

Although every young person's experiences of cardiomyopathy will be unique to them, there are some typical symptoms of the condition, or side effects of treatment, that they may experience. This guide can act as a discussion point with a young person, to identify what help and support they might need to manage their condition at school, college or university.

### Symptoms

Symptoms can vary from one person to another and include the following.

#### Fatigue (tiredness)

Fatigue, or *extreme* tiredness happens as the heart's function is reduced and less energy is delivered to the body. *People might need to take regular breaks or avoid some activities.*

#### Breathlessness

When the heart can't pump effectively, fluid builds-up in the lungs, making it hard to breathe. This can affect physical activity but can also happen even when not active (at rest). *People may need to take regular breaks, have additional time to do activities or avoid some activities.*

#### Palpitations

Palpitations (being aware of your heart beating too fast, too hard or 'fluttering') are caused by arrhythmias (abnormal heart rhythms). *Palpitations can be uncomfortable or distressing, and someone may need time to rest.*

#### Chest pain

Chest pain can be caused by reduced blood flow and oxygen levels getting to the heart. It can happen when active or when resting. *Chest pain can be uncomfortable or distressing, and someone may need time to rest.*

#### Dizziness or fainting

Reduced oxygen levels can cause light-headedness, dizziness and fainting. *Having time to recover is important until the feeling goes.*

#### Swollen ankles and tummy

As the heart struggles to pump, fluid builds up in the body, causing swelling. *This is managed with medication.*

### Treatment

Treatment varies depending on the symptoms someone has. It can include any of the following.

#### Medication

Medication is used to:

- reduce fluid build-up on the lungs or around the ankles;
  - reduce the workload on the heart and the volume of the blood, so it is easier for the heart to work;
  - reduce the rate and force of the heart's contraction;
  - control abnormal heart rhythms and maintain a normal rhythm; and
  - reduce the risk of blood clots (which could lead to a stroke).
- Medications can have side effects, depending on the medication and the individual. Side effects can include tiredness, dizziness, low blood pressure, a cough, and needing the toilet more frequently

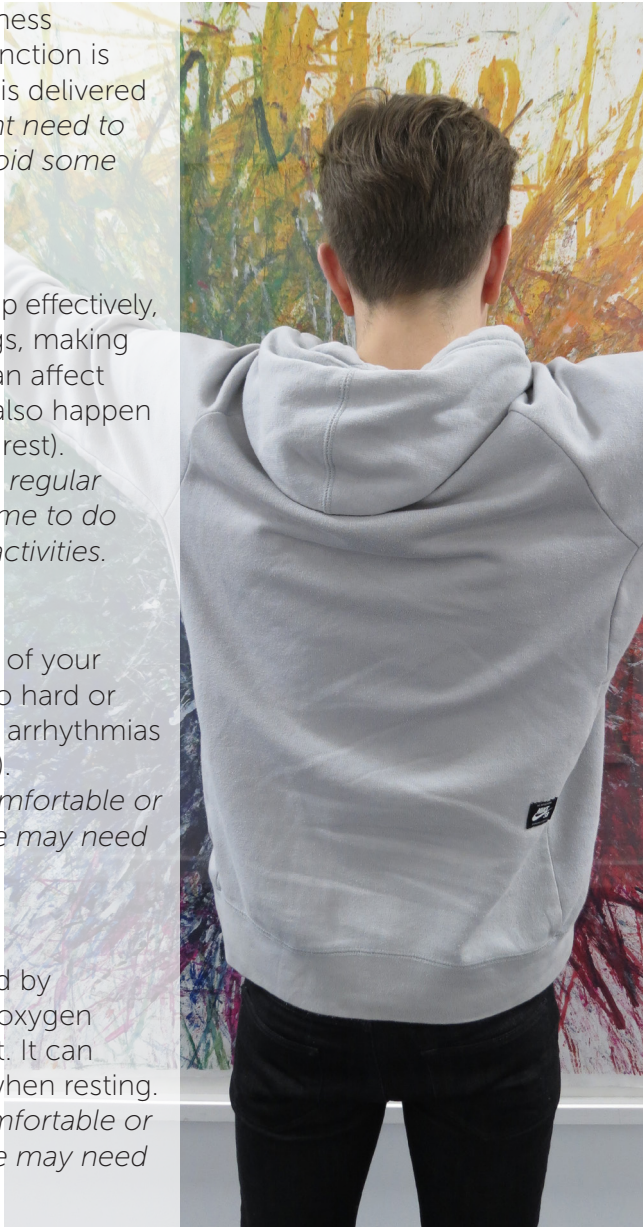
#### Implantable devices

Implantable devices can monitor the heart rate and treat abnormal rhythms, or take over control of the heart rate to keep a regular rhythm. They include pacemakers and ICDs\*. They are used for people who have, or are at risk of, life-threatening arrhythmias. Having a device can be worrying and feel over-whelming, and it can be difficult to come to terms with needing, or having, a device.

