle habits are important to maintaining good health when you have heart disease. These lifestyle changes can help you manage your symptoms and promote long-term success on your journey:

- Know your medicines and take them as prescribed
- Never smoke
- Get enough sleep
- Be mindful of your stress level and find ways to manage stress (e.g. reading quietly, meditation, yoga)

Sleep: A good night's sleep is important to keep your heart healthy. If you are not sleeping well, snore, or wake up tired, let your care team know.

I should get _____ hours of sleep per night.

Emotional Wellbeing

Emotional health can be used to describe how someone feels and copes in their daily lives. For those with heart disease, positive emotional health has been linked to shorter hospital stays, quicker recovery from surgeries, better quality of life, and more.

Feelings of sadness, worry, anger, and distress can be very normal responses to living with a heart condition. No one is expected to just be happy all the time! Here are important tips and actions to improve your emotional health:

- **Be gentle with yourself and your feelings.**
  Both positive and negative feelings are normal. You should check in on how you are feeling emotionally on a regular basis, and sharing how you feel with supportive family or friends is important. Journaling or writing about your feelings may also be helpful.

- **Develop a coping toolbox!**
  Coping skills are things we can physically or mentally do to help us feel better when having negative emotions. What helps you feel better when feeling down or stressed? Here are some ideas to consider from others with heart disease or their caregivers. Make sure to add your own to the list!

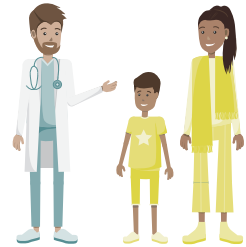
Coping Tool	Examples	Your Ideas
Positive Distraction	♥ Coloring ♥ Games ♥ Hobbies	
Movement	♥ Stretching ♥ Taking a walk	
Music & Media	♥ Creating playlists ♥ Reading	
Social Connection	♥ Activities with friends/family ♥ Calling a Friend/ Family Member ♥ Playing with a Pet	
Relaxation	♥ Deep Breathing Video ♥ Imagine a Favorite Place ♥ Sensory Activity (Fidget Toys)	

- **Build your support team!**
  No one is expected to cope with a heart condition all on their own. Is there someone you like talking to about your worries? Someone who makes you laugh? Your team could include family members, friends, doctors, nurses, psychologists, social workers, child life specialists, teachers, coaches and more. Use the space below to write down a few names of people on your support team.

My Support Team Includes:

- **Speak up!**
  Many times we need extra help with our emotional health. When we feel more negative emotions than positive ones, or when our feelings of sadness, worry, or anger get in the way of doing important things in our lives, like having fun, sleeping, learning or working, getting extra help is important. Psychologists, therapists, social workers, and counselors are experts in helping with emotional health. Use the space below to note your health experts. Your pediatrician, family doctor or school counselor may have additional recommendations for psychologists, therapists, social workers or counselors.

My Emotional Health Experts:



Neurodevelopment Considerations

Although all children with heart disease are strong and resilient you may be at risk of some developmental delays such as trouble at school or keeping up with your friends.

Additional Resources: *Check out the 'Hearts & Minds: Neurodevelopment in Patients with Heart Failure & VADs' handouts for various ages.*

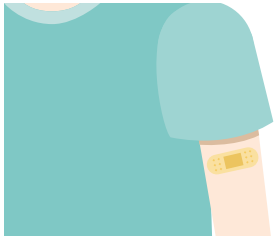
tinyurl.com/2p9hphjv

Vaccinations

Vaccines teach your body how to protect you from diseases. When you get a vaccine, your immune system is triggered to make antibodies that prevent or decrease severity of potential diseases.

- It is OK to receive multiple vaccinations at one time.
- Many illnesses (such as flu and COVID) may lead to worsening heart function or symptoms of heart failure. Vaccines can prevent or decrease severity of these illnesses.
- The risks of a virus or bacteria are much higher than the risks of a vaccine.

