

UR MEDICINE

**ADVANCED HEART FAILURE PROGRAM**





*This interactive workbook is designed to give you a better understanding of your heart failure diagnosis and provide the necessary tools to help manage your condition. We hope you find the information and resources in this workbook to be educational and useful.*



MEDICINE *of* THE HIGHEST ORDER

## UR Medicine Advanced Heart Failure Program

### Welcome from Dr. Chen

Thank you for trusting UR Medicine with your heart failure care.

UR Medicine has a long tradition of providing expert, cutting-edge treatment. Our dedicated team of experienced providers works tirelessly to provide the highest quality of care for our patients.

We were the first team in the nation to implant the HeartMate 3™ Ventricular Assist Device (VAD) using the Sternal Sparing technique. Since then, our team has contributed to dramatic advances in the design and use of implantable pumps.

Today, Strong Memorial Hospital is one of the busiest VAD centers in the country. And, we have performed over 300 heart transplants, providing second chances to some of the sickest patients in Upstate New York.

As we embark on this heart failure journey together, know we are committed to providing the care you need to enjoy the best quality of life.

It is our privilege to work with you and your loved ones.



## How does a healthy heart work?

The heart is a muscle about the size of your fist that pumps blood throughout your body. The heart has four chambers and four valves to help keep blood flowing in the right direction throughout your body. The right side of your heart pumps blood to your lungs and the left side of your heart pumps blood to the rest of your body.



# What is Heart Failure?

Heart failure is a long-term condition that gets worse over time. Although the name sounds like your heart has stopped working, heart failure means your heart isn't able to pump blood as well as it should. When your heart has less pumping power, your organs can become damaged and fluid can build up in areas of your body, such as your lungs, legs, and belly.

Some common signs and symptoms also include:

- Irregular heartbeat (palpitations)
- Feeling tired
- Shortness of breath
- Weight gain
- Dry hacking cough or a cough that produces a pinkish froth
- Poor appetite
- Waking up to urinate
- Dizziness, confusion, difficulty concentrating



## MY SYMPTOMS

I would like to discuss with my heart failure provider:

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**When properly managed with medication and a healthy lifestyle, many people lead full, enjoyable lives. It's also helpful to have the support of family and friends who understand your condition.**

## TYPES OF HEART FAILURE

There are many causes of heart failure, but the condition is generally broken down into three types:

### Congestive heart failure

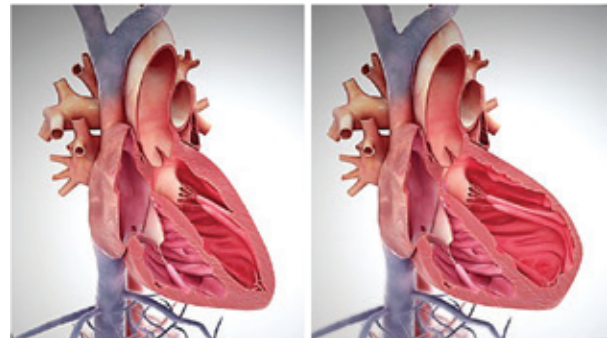
This is a state in which your heart hasn't been able to handle the blood volume. This causes an accumulation in other parts of your body, most commonly in your lungs and lower extremities (feet/legs).

### Left-sided heart failure

Heart failure with reduced left ventricular function. The lower left chamber of your heart (left ventricle) gets bigger and cannot squeeze (contract) hard enough to pump a sufficient amount of oxygen-rich blood to the rest of your body.

### Right-sided heart failure

Heart failure can also affect the right side of your heart. Left-sided heart failure is the most common cause of this. Other causes include certain conditions of the lungs or other organs.



Normal Heart

Enlarged Heart with Heart Failure

## What is My Ejection Fraction (EF)?

Ejection fraction is the measurement of blood that is pumped out of your heart. Several non-invasive tests can measure your EF. With this information, your healthcare provider can decide how to develop or adjust your treatment plan.

A normal left ventricular ejection fraction (LVEF) is 55% to 70%. For example, an LVEF of 65% means that 65% of the total amount of blood in your left ventricle is pumped out with each heartbeat. Your EF can go up and down, based on your heart condition and how well your treatment works.

MY EF IS:

\_\_\_\_\_ %.

# How Serious is My Heart Failure?

Heart failure is often classified in a set of stages that help clarify severity and track progression. Various symptoms are associated with these stages.



## MY CLASS

Record the date of your diagnosis.



### CLASS 1

No symptoms or limitations to physical activity.

