

Support for Carers

Support for those caring for someone with cardiomyopathy

- A carer is someone who cares for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support.
- Not everyone who cares for someone with cardiomyopathy will consider themselves a carer.
- Identifying yourself as 'a carer' means that you may be able to access certain help and benefits.

What is a 'carer'?

A carer is 'anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support'.

(Definition: Carers Trust www.carers.org)

'Carers' are different from 'care workers' (sometimes referred to as 'carers'). Care workers are employed (paid) to provide care for someone, for example, people working in residential or care homes or providing social care support.

Who is a 'carer'?

There are around 6.5 million carers in the UK. A carer is someone who provides care for another person.

This might be their parent, a partner, child or a friend. But it does not have to be someone they are related to, and they don't have to be living with the person. Carers can also be any age. Around 700,000 carers in the UK are under the age of 18.

(Statistics: Carers UK www.carersuk.org and Carers Trust www.carers.org)

What 'care' do carers give?

What 'care' means will vary depending on the needs of the person being cared for, and what the carer is able to provide. The following are some examples.

- Physical help – such as getting dressed or moving around.
- Medical help to manage their condition or treatment – such as planning and managing their medication, or helping them monitor their symptoms such as breathlessness or activity levels.
- Practical help with daily living – such as arranging transport or driving them, going with them to appointments, helping with social or leisure

activities, or helping with household tasks.

- Help with daily living such as dressing and washing, help with finances, helping to manage activities.
- Emotional support – such as supporting them with the emotional impact of living with a condition, and helping them to self-manage their condition.

These are just some examples, and there may be many other ways that someone provides care and support.

Some caring activities may be fairly constant, depending on the needs of the individual being cared for. But, as the symptoms of cardiomyopathy can change over time and people may have times of being well and times of being unwell, the need for care may also change or fluctuate. Here, the need for care can be unpredictable, and caring needs might come up unexpectedly.

Are you a 'carer'?

Not everyone who cares and supports someone with cardiomyopathy considers themselves to be a carer. For many people, how they care and support someone might feel no different to how they would expect to care for a parent, partner, child or friend, and they may consider this a normal part of that relationship.

Sometimes it can be difficult to see when a 'normal' relationship becomes a 'caring' relationship. For some, the role of carer can develop slowly over time, the person may not see their role changing, and it can be hard to see when they started to be a 'carer'. Suddenly, they may feel that how they are caring for someone is more than, or different from, what you might normally expect in a relationship. For example, a parent would expect to provide care and support to a young child, but if they continue to provide that level of support, or perhaps more support, as their child gets older, they may recognise that they are now a carer for their child.

Why it can help to identify yourself as a carer Some people may be uncomfortable identifying themselves as a carer. Others might recognise themselves in the



role more easily. While this is personal choice, there are some reasons why it can be helpful to recognise when you are a carer.

There are various sources of help and support available for carers. This might include practical help, carers assessments, carers allowance, and help with work. There are also sources of psychological support and counselling, peer support and self-management courses. In this factsheet we will look in more detail at some of these services (see page 3).

What is the impact on carers?

Caring can be a very rewarding and enjoyable experience. Carers may feel valued and helpful, take on the role willingly, and want to be able to care for their loved ones. However, being a carer can also have an huge impact on the carer themselves.

"I didn't want to focus on me when I didn't have the serious condition."

When someone is diagnosed with a disability or medical condition, it is natural that there is a focus on them: helping them to deal with a diagnosis, managing their condition and the impact that a long-term condition often has. However, the diagnosis can often have a big impact on those around that person: their family and friends. Over time, it can

feel like all the focus is on the individual with the condition, and that the impact on the carer is not recognised. Other people may ask the carer how the individual is, without thinking to ask the carer how they are. It can be easy to assume that a carer is coping, or that the carer doesn't need any help and support themselves.

"As a carer you sometimes feel the person who has the illness is looked after more than you. You're there for them but the professionals seem to forget you."

Taking on a caring role is something that most people don't plan for or expect. It can be something that starts gradually, the responsibility increases over time, and it can be hard to see when the caring role begins. It is sometimes seen as something that is just 'expected' in the role of parent, partner, child or friend. However, this change in relationship can be challenging, and is not always easy or welcomed.