  Possible side effects may include: Fever or pain at the site of injection



For children who are listed or may soon be listed for heart transplant:

- Children generally respond **better** to vaccines **before** heart transplant.
- Vaccinations will be strongly recommended by your heart transplant team, and you may have to "catch-up" on delayed vaccines before transplant.
- ***Live vaccines*** (MMR, Varicella) should not be given close to transplantation. Ask your cardiologist if you can receive live vaccines.

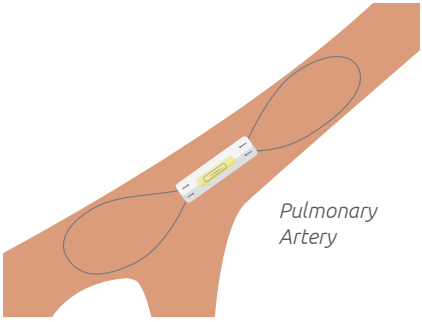
6

Advanced Therapies
(if needed)

- Pulmonary Artery Pressure Monitor (CardioMEMS™)
- Pacemaker/ICD
- Home Milrinone
- Ventricular Assist Device (VAD)
- Transplant

Sometimes your heart will need more help than just medicine. Your care team may decide that you would benefit from more monitoring or devices that help your heart function. If those therapies do not help your heart and allow you to do daily activities, you may be evaluated for a heart transplant. There are many options for advanced cardiac care. Your care team will help determine what is right for you.

Pulmonary Artery Pressure Monitor CardioMEMS™



A pulmonary artery pressure monitor is a wireless device that sits in the pulmonary artery, which is a blood vessel that carries blood from your heart to your lungs. In some cases a CardioMEMS™ System can be implanted to monitor your heart, measuring the pressure in your pulmonary artery. This pressure reflects how your heart is squeezing and relaxing, as well as signals how much fluid you have in your body.

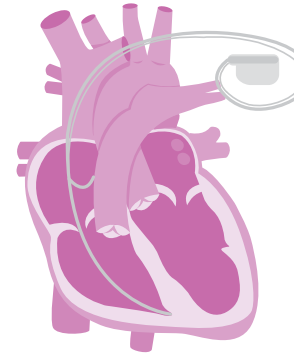
At home, you will lie on a special pillow that reads the pressures in your pulmonary artery and sends the readings to your care team electronically. These pressure readings help your care team manage your heart failure symptoms and check for early signs of worsening heart failure. Your care team will contact you if your pressure numbers are outside of the range they would like for you. They may need to make changes to your medicines or they may want to see you in person.

A CardioMEMS™ pillow measures the pressure in your heart.

tinyurl.com/3fw78ax4

Additional Resources: *Check out our CardioMEMS™ patient and family education webpage and download the CardioMEMS™ HF System patient and family education handout.*

Pacemaker/ICD



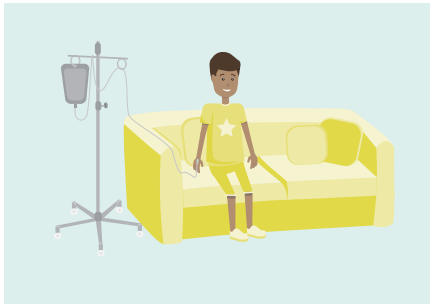
Pacemaker or ICD is placed in operating room or catheterization laboratory.

You may experience irregular heart rhythms, or your care team might think you have an increased risk of life-threatening heart rhythm problems. Irregular heart rhythms, known as arrhythmias, can make the heart beat too slowly (bradycardia), too quickly (tachycardia), or in an abnormal pattern (dysrhythmia). Additionally, if there's a blockage in your heart's electrical pathway between the upper and lower chambers, it can result in the heart beating at different rates, a condition called heart block. To address these issues, a pacemaker or an automatic implantable cardioverter defibrillator (ICD) can be used to regulate the heart's electrical activity and correct abnormal rhythms.

Home Milrinone

Milrinone is a medicine used for patients with heart failure and is given through an IV continuously, usually in the hospital. Milrinone helps the heart squeeze and relaxes the blood vessels so the heart can pump more blood

to the body. This medicine may improve symptoms like shortness of breath and fatigue. In some cases, your care team may be able to continue milrinone for you at home. At home, milrinone would need to be given through a PICC line, which is like an IV but longer and more stable.