#### Surgery

In some cases, surgery might be used to reduce any obstructions that affect the heart's effectiveness at pumping, or to support the heart. A small number of people may need a heart transplant, where a failing heart is replaced with the heart from a donor.

\*implantable cardioverter defibrillator



# Cardiomyopathy

## The emotional and psychological impact

Although cardiomyopathy is a physical condition, it can affect all areas of a young person's life, including how they feel physically, how they manage practically, and how they feel emotionally and deal with the impact it has on their life. This guide can help to identify what help and support a young person might need to manage the emotional impact of their condition at school or college.

### Anxiety

Anxiety can be related to many aspects of living with a life-altering condition. Concerns may focus on being a young person with a heart condition (often considered an 'older persons' condition), treatment, worry about dying or relatives having the condition, and not understanding the condition and its impact.

### Isolation

Cardiomyopathy can be an isolating condition as it is little known about. So it can feel like they are the only one with the condition, and that they are 'different'. It can be difficult to find someone who understands. Peers may make judgements about what having the condition means.

### Fear

Being diagnosed with a medical condition can be very frightening and worrying, particularly if the condition is not widely known about. It can affect *all areas* of life, so young people may have fears about the future, including career choices and lifestyle.

### Identity

Adjusting to having a condition can be hard. Balancing their own needs and limitations while carrying on a 'normal' lifestyle can be challenging, particularly when trying to avoid being defined by their condition. Over-protection by families can also be an issue.



### Anger

Anger is a natural reaction to a diagnosis. It is not unusual to ask 'why me?', particularly when their condition limits activities or feeling included by peers. Some young people react by pushing boundaries, which may result in risky behaviour while trying to find a coping mechanism.

### External misconceptions

There are many misconceptions about what someone with a heart condition 'looks like', and how it affects them. People may not 'look ill' but can be limited by their condition and its management. But this varies from person to person, and from day to day.

### Psycho-social

The psychological and social impact of the condition can be far-reaching. People may worry about what activities they can do, how it might affect relationships and intimacy, and how to 'fit in' with their peers. Knowing who and how to tell people about their condition can be worrying.

### Transition services

Around the age of 17 years, young people move from children's medical services to adult services (a process known as 'transition'). This is a time when young people will start to take ownership of, and responsibility for, managing their own condition, and parents become less involved. This can be a difficult time, and not all young people will welcome this change.

### How we can help

We have support services for children, young people and younger adults.

- Our peer support volunteers, with experience of the condition can talk by phone.
- Our helpline and Live Chat instant messaging service gives access to specialist nurses.
- Our Twitter account, Facebook page and closed Facebook group connect young people aged 14-25 years.  
[www.facebook.com/1425cardiomyopathyuk](http://www.facebook.com/1425cardiomyopathyuk)  
[www.twitter.com/Cardio1425](http://www.twitter.com/Cardio1425)



# Understanding the condition

Understanding cardiomyopathy can help you to identify and individualise support offered to young people. The following information is about the condition *in general*, and it is important to talk to the young person, and their family if appropriate, to understand their specific needs.

## Understanding cardiomyopathy

**Cardiomyopathy is a variable condition.** How the condition affects one person can be different to how it affects someone else. This is true even if two people have the same type of cardiomyopathy or experience the same symptoms.

## Cardiomyopathy is a hidden condition.

You can't tell that someone has cardiomyopathy just by looking at them. However, some of the *symptoms* of the condition, or its *impact*, may be obvious.

For example, it might be obvious that someone is feeling fatigued or out of breath, or if they need to use a wheelchair or walking aid because their condition makes it difficult to walk unaided.

## Cardiomyopathy is a fluctuating condition.

This means that the symptoms someone has, or its impact, can vary from day to day. So, they might have 'good days' when their condition affects them very little, and 'bad days' when their condition makes even the 'simplest' of activities challenging.

*"As cardiomyopathy is a hidden disability, it can be very hard for lecturers to imagine how it affects a person, sometimes there is even disbelief inferring the student is lazy. There needs to be recognition that this is a disability which limits what you can do."*

## Identifying symptoms

Be aware that some young people may experience symptoms (such as breathlessness, palpitations and fatigue), which can be stressful. Support and understanding is important in this situation.

