GoToGuide
Cardiomyopathy
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If you’ve just been diagnosed with cardiomyopathy, you probably have many questions and concerns. Cardiomyopathy is an underdiagnosed disease, and it can be hard to find helpful information designed with the patient in mind.

The purpose of this GoToGuide is to help you and your loved ones understand what it means to have cardiomyopathy, how it is diagnosed and treated, information to help you live with cardiomyopathy, and to get you connected to tools and resources that will help you on your journey.

Understanding your condition, along with the seven steps to becoming an empowered patient, will help you work with your health care team and your support network to help you manage your condition effectively, and find a plan and solutions that are right for you.

The Seven Steps to Becoming an Empowered Patient are:

- **Step 1:** Take control
- **Step 2:** Educate yourself
- **Step 3:** Know your rights
- **Step 4:** Be part of the team
- **Step 5:** Get information
- **Step 6:** Voice your opinion
- **Step 7:** Make informed decisions that are right for you
7 Steps to Becoming an Empowered Patient

1. **Take control**
   By using this Guide, you are taking control of your health care and taking the first step to becoming an empowered patient. In this Guide, you will receive valuable information along with tools and resources to help you reduce your risk and live with cardiomyopathy.

2. **Educate yourself**
   For you to be truly empowered, it is important to understand what your cardiomyopathy diagnosis means. Ask your doctor to explain your condition and where you can learn more about it from reliable sources.

3. **Know your rights**
   Many patients feel they are at the mercy of the system and just need to do “what the doctor says.” While it is very important to follow your treatment plan, you also need to know, and insist on, when needed, your rights as a patient.

4. **Be part of the team**
   You know yourself better than anyone. Talk to your health care team about any questions, issues or concerns you may have, communicate your needs, and keep your appointments.

5. **Get information**
   If you need medication, surgery or a device, you can never ask too many questions. Your doctor’s job is to help you feel confident about your treatment plan, so don’t be afraid to ask questions until you feel like you understand.

6. **Voice your opinion**
   Your voice matters. Your needs, thoughts and opinions matter. Don't be afraid to speak up if you feel confused or uncomfortable with any course of action.

7. **Make informed decisions that are right for you**
   You might hear people talk about shared decision making. Shared decision making means that there is ongoing communication between the patient and the person providing care. What you want matters. Make sure you’re part of the conversation about your cardiomyopathy and actively involved in treatment option decisions.

Download the worksheet
Step 1: Take Control

When you are diagnosed with a disease like cardiomyopathy that affects your heart, you may feel that your heart—something you have relied on your whole life—has let you down. You might even feel like you have no control over your health or your future. However, while there are some things you can’t control, you can control your decisions, your plan, and choices about your life that can help you live better even with cardiomyopathy. About 1 in every 500 people have this condition and must learn to manage it. Also, remember, you are not your disease. It’s up to you to decide how you are going to live your life despite the challenges.
**Step 2:**
**Educate yourself**

After you decide to take control over your health and your life, it’s vital to educate yourself. Having information about cardiomyopathy, symptoms, tests, and treatment options is your next step toward taking control of your health.

Step 2 of becoming an empowered patient, educating yourself, can make a difference in how well you do living with cardiomyopathy. At The Mended Hearts, Inc. (MHI), our patients, caregivers and family members living with many forms of heart disease understand that knowledge is power. So, they arm themselves with the information they need to truly understand their disease and their options.
There is so much information out there that it can be hard to know what is accurate and what isn’t. This Guide will provide the essentials about cardiomyopathy and what you can do to stay as healthy as possible. If you are interested in learning more, there is a list of resources at the end of the guide that you can go to for reliable information.

**What is cardiomyopathy?**

Cardiomyopathy is a term used to describe a variety of conditions that can affect the heart muscle. The disease causes the heart muscle to thicken, become stiff, enlarge, thin out, or become filled with substances that don’t belong. This makes it hard for the heart to pump blood properly.

