

# Cardiac Care for Neuromuscular Disease: A Guide for Individuals with Neuromuscular Diseases and Their Caregivers

Cardiac care is an essential part of managing neuromuscular conditions, even when symptoms are not obvious. Regular monitoring and early interventions help protect heart health and quality of life.

## How Neuromuscular Disease May Impact Heart Health

Neuromuscular diseases, such as muscular dystrophies, affect the skeletal muscles and, in some cases, also the heart muscle. Heart involvement in neuromuscular diseases includes abnormal electrical activity, such as abnormal heart rhythms, heart muscle scar tissue, and weakness of the heart muscle. These changes can occur without obvious symptoms early on, which is why regular heart care check-ups are an important part of overall care. This is because early detection and treatment can make a big difference in heart care and overall care for patients living with neuromuscular diseases.

## Key Cardiac Issues to Watch

People living with neuromuscular diseases may be at risk for certain heart conditions that can develop gradually and sometimes without early warning signs. Understanding the most common cardiac concerns can help individuals and families stay proactive in monitoring heart health and seeking timely care.



### Common heart issues:

- **Dilated cardiomyopathy:** Weakening and enlargement of the heart muscle
- **Arrhythmias:** Abnormal heart rhythms that can lead to serious complications
- **Cardiac fibrosis:** Scarring in the heart that can affect how well it pumps
- **Heart failure:** Reduced heart pumping ability, which may not always cause immediate symptoms

## Common Symptoms That May Indicate Heart Problems

Some signs of heart issues can be subtle and easily mistaken for symptoms of other conditions. Recognizing changes is important, even if they seem mild. Always talk to your medical team if you notice new or worsening symptoms, such as:

- Shortness of breath
- Palpitations (irregular heartbeats)
- Fluid buildup (especially in the legs or lungs)
- Fatigue or lethargy
- Chest discomfort

**Note:** These symptoms can have other causes too, such as lung or muscle issues, so it's important to work closely with your medical team.

## Monitoring Heart Health

Regular heart checkups are an important part of care for individuals with neuromuscular disease, even if no symptoms are present. Routine screening can help detect changes early and guide treatment decisions. A variety of tools may be used to keep a close eye on heart function and rhythm.

Frequency of monitoring depends on symptoms and individual risk factors. Often, annual testing is recommended.

### Routine screening may include:

- **Echocardiogram:** Ultrasound images of the heart's structure and function
- **Cardiac CT scan:** 3D images of the heart and surrounding blood vessels
- **Cardiac MRI:** Highly detailed images to detect scarring or flow issues
- **Cardiac monitoring:** Holter monitors, event recorders, or wearable devices (like smartwatches) to detect irregular heart rhythms

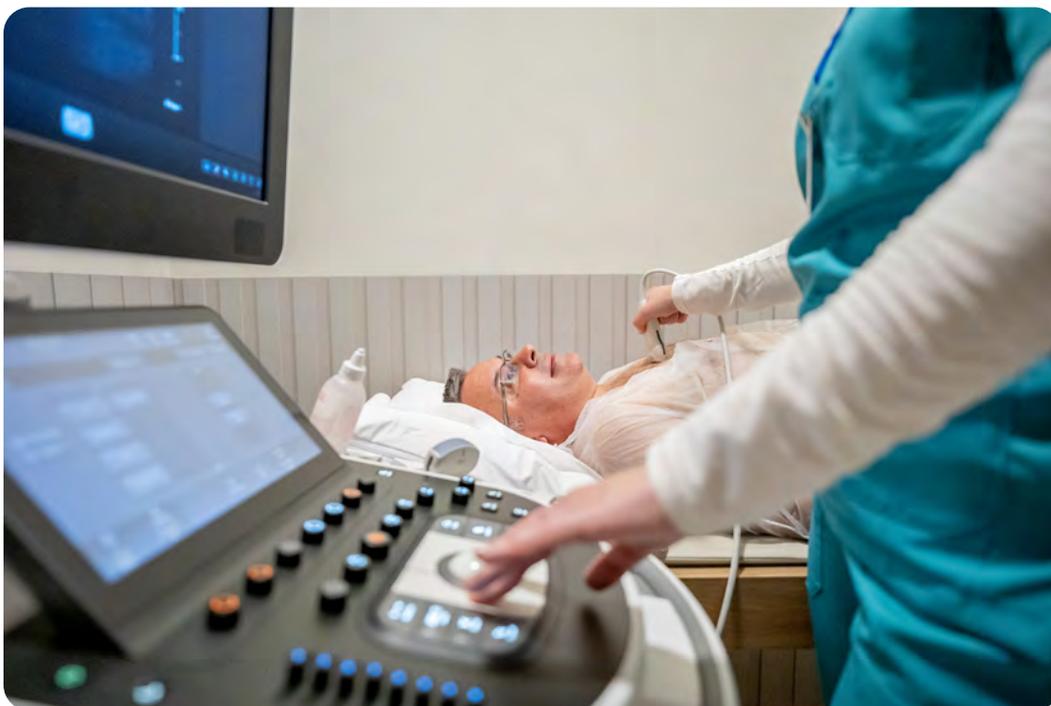


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# Treatment Options

A range of treatments are available to help manage symptoms and support heart function. Medications are often the first line of defense, and some therapies offer proven heart benefits. In more advanced cases, devices or surgical options may be considered. Treatment plans are personalized, based on the type and severity of heart involvement.