DATE:

\_\_\_ / \_\_\_ / \_\_\_



### CLASS 2

Slight limitations to physical activity. Comfortable at rest. Ordinary physical activity results in feeling tired and short of breath.

DATE:

\_\_\_ / \_\_\_ / \_\_\_



### CLASS 3

Major limitations to physical activity. Less than ordinary activity results in feeling tired and short of breath.

DATE:

\_\_\_ / \_\_\_ / \_\_\_



### CLASS 4

Unable to carry on any physical activity without discomfort. Tired and short of breath even at rest.

DATE:

\_\_\_ / \_\_\_ / \_\_\_



**Advanced heart failure can be the final stage of a long-standing illness.**

Patients may gradually decline over years of treatment and develop symptoms at rest, very poor quality of life, and have escalating symptoms despite the best medical care.



## Causes and Risk Factors

Heart failure usually develops slowly, often as a result of an underlying heart condition, such as coronary artery disease, high blood pressure, damaged heart valves, a congenital heart defect, or arrhythmia. Heart failure may also arise as a complication of a heart attack.

### RISK FACTORS:

- Age
- Gender
- Heredity and race
- Obesity
- Diabetes
- Stress
- Smoking
- High blood pressure
- High cholesterol levels
- Lack of exercise
- Alcohol and illicit drug use

### MY IDENTIFIED RISK FACTORS:

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## OTHER CONDITIONS CAN LEAD TO HEART FAILURE AS WELL, SUCH AS:

### Congenital heart disease

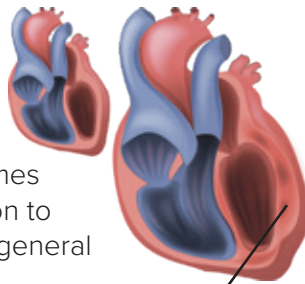
If a baby is born with a heart defect (congenital), the heart may not be working properly. This is usually due to something being wrong (defective) with the valves or the blood vessels around the heart. The defect can keep blood from flowing normally and can affect heart development.

### Cardiomyopathies

Cardiomyopathy refers to conditions that affect the myocardium (heart muscle). Cardiomyopathy can make your heart stiffen, enlarge or thicken, and cause scar tissue. As a result, your heart can't pump blood effectively to the rest of your body. In time, your heart can weaken and cardiomyopathy can lead to heart failure.

### Myocarditis

Myocarditis is an inflammation of the heart muscle (myocardium). The inflammation can reduce the heart's ability to pump and cause rapid or irregular heart rhythms (arrhythmias). Infection with a virus is the usual cause. Sometimes it is the result of a reaction to a drug or part of a more general inflammatory condition.



Myocardium

### Amyloidosis

Amyloidosis is a group of different diseases that occur when an abnormal protein called amyloid is produced. Each of these diseases has different treatments and can affect different parts of the body. That is the reason we have established a cross-disciplinary team of physicians to treat patients from fields as diverse as neurology, imaging, electrophysiology, radiology, otolaryngology, orthopaedics, and nephrology.

### Sarcoidosis

Sarcoidosis is a systemic inflammatory disease that creates inflammatory cells known as granulomas that can deposit in different organs, including the heart.

Clinically symptomatic cardiac involvement is present in 25% of patients with sarcoidosis and can be difficult to diagnose. In some cases, a biopsy of the heart may be necessary to make a definitive diagnosis. However, since the granulomas are randomly distributed in the heart, a cardiac biopsy may be abnormal in only 30 to 50% of patients with cardiac sarcoidosis.

*UR Medicine has the region's only certified WASOG (World Association of Sarcoidosis and Other Granulomatous Disorders) Center of Excellence.*

## MY CONDITIONS

List conditions and related questions:

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## How is Heart Failure Diagnosed?

The following tests will help your doctor confirm your diagnosis and determine the cause and severity.

### Blood Tests

Laboratory testing helps check for potential problems with other organs in your body, such as your liver and kidneys. Blood tests can be used to evaluate your cholesterol and lipid levels, anemia, and thyroid disease.

### B-type natriuretic peptide (BNP or NT-proBNP) blood test

B-type natriuretic peptide (BNP) is a hormone produced by your heart. N-terminal (NT)-pro hormone BNP (NT-proBNP) is a non-active prohormone that is released from the same molecule that produces BNP. Both BNP and NT-proBNP are released in response to changes in pressure inside the heart. These changes can be related to heart failure and other cardiac problems. *Levels go up when heart failure develops or gets worse, and levels go down when heart failure is stable.* In most cases, BNP and NT-proBNP levels are higher in patients with heart failure than in people who have normal heart function.