Cardiomyopathy has many causes and can affect people of all sexes, ages and races. It is estimated that as many as 1 in 500 adults has a form of cardiomyopathy. That number could be much higher due to underdiagnosis and misdiagnosis. If you have a history of cardiomyopathy in your family, it is important to discuss this with your health care provider.

Cardiomyopathy is a serious condition that can lead to other complications. Some of these are:

- Heart Failure
- Sudden Cardiac Arrest
- Blood Clots
- Heart Valve Disease

**As many as 1 in 500 adults has a form of cardiomyopathy**

**CDC FACT SHEET**

Download the fact sheet
Types of cardiomyopathy

There are several types of cardiomyopathy that have different characteristics and causes. All cardiomyopathies involve the heart muscle and can make it difficult for the heart to pump blood to the body.

The two most common types of cardiomyopathies are **dilated cardiomyopathy** and **hypertrophic cardiomyopathy**.

**Dilated Cardiomyopathy (DCM)**

DCM is where one of the bottom two chambers of the heart, called ventricles, is enlarged—usually the left ventricle that pumps blood to the body. Dilated cardiomyopathy is more common in males. It is also the most common form of cardiomyopathy in children. This type of cardiomyopathy can occur at any age. In some cases, it can be an inherited disease.

**Hypertrophic Cardiomyopathy (HCM)**

HCM occurs when the heart muscle is thickened. It is a type of cardiomyopathy often seen in children and young adults. It also is often an inherited condition. In fact, according to the Centers for Disease Control and Prevention (CDC), it is “thought to be the most common inherited or genetic heart disease,” yet many people are unaware of this and therefore don’t realize the need to be checked when a family member has this condition. Hypertrophic cardiomyopathy may not cause any symptoms, but it can cause sudden death in adolescents and young adults (especially athletes).

**Other types of cardiomyopathy include:**

**Arrhythmogenic right ventricular cardiomyopathy**

This is a rare type of cardiomyopathy that causes the muscle in the right lower ventricle to break down over time, possibly leading to irregular heartbeats or rhythms and sudden cardiac death. This condition is often caused by genetic changes.
Restrictive Cardiomyopathy
Can occur when the heart muscle becomes stiff, and the heart can’t fill with blood to pump to the body. Restrictive cardiomyopathy is the rarest type and is most commonly seen in older adults. It may develop due to amyloidosis (a problem with the blood cells) or hemochromatosis (in which too much iron builds up in the blood) and other underlying health conditions.

ATTR-CM
Transthyretin amyloid cardiomyopathy (ATTR-CM) is a rare but serious type of restrictive cardiomyopathy where a protein called transthyretin (TTR) folds incorrectly and sometimes builds up in the heart, nerves and other organs. As a result, the heart can become unable to pump blood adequately, ultimately leading to heart failure. ATTR-CM is often misdiagnosed or undiagnosed.

Cardiomyopathy is considered the most common genetic heart disease.

Peripartum Cardiomyopathy
This type can happen during the end of pregnancy or up to a year after giving birth. In this type of cardiomyopathy, the heart muscle weakens, and fluid may build up in the lungs. If you have any symptoms of cardiomyopathy during the end of your pregnancy or after giving birth, get medical treatment right away.

ATTR-CM INFOGRAPHIC
Download the infographic
Cardiomyopathy is often undiagnosed and can occur in children and adults.
Causes of cardiomyopathy

There are many different causes of cardiomyopathy, and sometimes the cause is unknown. Cardiomyopathy can be inherited and will run in families. In fact, if one parent has a gene for cardiomyopathy his or her child has a 50% chance of getting it. Other times, cardiomyopathy is acquired—meaning that it develops sometime in a person’s life and is often the result of another type of heart disease, another health condition, or some other factor.