"Not having to stand in long queues for lunch or at the library would help."

"Support looking for books when I'm out of breath and help carrying the books."

"People just don't understand. You don't look ill so they don't believe you are ill."

"School can make you feel like you are a problem."

"When you keep having to tell people you have the condition it can make it hard to feel 'normal'."

## Cardiomyopathy and disability

A disability is a physical or mental impairment that has a substantial and long-term adverse effect on someone's ability to carry out normal day-to-day activities (The Equality Act, 2010).

There is no definitive list of conditions that are considered 'a disability', as the emphasis is on the *impact* of the condition on the individual, rather than the *cause*. It includes both the physical and psychological impact.

A medical condition may be a disability if it has a significant impact on an individual's ability to carry out their normal activities. (These include things like washing and dressing, preparing and eating food, getting around, and activities related to education, or social interaction).

So cardiomyopathy is a disability if the person *is disabled by it*.

## The Equality Act

The Equality Act protects people with certain characteristics, such as a disability, from unfair treatment. It applies in all educational settings. It means that education must be inclusive of all pupils, and reasonable adjustments considered so that pupils with a disability are not at a disadvantage compared to other pupils. *See our factsheet The Equality Act for more about the act and the definition of a disability.*

## What helps?

There are many ways to help a young person with cardiomyopathy to be included and ensuring reasonable adjustments are considered. It is important to avoid making assumptions about how to help, but to look at the individual's circumstances to identify what is appropriate *for them*.

When supporting a young person with cardiomyopathy, it is important to consider what help is appropriate, what adjustments can be made, and when extenuating circumstances should be considered.

### Time off and appointments

Young people with cardiomyopathy may need time out of school for medical appointments, depending on how their condition affects them and their treatment. They may also need time off due to their symptoms. Ensuring a procedure is in place to keep up with school work, where it is possible and appropriate for the student to do so, is important.

### School work and home work

The symptoms of their condition, and the impact of treatment, can make doing work at school, or completing homework, difficult. For example, extreme fatigue may mean that they are not able to complete work to deadlines, so flexibility to take account of this is helpful.

### Extra time and rest breaks

Cardiomyopathy can cause extreme fatigue and shortness of breath, which can be very limiting. It can affect physical activities (such as sports), but also more stationary activities such as concentrating and writing. Giving extra time for work to be completed, identifying support that might help, and allowing rest breaks when needed, can be helpful.

### Drinks and toilet breaks

Many young people will take diuretics (water tablets). So they will need regular access to drinks as well as needing frequent toilet breaks.

### Useful organisations

#### Advisory Centre for Education

Advice and information about education issues for parents.  
[www.ace-ed.org.uk](http://www.ace-ed.org.uk)

#### Citizens Advice

Information on the Equality Act.  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

#### Contact

Information on education and support, including identifying when EHC plans are needed.  
[www.contact.org.uk](http://www.contact.org.uk)

#### Equality Advisory and Support Service

Information about equality and human rights  
[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

#### Equality and human rights commission

Information on the Equality Act.  
[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

#### GOV website

Details on Supporting pupils at school with medical conditions  
[www.gov.uk](http://www.gov.uk)

#### Information Advice and Support (IAS) Services

Information, advice and support for young people and parents. Local authorities have a service.  
[www.cyp.iassnetwork.org.uk/in-your-area](http://www.cyp.iassnetwork.org.uk/in-your-area)

#### Independent Parental Special Education Advice

Educational advice for parents.  
[www.ipsea.org.uk](http://www.ipsea.org.uk)

### Support in exams

Giving extra time for exams due to fatigue can be important, as well as regular toilet breaks. Some schools may isolate pupils with medical conditions during exams, so that they don't disturb other students. However, for some this can feel like being negatively singled out and they don't feel 'normal' or included.

### Bullying

Some young people are bullied at school, often because others don't understand that they are ill. Being seen as 'different' or having 'special treatment' can make this worse. Knowing about the condition, and how it can affect someone, helps raise awareness and understanding.

### Education, health and care plans

Many children and young people will *not* need any special provision at school. However, for some, their condition affects their learning and they may need additional support. An Education, Health and Care (EHC) plan identifies additional help that may be needed to support a pupil. Education providers have a legal duty to support pupils with educational needs.

### Risk assessments

As each young person's condition will be different, it is important to avoid making assumptions about what they can, and can't, do. Risk assessments are an opportunity to review situations and activities on an individual basis so that the person can be safely included in activities, and appropriate adjustments made to include them.

