

Cardiomyopathy UK position statement on welfare and benefits

Cardiomyopathy can affect people in different ways and some may face additional costs, such as for essential prescriptions and heating the home. Furthermore, some of the symptoms of can make it hard to access or stay in employment. The cost-of-living crisis has compounded these financial concerns.

In [previous surveys](#) of people affected by cardiomyopathy, we found that 45% of respondents applied for benefits and were initially or completely refused.

Cardiomyopathy UK conducted a survey in May 2024, then ran two focus groups in July 2024 with people with cardiomyopathy to understand their experiences of accessing the welfare system. This position statement is based on the responses to the survey and experiences of participants in the focus groups.

The experiences of people with cardiomyopathy of accessing and using the welfare system

Why do people with cardiomyopathy need to access the welfare system?

In our surveys and focus groups, a significant proportion of people with cardiomyopathy told us that they have had to stop working, or reduce their working hours, as a result of the [symptoms of cardiomyopathy](#). While some people have an income protection policy, many are left with a much reduced, or no income. This inevitably has an impact on a person's financial security.

Even for people with cardiomyopathy who are enabled to stay in work, there can be additional costs. For example, where a person could use public transport when well enough to commute to work, their condition may make that harder if they are unable to walk any distances to the nearest bus stop or train station. They may become dependent on using taxis or need to use their own vehicle door-to-door, which is more costly.

People living with cardiomyopathy have told us that they use their benefits to enable them to live well with their condition. This ranges from buying good-quality food to meet their nutritional needs, attending clubs, like art and crafts, using taxis to travel to social activities, and paying for energy bills in winter. Some people living with cardiomyopathy receive the higher rate mobility component of Personal Independence Payment (PIP) and have a Motability car.

Cardiomyopathy UK believes that the welfare and benefits system is necessary for people with cardiomyopathy to maintain their wellbeing, and to enable them to live the best life they can with the condition. Equally, we believe that people with cardiomyopathy should be supported to access and stay in work for as long as they are willing and able, with reasonable adjustments in place, as stated in the Equality Act 2010.

How do people with cardiomyopathy access the welfare system and benefits to which they are entitled?

People with cardiomyopathy, involved in our research, report finding it difficult to find out the financial support to which they could be entitled. Most frequently, people learn about benefits through an Occupational Health assessment, or Cardiomyopathy UK's peer support groups.

From Cardiomyopathy UK's previous research with the community ([Cardiomyopathy UK, 2020](#)), we know that people affected by cardiomyopathy, upon diagnosis, want an integrated package of care appropriate to their needs which would include information on welfare rights.

We believe that there should be closer links between the Department for Work and Pensions and Integrated Care Boards to ensure that healthcare professionals can signpost people with cardiomyopathy (and other long-term health conditions) to information on welfare rights.

What are the issues in applying for benefits?

With regards to applying for benefits, the application process for certain benefits, especially PIP, can be lengthy and complicated, and people with cardiomyopathy often require support to complete it with enough detail that it is accepted. This support either comes from the Citizen's Advice Bureaux (CABs), Age UK, social prescribers within GP practices or from Cardiomyopathy UK's benefit support service. This complex application process demonstrates a dependency on the voluntary sector and health services in supporting people through it, to achieve the optimum outcome for each person.

The practicalities of completing application forms for other benefits can also pose a barrier, especially as these are all done online. Some survey respondents stated having to go to Jobcentre to use the computers to complete the application for Universal Credit (UC), although no other support was available from the Jobcentre to complete the application.

We believe that people with cardiomyopathy should have access to high quality information to enable a smooth journey through the process of applying for and receiving benefits.

What the experiences of people with cardiomyopathy in assessments for benefits?

The assessments for certain benefits, such as PIP, Employment Support Allowance (ESA) or Universal Credit with Limited Capability for work (UCLCW), are stressful and can appear as not always relevant to the symptoms of cardiomyopathy. Some people need more than one form of social security benefit and have to go through more than one application and assessment process, which increases stress and anxiety.

Some of the issues with assessments for benefits include:

- Accessibility of assessment centres, which can be far away from a person's home, requiring long travel, which can cause fatigue in people with cardiomyopathy.
- The need to rest the day before an assessment in order to be well enough for the assessment itself, but then the assessor doesn't take this into account and assumes that this is a normal health day for that person.
- A lack of understanding of cardiomyopathy, the symptoms and the impact on a person.

We believe that, where a person could be eligible for more than one benefit, that they should only require one assessment (for example combine the Work Capability Assessment and the PIP assessment).

Some benefits are awarded for a length of time and a reassessment is required to continue receiving the benefit, in case there has been a change in the condition. This is applicable to people with cardiomyopathy, despite cardiomyopathies being progressive. There are also wide discrepancies in the length of awards, especially for PIP, which can be between anything from one to five years. This subjects people to further assessments which can be stressful and cause anxiety.

We understand that the impact of cardiomyopathy on a person's life will be different from person to person; however, we recommend that there is recognition that a person with cardiomyopathy will not experience an improvement in their condition when deciding on the length of an award.