Things that put you at higher risk of getting cardiomyopathy are:

- A family history of cardiomyopathy or other heart conditions
- Heart attack causing damage to the heart
- Heart valve disease
- Long-term tachycardia or fast heart rhythm
- Diseases that cause substances to build up in your heart (e.g., amyloidosis, sarcoidosis or hemochromatosis)
- Heart inflammation from certain infections of the heart such as endocarditis (infection of the inner lining of the heart), myocarditis (infection or damage of the heart muscle) or pericarditis (infection of the thin membrane around the heart)
- Cancer treatments (chemotherapy or radiation)
- Infections, i.e., COVID-19, viral hepatitis, HIV
- Obesity
- Diabetes, thyroid disease or other diseases that affect metabolism
- Connective tissue disorders
- Pregnancy complications
- Long-term use of alcohol, cocaine or amphetamines
Not everyone with cardiomyopathy will have symptoms. Some people may only develop symptoms in later stages of the disease when the heart has weakened.

When symptoms do occur, they may include:

- **Shortness of breath** especially with physical activity
- **Fatigue**
- **Swelling (Edema)** in the ankles, feet, legs, abdomen, stomach and neck
- **Dizziness & Lightheadedness** or fainting (syncope) during physical activity
- **Coughing** especially when lying down
- **Arrhythmias** abnormal heart beats
- **Heart palpitations**
- **Chest pain** especially after physical activity or after eating a large meal
**Diagnosing cardiomyopathy**

Cardiomyopathy is an underdiagnosed disease, and it is often hereditary. If you have cardiomyopathy in your family, talk to your health care provider about your risks.

If you have a high risk of cardiomyopathy, have symptoms of cardiomyopathy, or if your doctor is concerned that you might have it, there are different tests to help you find out whether you have it or not.

- **Blood tests:** Blood tests check the levels of certain substances in your blood that are raised when you have cardiomyopathy or heart failure.
- **Chest X-ray:** A chest X-ray can show whether your heart is enlarged and/or whether fluid is building up in your lungs.
- **Electrocardiogram (EKG or ECG):** An EKG records the heart’s electrical activity. This test can show how fast the heart is beating and if it is beating normally or not.

- **Holter and event monitors:** These are portable devices that you wear, typically for a day or two. They record your heart’s electrical activity (how your heart is beating) as you go about your day.
- **Echocardiogram (echo):** An echocardiogram uses sound waves to create a moving picture of your heart. It reveals what your heart looks like and how well it is working, as well as its size and shape. One type of echo is a “stress echo.” With this, the echo is done as part of a stress test (in which you will walk on a treadmill (usually) to see how physical exertion affects your heart).
- **Positive emission tomography (PET) scan:** With a PET scan, a radioactive substance is injected into your veins before an imaging test. Healthy heart tissue will absorb more of the substance than tissue that’s no longer healthy.
- **Genetic Testing:** Genetic testing may be ordered to determine if you have a genetic or inherited form of cardiomyopathy.

Diagnostic Procedures

If more testing is required to confirm a diagnosis of cardiomyopathy, you may undergo a minor medical procedure such as a:

**Cardiac catheterization:**
Cardiac catheterization is used to examine the heart valves or take samples of the heart muscle (called a heart biopsy). A long, thin, flexible tube called a catheter is put into a blood vessel in your arm, groin or upper thigh, or neck. The catheter is then threaded through the blood vessels to your heart.

**Coronary angiography:**
This is a procedure is often done using cardiac catheterization. After the catheter is in place, your doctor will inject a contrast dye through the catheter. The dye highlights any blockages in the heart.

Click on the right to hear from a patient about What is HCM.

Click on the right to learn myths about HCM from a patient.
Treating Cardiomyopathy

Treatments for cardiomyopathy cannot cure it, but they can help slow it down and help to prevent it from getting worse. There are also treatments to help with symptoms, to improve the heart’s function, and help with complications of cardiomyopathy like heart failure, heart rhythm issues, and sudden death. Your doctor will find a treatment based on the type of cardiomyopathy you have and how severe it is.