### Cardiac Catheterization

Cardiac catheterization is an invasive imaging procedure that allows your doctor to evaluate your heart function.

During cardiac catheterization, a long, narrow tube called a catheter is inserted through a plastic introducer sheath (a short, hollow tube that is inserted into a blood vessel in your leg or arm). The catheter is guided through the blood vessel to the coronary arteries with the aid of a special X-ray machine.

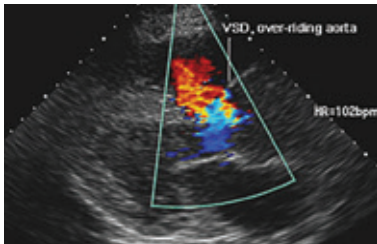
Contrast material is injected through the catheter and X-ray movies are created as the contrast material moves through the heart's chambers, valves, and major vessels. This part of the procedure is called a coronary angiogram (or coronary angiography).

### Chest X-ray

A chest X-ray is a test that creates an image of your heart, lungs, and bones.

### Echocardiogram (ECHO) to help determine your ejection fraction (EF)

An echocardiogram is a graphic outline of the heart's movement. During an echo test, ultrasound waves from a hand-held wand provide pictures of the heart's valves and chambers and help the sonographer evaluate the pumping action of the heart. Echo is often combined with Doppler ultrasound and color



Doppler to evaluate blood flow across the heart's valves.

### Electrocardiogram (EKG or ECG)

ECG is a device used to record the electrical activity of the heart. The picture is drawn by a computer from information supplied by electrodes. The ECG will assess your heart rhythm, aid in the diagnosis of poor blood flow to the heart muscle (ischemia), a heart attack, abnormalities of your heart, and abnormal electrical conduction.



### Stress test

A stress test is a common test that evaluates:

- How well your heart pumps blood
- Whether your heart is receiving an adequate blood supply
- How you perform during physical activity (riding a treadmill or stationary bike) compared with other people your age and sex
- If your symptoms (chest discomfort, shortness of breath, feeling like your heart is racing, or even dizziness) can be reproduced while performing physical activity

Healthcare providers assess your response to the increased workload by measuring:

- Blood pressure
- Heart rate
- Oxygen levels
- Electrical activity in your heart
- How hard your heart is working compared with other people your age and sex

### Cardiac MRI

Magnetic resonance imaging (MRI) is a painless test that produces very clear images of the organs and structures within the body. MRI uses a large magnet, radio waves, and a computer to produce these detailed images. It does not use X-rays (radiation).



## MY TESTING

Testing I have done:

TEST TYPE	DATE/ PLACE	RESULT	FOLLOW UP NEEDED?	QUESTIONS?
BNP or NT-proBNP (circle one)				
Cardiac catheterization				
Chest X-ray				
ECHO		EF _____ %		
EKG				
Stress test				
Cardiac MRI				

# Living with Heart Failure

Diet adjustments and other lifestyle changes will be a part of your care program, including personalized physical exercise recommendations. These changes, coupled with properly taking your medications, can lead to significant improvement in your quality of life – both physical and emotional.

## TOOLS FOR MANAGING HEART FAILURE

- Heart-healthy diet
- Exercise
- Smoking cessation
- Avoid alcohol
- Daily weight measurement
- Sleep, rest, and stress management
- Take your heart failure medication as prescribed
- Maintain appointments with our advanced heart failure team

## OTHER HEALTH CONDITIONS

It's very important for you to manage your other health conditions, such as:

- Diabetes
- Kidney disease
- Anemia
- High blood pressure
- Thyroid disease
- Asthma
- Chronic lung disease

Some conditions have signs and symptoms similar to heart failure. If you have new or worsening non-urgent symptoms, tell your healthcare provider.



# Guideline Directed Medical Therapy

## **ACE Inhibitors (ACE)**

Research shows that ACE inhibitors help people with heart failure live longer. They work by blocking the stress hormones in your body that cause extra work for your heart. They will help lower your blood pressure and can protect your kidneys.

## **Angiotensin Receptor Blockers (ARB)**

This medication will help reduce the workload of your weakened heart. Your doctor may prescribe an ARB if you experience side effects from an ACE inhibitor, like a cough.

## **Angiotensin Receptor-Nepriylsin Inhibitor (ARNI) (Entresto)**

Entresto can help reduce hospital visits and lower the risk of death in patients with chronic heart failure. It is a combination of two drugs: sacubitril and valsartan. This medication may be given in place of an ACE or ARB.