"It's the family that kind of suffer... having to care for me and do full time work at the same time was incredibly stressful." (Person with cardiomyopathy)

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Being a carer can significantly change a carer's life, both practically and physically. Some carers change or give up work to be able to provide care and, if the person they care for is not able to work, this can lead to financial hardship. They may become the only driver in the household. They might have to do more practical tasks around the home. They may become responsible for managing paperwork, or organising the household. They might also find that they have very little time for themselves, to do what they want to do, and it can feel like they have lost their identity.

"I've just gone back to work... I'm getting something out of life for myself and it's not just all centred around my husband, because it was before."

"If you're looking after someone, you can't be ill too. You just carry on and don't admit your own issues."




Being a carer can impact on the physical health of the carer themselves. Carers are more likely to have poor health than people without caring responsibilities. (Reference: Carers UK - Looking after your health.)

"I think you just feel you have to cope with it. It feels selfish to be thinking about yourself. You think you are coping and then things fall apart, but you have to be strong for everyone else."

The emotional impact of being a carer can be significant. Some carers feel overlooked and overwhelmed, that they don't have time for themselves as they always have to put the person they care for first, and that no one understands. This can lead to feeling resentful which, in turn, can lead to feeling guilty for feeling this way. It can be a difficult, vicious circle, and very isolating. Caring can affect a carer's emotional wellbeing, and they are more likely to experience stress, anxiety and depression than non-carers.

"My son would think it was his fault that his condition affected me. I think this prevents me from asking for help with my own anxiety."

Carers may find it difficult to talk about the affect of being a carer, and how they feel about this. They may not want to share this with the person they care for, or with close family. They may feel that they don't have anyone to share this with, or that other people may not understand. Some feel that they 'should be able to cope', and 'shouldn't' focus on their own needs. They may feel that they have had little choice about taking on a caring role, but equally feel guilty for considering their own needs, or that they might be judged if they talk about their feelings. These are natural and common feelings and concerns.

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"I find it very difficult to talk about."

"..... but I think they [healthcare professionals] forget you are part of that person as well. You've got their day-to-day health to think about and you are the one who sees them when they are not well... so just maybe now and again you could be taken away from the patient and just asked 'Are you OK? Do you need somebody to talk to?'"

The quotes above in red are from family, friends and carers of people with cardiomyopathy, who have shared their experiences with us.

What help is available to carers?

There are sources of help and support for carers, and some entitlements. For some of these, you may need to meet certain criteria, or be able to show how much care and support you provide for someone (for example, what you do to help the person and for how many hours a week you provide this care).

The Care Act 2014

The Care Act 2014 sets out the services that local authorities must provide to adults in their area who have care needs. This includes considering the health and social care needs of individuals, as well as identifying what services they should provide to support people to promote their wellbeing. The Act says that local authorities must provide information and advice on an individual's rights and entitlements, and how to access services locally.

The Act also specifically gives carers access to certain entitlements. For example, it gives eligible carers the right to have a carers assessment when necessary (when there is seen to be a need for this). It also sets out when the local authority has to provide support to carers, and what this support should be.

For more about the act visit www.gov.uk and search 'care act' or www.carersuk.org and search 'care act faq'.

The Equality Act 2010

The Equality Act 2010 is a law that protects people with certain 'protected characteristics' from being discriminated against or treated unfairly due to

these characteristics. There are nine protected characteristics, including disability.

The Act gives protection in various areas, such as employment, education, public services and in shops, restaurants and various other settings.

Discrimination means treating someone in a way that is unfair or puts them at a disadvantage, because of a protected characteristic. There are different types of discrimination, including:

- **Direct discrimination** – treating someone with a protected characteristics less well than someone without a protected characteristic.
- **Indirect discrimination** – applying a condition or rule to everyone which puts someone with a protected characteristic at a disadvantage.
- **Perceived discrimination** – discriminating against someone on the assumption that they have a protected characteristic.
- **Harassment** – treating someone with a protected characteristic in a humiliating or offensive way.
- **Victimisation** – treating someone unfairly because they make a complaint of discrimination.

There is a further type of discrimination called 'Associative discrimination'. This is when someone is treated unfairly because they are associated with (or connected to) someone with a protected characteristic. For example:

- an employer cannot refuse to employ you, or treat you less well than other employees, because you have caring responsibilities; or
- a shop or restaurant cannot refuse to serve you, or give you poor service, because you are with someone with a disability.