Lifestyle changes

Sometimes your doctor will ask you to make some lifestyle changes (more on these on page 24) to help your heart and prevent some complications from cardiomyopathy. Things that are good for all of us, like eating a heart-healthy diet, getting exercise, and avoiding alcohol and recreational drugs, are things that will help you if you have cardiomyopathy too. Talk to your doctor about lifestyle changes that will help you.

Medication

Medication may be prescribed to treat symptoms, complications of cardiomyopathy, and conditions that cause cardiomyopathy,

**Medicines that help prevent arrhythmias**

Antiarrhythmics help your heart beat at a normal rate and prevent abnormal heartbeats

**Medicines that lower blood pressure**

Ex. ACE inhibitors, angiotensin II receptor blockers, beta blockers and calcium channel blockers

**Medicines that slow heart rate**

Ex. Beta blockers, calcium channel blockers and digoxin
Other medications

- Myosin inhibitors reduce how hard the heart squeezes.
- Aldosterone blockers balance electrolytes in your body.
- Electrolytes help muscle tissue and nerves work properly.
- Diuretics ("water pills") help remove excess fluid and sodium from the body.
- Cholesterol medications lower cholesterol levels.
- Anticoagulants, or blood thinners, help prevent blood clots.
- Corticosteroids reduce inflammation.

Medication Tips

Many patients who are members of Mended Hearts® told us what tips help them the most with taking medications. Their Top 10 Tips can be downloaded from this page. Here are some additional medication tips:

- Fill your prescriptions on time
  Be sure to get your prescriptions refilled BEFORE you run out. If possible, ask for automatic refills. Also, you may be able to get your prescriptions mailed so they come right to your home.

- Follow instructions
  There are instructions on medication labels and some that come with the medication that tell you when and how often to take it and what to avoid when taking it too. If you don’t understand the instructions, call your doctor and ask as soon as possible.

- Don’t stop taking medication
  Don’t stop taking your medication without your doctor’s permission. If you experience side effects, call your doctor to discuss what to do.

- Prepare when traveling
  When traveling, pack all your medications and take a few extra doses in case you’re delayed getting home. Keep your medication with you, and never place it in a checked bag.

- Keep a list
  Keep a current list of your medications and take it to appointments. If you have access to a health app, your medication may be stored.

TOP 10 MEDICATION TIPS

Download the Top 10 Tips
Devices

In some cases, people will need devices to help them manage their cardiomyopathy. These are usually needed when your cardiomyopathy is severe, and they are needed to help with heart function. Some of these devices are:

- **Pacemaker**
  A pacemaker is a small device that is implanted under the skin in the chest to help the heart beat normally. Pacemakers are commonly used to treat arrhythmias (irregular heartbeats). Implanting (putting in) a pacemaker involves a minor surgical procedure that can often be done on an outpatient basis.

- **Implantable cardiac defibrillator (ICD)**
  An ICD is similar to a pacemaker, but it works a little differently and is used for people with life-threatening arrhythmias. When it senses dangerous heart rhythms, it delivers a shock to the heart. This is called defibrillation. Many of the newer ICDs can act as both a pacemaker and a defibrillator. Implanting an ICD is similar to implanting a pacemaker.

**Left ventricular assist device (LVAD)**
An LVAD is a device that helps pump blood from the left bottom chamber (ventricle) of your heart to the rest of your body. LVADs are usually only used in people with severe heart failure or for those awaiting a heart transplant. Open-heart surgery is often required to put in an LVAD.

If your cardiomyopathy is severe and hasn’t improved with medications or devices, you may require open-heart surgery. For people who have extremely severe (end-stage) heart failure, a **heart transplant** may be the only option.
Step 3: 
**Know Your Rights**

Step 3 of becoming an empowered patient is to know your rights. Even empowered patients may be afraid to ask questions, express concerns and assert their rights, but it is important to do so. Your health is on the line, and you are the best person to manage it in a way that works for you. You have rights as a patient, and these rights should be respected.