## **Beta-Blockers (BB)**

Research shows that beta-blockers improve heart function and can help you feel better. They work by blocking the harmful effects of stress hormones. They control blood pressure and prevent heart attacks.

## **Mineralocorticoid Receptor Antagonist (MRA) or Aldosterone Receptor Antagonists**

These drugs help get rid of excess fluid. These medications may cause frequent urination. They will help you breathe more easily, reduce swelling, and ease your heart's workload. Frequent monitoring of certain lab values, especially your potassium, may be necessary while on these medications.

## **Sodium-Glucose CoTransporter-2 Inhibitors (SGLT2)**

SGLT2 inhibitors are associated with a 30% to 35% lower risk of hospitalization for heart failure. These medications have historically been used in the treatment of diabetes; they can also be used to treat heart failure in people with or without diabetes.

## **Additional medical therapy your provider may prescribe:**

### **Digoxin**

Digoxin strengthens and slows down your heart rate. This can help reduce some of the symptoms of heart failure.

### **Ivabradine**

A type of drug used to slow the heart rate. Your doctor might prescribe ivabradine if your heart rate is still a little fast with a beta-blocker, or if you cannot take a beta-blocker.

### **Iron**

Intravenous (IV) iron has been shown to reduce hospitalizations in patients with heart failure. Many patients have reported improvement in their symptoms, less fatigue, and better functional status.

### **Additional Diuretics**

Diuretics, or water pills, help get rid of excess fluid. These medications will cause frequent urination. Diuretics help you to breathe more easily, reduce swelling, and decrease how hard your heart works.

## TIPS FOR TAKING YOUR MEDICATIONS:

- ▶ Take all medications **as prescribed**, including the correct dose and at the right time(s) of day.
- ▶ Use an **alarm or phone app** to remind you to take your pills.
- ▶ Make sure your doctor and pharmacist know of any **vitamins or over-the-counter medications** you are taking to check for potential interactions.
- ▶ Use a **pill box** to organize your daily medications.
- ▶ Make sure that you are getting your **routine blood work** done as prescribed by your heart failure provider.
- ▶ **DO NOT change or stop** taking your medications without talking to your heart failure provider! Keep taking your medications even if you feel better – that means they are doing their job!



Often, as heart failure becomes more advanced, you may become intolerant to certain medications. Your heart failure provider will monitor and make any necessary adjustments as your disease progresses.



# MY MEDICATIONS

Circle the name or write it in if you don't see your medication listed

MED	NAME	DOSE	FREQUENCY	SIDE EFFECTS	QUESTIONS
ACE	Lisinopril, Captopril Ramipril, Enalapril				
ARB	Valsartan, Irbesartan Candesartan, Losartan				
ARNI	Entresto (combination of sacubitril & valsartan)				
BB	Metoprolol, Uccinate Carvedilol, Bisoprolol				
MRA	Spirolactone, Eplerenone				
SGLT2	Dapagliflozin (Farxiga) Empagliflozin (Jardiance)				
Other					

## POSSIBLE ADDITIONAL MEDICAL THERAPY YOUR PROVIDER MAY PRESCRIBE:

Circle the name or write it in if you don't see your medication listed

MED	NAME	DOSE	FREQUENCY	SIDE EFFECTS	QUESTIONS
DIGOXIN	Lanoxin				
IVABRADINE	Also known as Corlanor				
IRON	May be given intravenously				
ADDITIONAL DIURETIC	Furosemide				
Other					

Additional questions about my medication:

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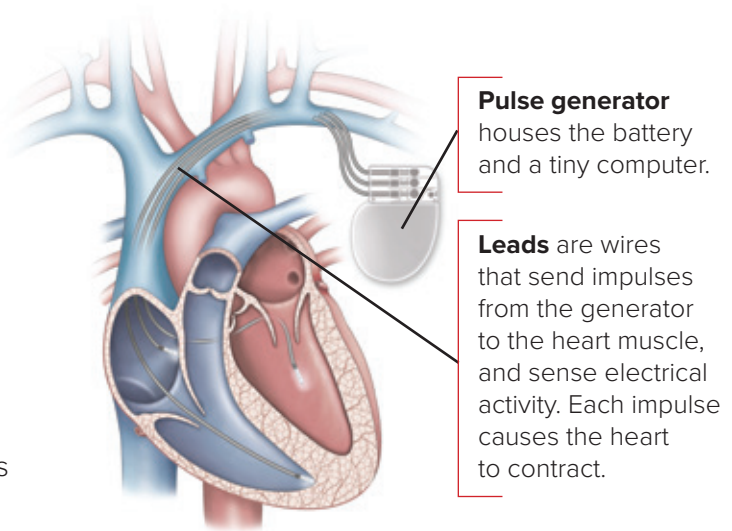
# Treatment Options and Procedures