In this way, the Equality Act gives protection to family members and carers of people with disabilities.

Is cardiomyopathy a disability?

Someone is considered to have a disability if they have a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

This means that they have a significant impairment, which has lasted (or is likely to last) for 12 months or longer and which affects their daily activities.

The Act does not list medical or long-term conditions that are considered disabilities. This is because it looks at the effect of the impairment, and not at the cause of it. To be covered by the Act, the effect of the impairment needs to meet the definition of disability above. So some people with cardiomyopathy will



be considered disabled, if their cardiomyopathy has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

For more about disability and the Equality Act see: www.equalityhumanrights.com and the GOV website at www.gov.uk and search 'Equality Act'.

Carer's Allowance

This is the main benefit available to carers. You may be entitled to Carer's Allowance if you are over 16 and under retirement age, and you give at least 35 hours of care a week to someone who gets certain benefits (such as Personal Independence Payment).

Although it is not means tested (not dependent on your income or savings), you must not be earning more than £116 a week, and it could affect other benefits (such as working tax credit). However, if you receive Carer's Allowance you will also get National Insurance credits. For people who are not paying National Insurance contributions through work, these credits are required in order to claim a state pension when they reach retirement age.

For more about eligibility criteria and how to apply, see Carers UK's factsheet 'Carer's Allowance', or call the Carer's Allowance Unit on 0845 608 4321.

Carer's Credit

If you are under retirement age and care for someone for at least 20 hours a week, but you do not receive Carer's Allowance, you may be entitled to Carer's Credit. This is a National Insurance contribution which counts towards your eligibility to claim a state pension when you reach retirement age.

Usually the person you are caring for must receive certain benefits (such as Personal Independence Payments). If they are not receiving benefits, you will need evidence from a medical or social care professional involved in their care that they require the support from a carer.

For more about eligibility criteria and how to apply, see www.gov.uk/carers-credit or call the Carer's Allowance Unit on 0845 608 4321.

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Carer's assessments

If you are a carer, you can ask your local authority for a 'carer's assessment'. You can ask for this even if the person you care for hasn't had an assessment, or doesn't receive any support.

A carer's assessment looks at the impact caring has on you. This includes physically (such as your own health) and emotionally (such as causing stress or worry). It also looks at how caring affects your life and activities, and what your hopes and aspirations are. It aims to identify what help or support would be helpful for you. The assessment might be online, in person, or on the phone, and will be either with someone from the council or another agency that the council arranges.

If the assessment finds that you have 'eligible needs', the local authority has to meet these needs. For example, this could be money for things that would help you (such as a computer to keep in touch with other people), help with practical things such as housework, or giving you respite care (where someone comes to look after the person you care for so that you have a break). If you don't have 'eligible' needs, you should be given information about local help.

For more information see Carers UK's factsheet 'Assessments - Your guide to getting care and support'.

For more information and support

There are a number of carers charities, and other sources of information and support available.

Carers Trust

Support and services for carers including grants and local sources of practical and emotional help. Also offers information and support to young carers.
www.carers.org or support@carers.org




Carers UK

Help and advice on all aspects of caring, including practical help, carer's entitlements and forum.
www.carersuk.org or advice line 0808 808 7777

GOV website

Information from the government including carer's rights and entitlements.
www.gov.uk

Carers Direct helpline on 0300 123 1053.

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NHS choices

Information about carer's rights and the Care Act, as well as other entitlements.

www.nhs.uk and look under 'care and support'.

Self management UK

Provide 'The Self Management for Life Carers' course for carers, to look after their own health and wellbeing.

www.selfmanagementuk.org

The Children's Society

Has information about and for young carers, including support through their 'Include' service.

www.childrenssociety.org.uk

Benefits calculators

The following websites have calculators to help you see what benefits you might be entitled to:

entitled to - www.entitledto.co.uk

Turn2us - benefits-calculator.turn2us.org.uk

We're here for you

At Cardiomyopathy UK we offer help and support for you and your family. We have information about each type of cardiomyopathy as well as diagnosis, treatment and lifestyle issues. Look on our website or call us for more information. Call our helpline to talk to our cardiomyopathy support nurses. We can put you in contact with other people affected by cardiomyopathy through our support groups, peer support volunteers and social media. Contact us for more about our services, or look online – www.cardiomyopathy.org.

Send your feedback to contact@cardiomyopathy.org

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