**YOU HAVE THE RIGHT TO:**
- Be treated as part of the team
- Ask questions and get answers
- Have your concerns heard
- Have easy access to notes and medical records
- Get a second opinion (and third and fourth, if needed) to help you feel confident in your decisions
- Suggest alternatives
- Feel confident in your health care team
- Change your mind
- Appeal decisions if you don’t agree
Step 4: Be Part of the Team

Step 4 in becoming an empowered patient is to be part of your health care team. This may feel a bit odd for patients who are used to viewing medical professionals as “all-knowing.” It can seem easier to allow your health care professionals to tell you what to do and to simply follow it, but patients actually do better and are more likely to stick to their treatment plan when they play a part in their health care team. In fact, doctors today typically want their patients to be actively involved in their care.

When you are part of the team, you make sure you understand your condition, you ask questions any time you don’t understand something, you get all the information you need, and you make suggestions. You participate in coming up with a plan that will help you manage your cardiomyopathy in a way that is right for you.
Step 5: Get information

You’ve already taken Step 2 by educating yourself, but there is often more information that is needed from your health care professionals for you to manage your condition. Therefore, Step 5 to becoming an empowered patient is to make sure you understand everything you can about your disease—not only by knowing what cardiomyopathy is in general, but how it is affecting you specifically and what you can do about it.
Here are some suggestions for questions you may want to ask your doctor or health care provider—but be sure to ask questions about any concerns you have too. Writing them down in advance will help you remember them. Take them to your appointments and don’t be afraid to contact your doctor to ask questions between appointments.

- What caused my cardiomyopathy?
- What type of cardiomyopathy do I have?
- How severe is my cardiomyopathy?
- What are possible complications from my cardiomyopathy?
- What medications might help manage my cardiomyopathy and what are their risks and benefits?
- What other treatment options are available to me with the risks and benefits of each option?
- How can I keep my cardiomyopathy from worsening?
- What changes to my diet or exercise routine should I make?
- What other lifestyle changes, if any, do I need to make?
- Where can I find more resources and trustworthy information on cardiomyopathy?
- What signs and symptoms should I look for that would let me know I need to call the doctor, or 911?
- How can I get connected to other patients like me for peer support and information on living with cardiomyopathy?
Step 6:

Voice your opinion

You’ve learned how important it is to be a part of the team in Step 4. Step 6 in becoming an empowered patient is to learn how to be comfortable voicing your opinion as part of that team.
It can be hard to speak up on your own behalf. This is especially true if you disagree with your doctor. However, since you are part of the team, your doctors want you to voice your opinion (without being argumentative, of course). You should not feel like you are bothering them or being a difficult patient. Remember, you are the one living with cardiomyopathy. Your needs, preferences and concerns matter.

**Top 10 Tips**  
Tips from Patients about Communicating with Your Doctor or Health Care Provider

1. Be clear about your health goals and specific about what you want to know.
2. Don’t be afraid to keep asking questions until you understand.
3. Learn about your condition so you are better prepared.
4. Find the right health care professional for you and be willing to get a second opinion.
5. Ask about the best way to communicate with your health care professional.
6. Keep a list of questions and take it with you to appointments.
7. Ask your health care professional for resources and educational materials so you can learn more.
8. You are the expert on you. Don’t be afraid to share your thoughts and opinions.
9. Take someone with you to appointments so you have an extra set of ears.
10. If you have questions or concerns, don’t wait for an appointment to communicate.
Step 7: Make informed decisions that are right for you

The last step in becoming an empowered patient is putting it all together and making informed decisions that work for YOU. You’ve educated yourself, learned how to work as part of the team, and become comfortable with the idea that your opinions matter. The payoff is that you feel in control. When you’re in control, you can make informed decisions about your care. You are also more likely to follow a treatment plan when you and your doctors agree that it’s the right one for you.