All patients follow different paths in their treatment journey. Further discussion with your provider will determine the best treatment options for your needs. These may include:

## Implantable Cardioverter-Defibrillator (ICD)

Your doctor may recommend that you receive an ICD because you have had at least one episode of a life-threatening heart rhythm. Heart failure can cause irregular rhythms that cause the heart to beat very fast. These conditions can be fatal if not treated immediately.

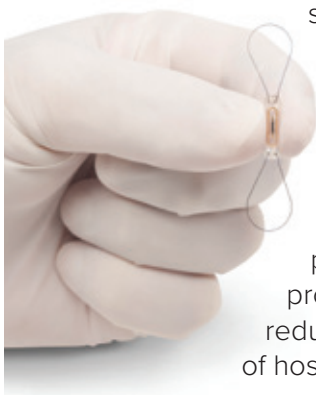
An ICD is an electronic device that constantly monitors your heart rhythm. When it detects a very fast, abnormal heart rhythm, it delivers energy (shock) to the heart muscle. This causes the heart to beat in a normal rhythm again.



## Pulmonary Artery Pressure Monitoring (CardioMEMS)

The CardioMEMS HF System is an implantable miniaturized, wireless monitoring sensor to manage heart failure and reduce the number of hospitalizations.

This device measures pulmonary artery pressure, which is an indirect measure of worsening heart failure. A monitor built into a pillbox allows the system to transmit daily information from patients' homes directly to their UR Medicine heart failure team. This allows for personalized and proactive care to reduce the likelihood of hospitalization.



## Cardiac Resynchronization Therapy (CRT) or a Biventricular Pacemaker

Cardiac resynchronization therapy (CRT) is used to treat the delay in heart ventricle contractions that occur in some people with advanced heart failure.

A weakened heart's blood moves through the heart and body at a slower rate, and pressure in the heart increases. A delay between the contraction of the right and left ventricles often occurs with heart failure, so the walls of the left ventricle are unable to contract at the same time.

CRT can help your heart to pump more efficiently. A CRT device uses electrical signals to help the heart beat in a more coordinated manner.

## Bypass Surgery

The most common surgery for heart failure treatment is bypass surgery. If a coronary artery becomes blocked, less oxygen-rich blood reaches the heart muscle. The heart muscle becomes “starved” for blood (ischemia) and is unable to pump normally. Your doctor will determine if your heart failure is caused by coronary artery disease and if you have blockages that can be “grafted” or bypassed. A coronary artery bypass graft—or bypass surgery—involves taking a blood vessel from another part of your body and using it to bypass the blocked artery, restoring blood flow to the heart. After blood flow is reestablished, normal heart function may return over time. Coronary artery bypass graft surgery (sometimes called CABG or “cabbage” for short) is the most common type of procedure known as revascularization.

Coronary artery bypass grafts are generally for patients who have multiple blockages, as opposed to those who have one or two blockages. In that case, angioplasty and stenting may be a more appropriate treatment.

For most people, CABG surgery extends the length and quality of their life. Most patients who undergo the procedure at UR Medicine experience long-term success. Many no longer have symptoms of angina and may even feel more energetic. Today there are new procedures available to make bypass surgery less traumatic.

## Valve Surgery

As heart failure progresses, remodeling of the left ventricle causes the papillary muscles

(which support the mitral valve leaflets) to stretch out of shape, causing the valve to leak. Mitral valve repair usually involves reshaping the leaflets and providing support to the mitral valve with a ring.

## Left Ventricular Assist Device (LVAD)

An LVAD is a mechanical pump that is implanted in patients with heart failure. It helps the bottom left chamber of your heart (left ventricle) pump blood out of the ventricle to the aorta and the rest of your body. That is why it is called a Left Ventricular Assist Device.

These mechanical devices are implanted in your heart and are powered by an external battery source. VADs have been shown to help extend and improve the lives of people with heart failure.

*UR Medicine has one of the largest VAD programs in the nation.*

## Heart Transplantation

A heart transplant is a surgery that replaces your heart with one from an organ donor. This is only used when you are too sick to survive without a transplant and only if you meet strict criteria. Thanks to advances in modern medicine, this procedure has a high success rate, and people may live years or even decades after this procedure.