## Medications to support heart health:

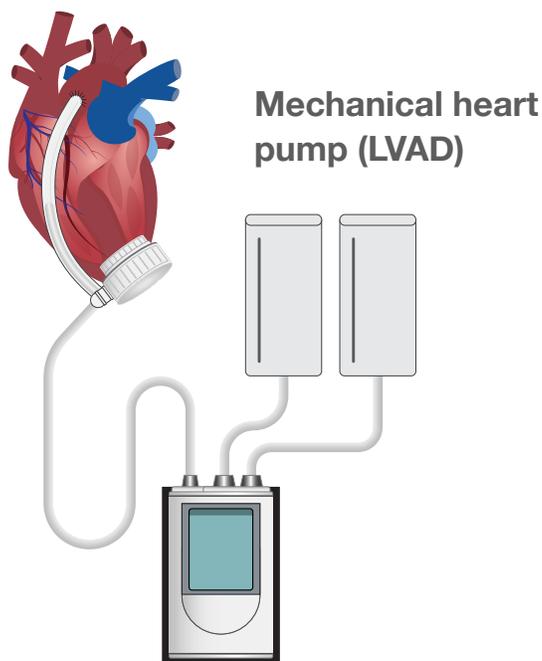
- **Beta blockers (e.g., carvedilol, metoprolol):** Help the heart beat more efficiently
- **ACE inhibitors/ARBs:** Relax blood vessels and protect the heart muscle
- **Aldosterone inhibitors:** Manage fluid balance and heart pressures
- **SGLT2 inhibitors (e.g., Farxiga, Jardiance):** Originally used for diabetes, now shown to benefit heart function

## Other therapies may include:

- **Diuretics (“water pills”):** For fluid buildup caused by heart weakness
- Implantable devices:
  - » **Implantable cardioverter defibrillators (ICDs):** Prevent sudden cardiac death in patients with low heart function
  - » **CRT devices:** Help synchronize the heart’s pumping
- **Mechanical heart pumps (LVADs):** Rarely needed, but an option for very severe cases
- **Heart transplant:** Extremely rare in the neuromuscular disease population



**Implantable cardioverter defibrillator (ICD)**



# Supporting Heart Health

## Lifestyle Factors

Everyday habits play a big role in protecting heart health. Collaborating with your care team, including cardiac and pulmonary specialists, can help create a plan that fits your needs and supports overall well-being.

### Your plan may include these actions:

- Control your blood pressure and blood sugar.
- Maintain a healthy weight.
- Avoid smoking, alcohol, and illicit drugs.
- Monitor your cholesterol carefully. (Statins are used cautiously in neuromuscular disease.)

## Questions to Ask Your Doctor

Being informed and proactive can help you feel more confident in managing your heart health. Bring a list of questions to your appointment to help guide the conversation and ensure your concerns are addressed.

### Consider asking your doctor:

- How often should I have my heart checked?
- What symptoms should I watch for and report?
- Are there medications or treatments that could help protect my heart?
- How do my neuromuscular symptoms affect my heart health?
- Should I see a cardiologist or other specialist?
- Are there any lifestyle changes I should focus on?



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MDA Care Centers provide specialized, multidisciplinary care for individuals living with neuromuscular diseases. Many locations include cardiologists on the team or can refer you to a heart specialist familiar with your condition. To find a Care Center near you, visit [mda.org/CareCenters](https://mda.org/CareCenters) and search by ZIP code.

This resource was developed with the expertise and knowledge of Forum Kamdar, MD, PhD, FAAN.

#### About Muscular Dystrophy Association

Muscular Dystrophy Association (MDA) is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 70 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our families.

MDA's mission is to empower the people we serve to live longer, more independent lives.

To learn more about neuromuscular diseases and MDA's programs, visit [mda.org](https://mda.org) or contact the MDA Resource Center at **833-ASK-MDA1 (833-275-6321)** or [ResourceCenter@mdausa.org](mailto:ResourceCenter@mdausa.org).

DISCLAIMER: This resource is meant to inform and educate the community. The information presented is not intended to replace discussions with your healthcare provider and is not and should not be considered to be medical advice. Please consult with your healthcare team for information specific to you/your loved one.

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