This next section explains the things you can do and the changes you can make to improve your chances of living a healthy life with cardiomyopathy.
Living with Cardiomyopathy

While you may not be able to reverse cardiomyopathy, there are lifestyle measures you can take to keep your heart as healthy as possible and to help prevent some of the complications of cardiomyopathy.

1. Get clear on where you are now.
2. Stick to your treatment plan.
3. Make any needed changes to your diet.
4. Make any needed changes to your physical activity level.
5. Make other lifestyle changes to improve your heart health.
6. Get connected.

1. Get clear on where you are now

When you are making any lifestyle changes, it’s important to know your starting point. Take a careful look at your diet, exercise, and habits to help you figure out where you can make changes. It can be helpful, if possible, to start with easier and smaller changes and move towards healthier habits overall.

One thing you can do is know your numbers, if you don’t already know them. Find out what your cholesterol numbers and your blood pressure are and what they should be. If either are too high, talk to your doctor about what you can do to lower them. Keeping these numbers in the right range will help your heart.

Also, take a careful look at your diet and exercise levels. Are you eating heart-healthy foods or foods high in sugar, sodium and saturated fat? Are you getting enough physical activity or are you spending too much time sitting and sleeping? There are often simple and easy ways to improve diet and exercise, but you must be realistic about where you are starting. It is very difficult to go from zero to full speed quickly, and most of the time that way of making changes doesn’t last either.
Finally, take a look at your habits. If you drink alcohol, smoke or use recreational drugs, that can be hard on your heart and worsen your cardiomyopathy. Again, look honestly at where you are now so you can make the changes you need to make.

When you know your starting point, you can also celebrate successes. It can feel good to look back on where you were after you make healthy changes.

2. Stick to your treatment plan

Hopefully, you came up with a good treatment plan with your health care team. Your treatment plan may include changes to diet and exercise, medications and in some cases, medical devices, such as a pacemaker. It is very important to stick to your treatment plan and discuss any needed changes with your doctor.

As part of your treatment plan, you may be asked to monitor your symptoms or keep track of sodium, fluid intake or other things. There are some apps your doctor may suggest that can help with monitoring if you have access to a smart phone or device. If not, ask your doctor for the best way to track these things. Mended Hearts® has forms that can help with tracking symptoms and medications.

Remember that your plan needs to be one that works for you and your lifestyle. If you notice any side effects with your medications or are having a hard time changing your habits, don’t be afraid to talk to your doctor. It’s common to make changes to a treatment plan with your doctor, especially if your health doesn’t seem to be improving or if your plan isn’t working for you.

Always consult with your doctor before making any changes to your medication or exercise plan.

3. Make any changes needed to your diet

It is always helpful to eat healthy foods, but it is especially important when you have a disease like cardiomyopathy that affects your heart. A healthy diet goes a long way toward improving
heart health. Eating right can give you more energy and help you fight fatigue. If being overweight is contributing to your symptoms, changing what you eat also can help you get to a healthy weight.

Here are some guidelines for heart-healthy eating:

- **Focus on fresh fruits, vegetables and whole grain breads, rice and pastas.** These are full of the nutrients you need and typically free of added fats or sugar.

- **Cut back on salt.** Foods that are high in sodium (salt) can raise your blood pressure and make your body retain water. Aim for less than 2,300 milligrams (mg) of sodium per day. Keep in mind that packaged foods—those that are canned, frozen, or in boxes—are higher in sodium than fresh foods you prepare yourself.

- **Limit fats.** Lean cuts of meat, skinless poultry, fish and low- or fat-free dairy products are less likely to lead to unhealthy cholesterol levels than fatty cuts of meat and full-fat products. Avoid or limit foods with saturated and trans fats; these are more common in packaged foods.

- **Limit your alcohol intake.** The recommended limits are no more than two drinks a day for men and one drink a day for women.

