



Severe Symptoms (Class IV)



What are severe symptoms?

Symptoms and functional impairment are obvious. Symptoms such as shortness of breath and fatigue may be quite limiting with any type of exertion (for example, showering or bathing), and they occur at rest as well as with activity. Symptoms at rest may include shortness of breath when lying down, which requires you to prop yourself up or sleep in a chair. Another at-rest symptom is sudden shortness of breath or a feeling that you cannot get enough air. This symptom will wake a person from sleep and require them to sit or stand up to relieve the feeling. It is not unusual to have difficulty sleeping because of these symptoms, not be able get to sleep (insomnia), or sleep for only short periods.

Some people may find it is difficult to leave home for long periods because of their symptoms. Their appetite may be poor, and they may notice they can only eat small portions before feeling full. Some people with severe symptoms sometimes use motorized chairs to help them get around outside of their home. Others with this



degree of impairment often end up needing treatment in the hospital. Some people with Class IV symptoms may be helped by a ventricular assist device (an implantable heart pump) or heart transplant. It is possible for individuals with severe symptoms to improve with appropriate therapies, resulting in moderate and even milder symptoms.

People with DCM who experience moderate to severe symptoms most of the time are usually unable to work and are quite impaired from their symptoms, and therefore, qualify for disability.



What are the treatments?

In general, the more severe the symptoms and impairments, the more complicated the treatment. Drugs are the primary treatment. Essential drugs are classified as beta blockers; the other essential class of drugs are ACE-inhibitors or ARBs. Both classes of drugs work to block the activated hormonal and neural systems. They have been studied in thousands of patients and have been shown to improve the survival rate of people with DCM.

In some people with DCM, these drugs may decrease the size of the heart and improve heart muscle function. An echocardiogram (ECG) should be performed after a minimum of six months of optimal drug therapy to determine if medications are improving the ejection fraction and/or heart size. It is likely that a person with severe symptoms is retaining fluid. If previously on diuretics, but there is worsening fluid retention, the dose may need to be increased to improve symptoms.

A person may now have indications for additional drugs that, when taken with most of their current medications, will improve life expectancy and symptoms



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even further. These drugs may include spironolactone, hydralazine-nitrate, and sacubitril/valsartan (entresto). Some people with severe symptoms and low blood pressures or kidney problems may need to have the dose of some of their drugs decreased or certain drugs may need to be stopped. Many patients with severe symptoms require hospitalization so they can receive intravenous medications to improve their symptoms.

If a person's ejection fraction is 35% or less, and they have been on optimal drug therapy, they may be a candidate for an implantable cardioverter defibrillator (ICD) to help prevent sudden cardiac death. This prophylactic or preventive therapy is an elective therapy; some people do not want this therapy, nor are the best candidates for it. Patients should discuss this option with their cardiologist.

If a person's ejection fraction is 30% or less, and they have certain abnormalities on their ECG, they may be a candidate for cardiac resynchronized therapy (CRT), which requires the implantation of a special pacemaker. This therapy helps people with DCM live longer and may improve heart muscle function.



Can severe symptoms improve?

Yes, improvement is one of the goals of treatment. Symptoms may move from moderate to severe and back to moderate for many people. Sometimes severe symptoms may improve to be mild and then may move back and forth between mild and moderate.

Some people will continue to have moderate to severe symptoms and may not be candidates for ventricular assist device therapy or a heart transplant. In this case, they



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may be at end of life (less than a year to live). Palliative care and/or hospice are appropriate options for these people.



Are there activities that should be avoided?

Stay as active as possible and do as much as possible. Activities that cause marked limitation from symptoms should probably be avoided or done in a manner that symptoms are less severe. A person may need to rest more, do activities slower, or use aids, such as a motorized chair, which help them exert less effort. The need for a handicap permit is likely.

Founded in 2017, the DCM Foundation is a non-profit organization with a mission to provide hope and support to patients and families with Dilated Cardiomyopathy through research, advocacy, and education.