Since donor hearts are in short supply, patients may need to wait months or even years for a heart to become available.



**UR Medicine has the only heart transplant program in Upstate New York and has transplanted over 300 hearts.**

With the right care, heart failure won't stop you from doing the things you enjoy. Your prognosis, or outlook for the future, will depend on:

- ▶ **How well your heart muscle is working**
- ▶ **Your symptoms**
- ▶ **How well you respond to your treatment plan**
- ▶ **How well you follow your treatment plan**



## MY TREATMENT

PROCEDURE	DATE	LOCATION
ICD		
CRT		
CardioMEMS		
Bypass surgery or valve surgery		
Stenting		
LVAD		
Heart transplantation		

Treatment questions for my heart failure provider:

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# Patient and Family Expectations

- ▶ Please arrive 15 minutes prior to your scheduled appointment time.
- ▶ If you cannot arrive on time for your appointment, please call the office and notify them of your delay: **(585) 273-3760** or **1 (800) 892-4964**. If the delay is more than 20 minutes, we will need to reschedule your appointment.
- ▶ RN staff is available during clinic business hours to take all urgent phone calls. Requests to speak solely to a provider will not be accommodated, as physicians and NPs/PAs are not available to take calls during clinic hours.
- ▶ In the case of unforeseen circumstances or emergencies, there is a provider on call for our patients 24 hours a day/seven days a week. This is a service that should only be used for things that cannot wait until normal business hours.
- ▶ Return calls to patients and their families are made in the order of urgency. All non-urgent matters and calls will be returned within 48 hours.
- ▶ Medication refills will be completed within 72 hours.
- ▶ We require seven days for completion of insurance or disability paperwork or letter requests.
- ▶ Clinic visits will occur with either an attending physician or one of our APP staff. All of our provider staff have extensive training and expertise in advanced heart failure.
- ▶ Please be sure to have your current medication list with you during your office visit.

**If you have heart failure, you can take steps to improve your heart health.** Take your medications as instructed, follow a low-sodium diet, stay active or become physically active, take notice of sudden changes in your weight, live a healthy lifestyle, keep your follow-up appointments, and track your symptoms. Talk to your healthcare provider about questions or concerns you have about your medications, lifestyle changes, or any other part of your treatment plan.



# Advanced Care Planning

Because heart failure is a chronic, long-term illness, talk to your doctor and your family about your preferences for medical care. Complete an *advance directive* or *living will* to inform everyone who is involved in your care of your preferences. A living will details the treatments you do or don't want to prolong your life. It's a good idea to prepare a living will while you are well in case you aren't able to make these decisions at a later time.

We are proud of our hospice and palliative care programs. We believe each individual has the right to choose the extent of his or her medical treatment. We will work closely with these teams when the time is right to ensure that symptom management and pain relief, as well as sensitivity to emotional needs, are the center of all we do for you and your family.

## Resources

American Heart Association (AHA)  
Heart.org

American Association of Heart Failure Nurses (AAHFN)  
togetherinhf.com

National Heart, Lung, and Blood Institute  
nhlbi.nih.gov

American Diabetes Association  
diabetes.org

Abbott  
abbott.com

Academy of Nutrition and Dietetics  
eatright.org

NYS Smokers' Quit Line  
nysmokefree.com  
1-866-NY-QUITS  
1-866-697-8487

Substance Abuse and Mental Health Services Administration (SAMHSA)  
samhsa.gov/find-help/national-helpline

*SAMHSA's National Helpline is a free, confidential, 24/7, 365-day-a-year treatment referral and information service (in English and Spanish) for individuals and families facing mental and/or substance abuse disorders.*

### Lodging

Harbor House of Rochester  
89 Rossiter Road  
Rochester, NY 14620-4125  
(585) 473-1779  
harborhouseofrochester.org

*The Harbor House of Rochester is a four-bedroom facility, located two short blocks south of the University of Rochester Medical Center. You will find our peaceful home situated in the quaint Upper Mt. Hope neighborhood.*

RIT Inn & Conference Center  
5257 West Henrietta Road  
Henrietta, NY 14467  
(585) 359-1800  
rit.edu



## **Advanced Heart Failure Program**

**Heart Failure | Heart Transplant | Mechanical Circulatory Support**

601 Elmwood Avenue, Box 679T  
Rochester, NY 14642

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800-892-4964  
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Part of Strong Memorial Hospital