**More tips for healthy eating**

- Cook your own meals whenever possible. Restaurant and take-out portions tend to be large and are often high in sodium.
- Broil, bake, steam, poach or grill your food instead of frying or sauteing.
- Use onions, garlic, spices and herbs to flavor food instead of salt.
- Try to eat a “rainbow” of different fruits and vegetables learn their nutritional benefits.
- Use ketchup, mayonnaise, soy sauce and other condiments sparingly, and buy low-salt varieties.
- Avoid foods that are pickled, brined, cured or barbecued. These tend to be high in sodium.
How to Read a Food Label

**Serving Size:** This tells you the amount of food in one serving. If you increase the serving size, all the other values on the label will increase as well.

**Fat:** This tells you how many grams of fat are in a serving. Limiting the amount of saturated fat and trans-fat in your diet is important for good heart health.

**Sodium:** This is the number of milligrams of sodium in a food. Talk to your doctor about how much sodium you should consume per day.

**Total carbohydrate:** This tells you the amount of carbohydrates (starches) in one serving of food.

The USDA’s MyPlate Plan is an illustration of a pie chart that shows you how much of each food group should make up a typical meal, based on your height, weight and overall health. A nutritionist or dietician can help you design the perfect plate for you based on your health goals.
4. Make any needed changes to your physical activity level

Being active is important for everyone. Exercising benefits your health, your mood, and your sleep quality. Exercise can help you control your blood pressure and cholesterol. It can also help you maintain a healthy weight. This is important because carrying excess weight can put stress on your heart.

The Centers for Disease Control and Prevention (CDC) recommends that most adults try to get at least 30 minutes of moderate physical activity a day. However, this may be unrealistic for some people with cardiomyopathy. Your ability to tolerate exercise will vary depending on the seriousness of your condition. If you have late-stage heart disease as a result of cardiomyopathy, you may be limited in what you can do safely. You may only be able to do 5 or 10 minutes at a time and increase your activity slowly.

If your doctor gives you the green light to exercise, choose activities that you enjoy so you are more likely to stick with them. If you are able to, you might want to take a walk in a nearby park, for example. If leaving the house is not an option, consider trying one of the many free exercise videos available online.

Always talk to your doctor before starting an exercise program or a new activity. Stop exercising right away if you are in pain, feel short of breath or feel dizzy or nauseous.

TOP 10 EXERCISE TIPS

Download the Top 10 Tips
5. Make other lifestyle changes to improve heart health

Lifestyle measures such as getting enough sleep, reducing stress and stopping smoking can reduce your risk of complications from cardiomyopathy and make you feel better, too.

**Stop smoking**

Smoking increases your risk for heart disease and is bad for your overall health. Also, when people around you are regularly exposed to secondhand smoke, it increases their risk of heart disease as well. Using chewing tobacco and vaping are equally bad for your health.

When you quit smoking and using tobacco products, your health starts to improve right away. Ask your doctor for tips on the best way to quit and for information about programs and support groups to help you stop smoking.

**Reduce or manage stress**

There’s no doubt about it, living with a chronic disease is stressful. Experiencing some stress is normal, but too much stress can raise your blood pressure, make it harder to breathe and speed up your heart rate. You may also be tempted to relieve stress by overeating, drinking too much or smoking, especially if you’ve relied on these behaviors to help you cope in the past.

It’s important to find healthy ways to relax and avoid stress. You might try yoga or meditation. Practicing mindfulness and keeping a journal are other possibilities. If you are still finding it hard to get on top of stress and anxiety, talk to your healthcare provider, who can refer you to a therapist or support group.
Get enough sleep

Ideally, the average adult should get seven to eight hours of sleep a night, but this can be a challenge if you have cardiomyopathy or heart failure. Research has shown that over 75 percent of patients with heart failure experience sleep disorders such as sleep apnea (in which breathing stops and starts periodically during the night) insomnia, and restless legs syndrome (in which the legs move throughout the night).