Possible side effects may include: redness, nausea, tingling feeling or shakiness, headache, or possible change in blood pressure

Ventricular Assist Device (VAD)

VAD stands for "Ventricular Assist Device." It is a pump surgically placed in a sick or weak heart to help deliver blood to the body.

If you have symptoms like feeling short of breath, having trouble eating or gaining weight, and having low energy, a VAD may help you feel better. Depending on the type of VAD you receive, you may feel well enough to leave the hospital and return to school or work.

Additional Resources: *See more information on the VADs page of MyACTIONEducation.org.*

tinyurl.com/386jcd2v

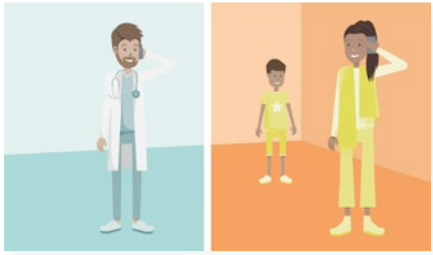
Listen to a patient with heart failure tell you about her VAD journey.

tinyurl.com/23edabaa

Transplant

If you and your care team decide the next step in your heart failure journey is transplant, you will undergo a transplant evaluation. If a transplant is the right therapy, you will be placed on the transplant list until an organ becomes available.

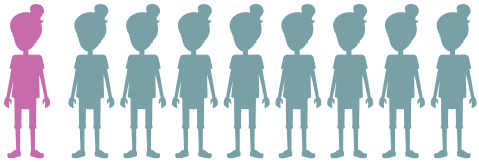
Additional Resource: *Check out the Pre-Transplant information and watch the 'Waiting for my New Heart' video on MyACTIONEducation.org.*



tinyurl.com/3pwa9emb

Make sure to talk to your friends and family about their wishes for possible organ donation.

Become an organ donor: If you're over 18, sign up online through your state registry or in person at your local motor vehicle department. If you have an iPhone, you can use the Health app. It sends your information to a national computer system.



1 gift of life
can save up to
8 lives[1]

Additional Resources: *If you would like more information about transplant, see our '10 Things to Know About Pediatric Heart Transplants' info sheet on MyACTIONEducation.org.*

tinyurl.com/4khfx482

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Glossary

- Glossary
- Word Search

Glossary

Aerobic: Cardiovascular exercise that gets your heart pumping. During this exercise your lungs are getting the oxygen that is needed to your muscles.

Anticoagulation: Medicines to make your blood thinner so it does not clot.

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

Atria: The two upper chambers of the heart

Blue Blood: Blood that has a low amount of oxygen in it (vs red blood which has a high amount of oxygen in it).

Clot(s): 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.

Dehydrated: When you don't drink enough water, or you have diarrhea, the volume of fluid in your body decreases.

Diagnosis: Determining the cause of the disease or problem.

Diastole: Relaxation of the ventricles to allow the heart to fill with blood.

Discharge Summary: The report your hospital care team fills out before you leave the hospital.

Diuretics: Medicine to make you pee more.

Ejection Fraction: A percentage calculation measuring how well the heart is squeezing (pumping) blood. Normal EF is usually > 55%

EKG (Electrocardiogram): A heart test measuring the heart rate and checking the heart rhythm electrical activity for 10 seconds.

Fontan Circulation: Surgery that allows for one ventricle to do the job of two ventricles.

Gastrointestinal: Part of the body consisting of the stomach and intestines.

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.

Live Vaccine(s): This type of vaccine uses a weakened form of the germ that causes a disease but it has been altered and made less harmful for patients with a normal immune system.

Myocytes: Muscle cells that make up the heart muscle.

Neurohormones: Chemicals the body makes which can change blood pressure and fluid retention and make the heart work harder.

Red Blood: Blood that has a high amount of oxygen in it (vs blue blood which has a low amount of oxygen in it).

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

Systole: Squeeze of the ventricles to pump blood to the body.

Trabeculations: The "lumps and bumps" in the heart muscle, which is supposed to be more smooth.

Ventricles: The two lower chambers of the heart.