If you have one of these sleep disorders, or you experience narcolepsy (a condition in which people fall asleep during the day while doing normal activities), it is important to get these conditions under control, so they don’t prevent you from getting the rest you need.

Another thing you can do to help you sleep well to make sure you have a comfortable bed and a bedroom that you find relaxing. Turn off your phone and other electronics an hour before bedtime. (You might use this time to read a book or take a bath.) Avoid eating heavy meals and drinking alcohol close to bedtime and try to go to bed and get up around the same time every day.

Get connected

Connecting with other people who have received a similar diagnosis can keep you on track. It can also make you feel less alone. In fact, research has shown that getting the support you need can actually reduce doctor visits and hospitalizations.

Peer support

Getting emotional support from another patient with cardiomyopathy can make you feel less scared and alone. Peer support has many benefits not only for emotional health, but for your physical health too. Join an in-person support group or get support by phone or online. The Mended Hearts, Inc. has a Heartline hotline (1-844-HEART87), a toll-free number you can call to talk to another patient like you.
Supporting others
If possible, join a group or get involved in a community that helps others. Joining a support group like Mended Hearts® and Young Mended Hearts® where you can give and receive support can make a big difference in your sense of well-being.

Volunteering can also make you feel better. By sharing your own experience with cardiomyopathy, you are helping others with the same disease.

We know through research that patients who are trained as The Mended Hearts, Inc. Accredited Visitors and provide peer support to patients in the hospital report a better quality of life than those who don’t. Connecting with others is an important part of healing.

Other resources for living with Cardiomyopathy
At The Mended Hearts, Inc., our mission is to make sure that you are educated and supported on your journey, whether you are a patient or a caregiver. Our trained volunteers — who are patients, parents and caregivers themselves — make hundreds of thousands of connections each year to those in the hospital and in recovery. They lead support groups, visit patients and caregivers in the hospital, help educate others, and provide many valuable services to hospitals and cardiology offices. Our goal is to make sure that no one walks this journey alone; when you need us, we are there.

JOIN the world's largest cardiovascular disease peer support network today!
Here are ways that you can find the support you need:

- **Become a member**
  The Mended Hearts, Inc. memberships start at $0.00 — FREE! With your free membership, you can access our member-only content, read our award-winning Heartbeat® magazine online, receive our national e-newsletter and participate in other educational and support opportunities. If you choose to donate, your membership benefits increase. To become a member, sign up at:
  [www.mendedhearts.org](http://www.mendedhearts.org)

- **Join a local chapter or group**
  We have more than 220 local chapters in communities across the country that host support group meetings, provide educational opportunities and engage heart patients and their families in community activities. Find contact information for our chapters on our website here:
  [www.mendedhearts.org/connect/chapters_gr oups/find-your-chapter/](http://www.mendedhearts.org/connect/chapters_groups/find-your-chapter/)

- **Receive and give support online or by phone**
  Telephone, email, text and video chat support are available through our Accredited Visiting Program, MyHeartVisit®. Anyone can request a visit from a trained volunteer. You can schedule a visit at [www.myheartvisit.org](http://www.myheartvisit.org) or simply call our Heartline hotline at 1-844-HEART87 (1-844-432-7887) to be connected with someone Monday through Friday from 8 a.m. to 5 p.m. Eastern Time. This is a great opportunity to share your feelings and ask trained patients and caregivers questions about living with heart disease.
  [www.myheartvisit.org](http://www.myheartvisit.org)

- **Online support**
  Our online discussion communities offer a network where participants can ask questions, share their journey and find support. Heart patients, caregivers and families are all welcome. To connect with us online, visit [www.connect.mendedhearts.org/home](http://www.connect.mendedhearts.org/home)
Learn more today

The Mended Hearts, Inc. HeartGuide® is a guide to living with heart disease. Use it as your trusted companion along your journey to heart health. Read it online or download your copy here.

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