Vital Signs: These signs, including your heart rate, breathing rate, blood pressure, temperature, and oxygen levels, measure the basic functions of your body.

Word Search

- [ ] Aerobic
- [ ] Anticoagulation
- [ ] Aorta
- [ ] Atria
- [ ] Blue Blood
- [ ] Clot
- [ ] Complications
- [ ] Dehydrated
- [ ] Diagnosis
- [ ] Diuretics
- [ ] EKG
- [ ] Fontan
- [ ] ICU
- [ ] Kidney
- [ ] Liver
- [ ] Neurohormones
- [ ] Red Blood
- [ ] Systole
- [ ] Trabeculations
- [ ] Ventricles
- [ ] Vital Signs

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Appendix

- Heart Failure ACTION Plan

Heart Failure ACTION Plan

NOTE: *If you are a patient, please note the information below was written for parents and or caregivers that are taking care of you.*

After your child is discharged from the hospital, it's important to monitor how they are feeling. See below for possible signs and symptoms and the suggested actions to take.

For Infants Between 0–12 Months:

Use the zones below as a guide to monitor your child after discharge and as a reference for when to contact your care team. In case of emergency, call 911.

GREEN ZONE

Your infant is doing great!

My infant has:

- No trouble breathing or breathing is at baseline
- Ability to eat normally and complete their feeds
- No swelling in their face, eyelids, legs, feet, or belly
- Been gaining weight appropriately

What to do: Continue current plan.

YELLOW ZONE

Your infant may have worsening heart failure.

My infant has:

- Shortness of breath, especially with feedings or activity
- Increased fatigue, taking more breaks than normal when feeding but is still able to complete
- Mild swelling in their face, eyelids, legs, feet, or belly
- Not gaining weight appropriately

What to do: (check all that apply)

☐ Make the following changes to your diuretic medicine:

_____

☐ Call your care team for further advice.

RED ZONE

Your infant has concerning signs of heart failure, requiring evaluation.

My infant has:

- Shortness of breath or trouble breathing at rest
- No energy and is unable to eat
- A lot of swelling in their face, eyelids, legs, feet, or belly
- Nausea, vomiting, especially after eating
- Not gaining weight appropriately and has lost weight
- No relief of symptoms after using the diuretic action plan for _____ days

What to do: Call your care team for further advice.

For Children Between the Ages of 1–18:

Use the zones below as a guide to monitor your child after discharge and as a reference for when to contact your care team. In case of emergency, call 911.

GREEN ZONE

Your child is doing great!

My child has:

- No trouble breathing, or breathing is normal for my child
- Ability to continue their normal activity
- No swelling in their face, eyelids, legs, feet, or stomach
- No trouble with eating, and has their normal appetite
- Weight is within goal range

What to do: Continue current plan.

YELLOW ZONE

Your child may have worsening heart failure.

My child has:

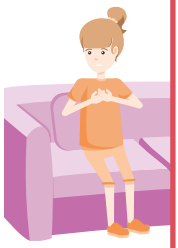
- Shortness of breath, especially with physical activity
- Weight: gained _____ lbs in _____days
  OR
  lost _____ lbs in _____days
- Increased fatigue (tiredness), need to take a more than normal amount of breaks while playing or exercising
- Mild swelling in their face, eyelids, legs, feet, or stomach
- Difficulty lying down or sleeping flat
- Nausea/vomiting or poor appetite

What to do: (check all that apply)

☐ Make the following changes to your diuretic medicine:

_____

☐ Call your care team for further advice.



RED ZONE

Your child has concerning signs of heart failure, requiring evaluation.

My child has:

- Rapid breathing, faster than normal even when sitting or resting
- A lot of swelling in their face, eyelids, legs, feet, or belly
- Nausea, vomiting, complaints of abdominal pain, especially after eating
- Continued weight gain, or weight gain more than _____ lbs in _____ days
- Continued weight loss, or weight loss more than _____ lbs in _____ days
- No relief of symptoms after using the extra diuretics in yellow zone for _____ days

What to do: Call your care team for further advice.

Notes

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02.2025

action