

Cardiomyopathy UK response: Modernising support for independent living: the health and disability green paper

About Cardiomyopathy UK

Cardiomyopathy UK is the specialist national charity for people affected by cardiomyopathy, a condition that affects the heart muscle. Our vision is that everyone affected by cardiomyopathy should live a long and fulfilling life. We do this by providing services, such as a national helpline and peer support, and campaigning for change in health and welfare services.

Cardiomyopathy UK ran two focus groups in July 2024 with people with cardiomyopathy to understand their experiences of applying for and using personal independence payments. The Cardiomyopathy UK response to this consultation is based on the experiences of the people who participated in the focus groups.

What is cardiomyopathy?

Cardiomyopathy is a disease of the heart muscle: '**cardio**' means heart, '**myo**' means muscle and '**pathy**' means disease.

It isn't a single condition, but a **group of conditions** that affect the **structure of the heart** and reduce its ability to **pump blood** around the body. Around **1 in 250 people** in the UK are affected, this is an estimated **246,000 people**. For context, there are 153,000 people living with Parkinson's in the UK, but there is a lot less awareness of cardiomyopathy. The symptoms of cardiomyopathy include:

- Wollen ankles and/or tummy.
- Chest pain.
- Dizziness and/or fainting.
- Breathlessness.
- Tiredness.
- Palpitations.

Cardiomyopathy UK response to the health and disability green paper

Overarching recommendation

Cardiomyopathy recommends an overhaul of the disability benefits system. The participants in our focus groups all described how receiving PIP has improved their quality of life. Although difficult to prove, this can reduce the need for NHS services, which is already under severe financial strains.

We call on the Department for Work and Pensions to devolve the PIP process to a regional level, in a similar way to that proposed in the Labour Party manifesto of devolving funding so local areas can shape a joined-up work, health, and skills offer for local people. To achieve this, DWP should have representatives on Integrated Care Boards. We also call on DWP to recognise that the benefit should not be dependent on a person's capacity to work, but should be offered as part of a whole package of wellbeing support, which could enable a person to stay in or go into work, where appropriate, as well as empowering them to live the life they choose. DWP should also recognise the important role of local voluntary sector organisations in providing support to people through their journey to receiving PIP.

Application process

At the start of the journey towards receiving PIP, focus group participants reported issues in identifying the benefits to which they could be entitled. One person said that they heard about PIP from the Occupational Health assessor who recommended that she took medical retirement, another found out from a cardiomyopathy UK peer support group.

In all cases, the focus group participants described the application process for Personal Independence Payment (PIP) as lengthy and complicated. Several participants explained that they required support in order to complete the application form. This support either came from the Citizen's Advice Bureau (CAB), 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.

From Cardiomyopathy UK's own 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.

Recommendation: The Department for Work and Pensions, on a regional level, has a place on every Integrated Care Board to ensure health services have the knowledge of local benefits and support, and healthcare professionals can signpost people with cardiomyopathy (and other long-term health conditions) to information on welfare rights.

Another issue highlighted in the focus groups was that some of the participants felt that the application form questions are not relevant to the needs of people with cardiomyopathy, which makes it challenging to explain why the person would benefit from receiving PIP. As one person described, it felt degrading and upsetting to talk about themselves on their worst day and feeling their worst, but that it was necessary to "play the system" in order that the application would be taken to the assessment stage. Another participant explained that she has a diagnosis of autism, as well as cardiomyopathy, and found it a challenge to twist the level of her needs to fit to the requirements of the application form.

Recommendation: The Department for Work and Pensions introduces 'how to' guides and an independent helpline which can support individuals through the application form for PIP.

Assessment

The assessment for PIP for people with cardiomyopathy also presented some challenges to the people in the focus groups. Inconsistency in decision-making was a common theme.

One person explained the difficulty of the accessibility of assessment centres. Many people with cardiomyopathy experience fatigue which prevents them from travelling distances, and this was the case for this participant. Fortunately, she had her assessment at home, but had to rest the day before and the day after to ensure she had the energy levels required to fully commit to the assessment. This resulted in being awarded the lower rates for PIP (due to resting, she was having a 'good' day during the initial assessment), and it took more energy and appointments to appeal this decision.

Similarly, another participant had only applied for the PIP mobility component, and was awarded the lower rate, as she was well-rested and having a 'good day' for the assessment. This decision was accepted on mandatory reconsideration, but, before the appeal took place, the decision was changed, in her absence, to award the higher rate for mobility.

Despite cardiomyopathy being a progressive condition, one person had received an enhanced award before the pandemic, but was awarded the lower rate upon reassessment. The assessor in that case was knowledgeable of cardiomyopathy. On reassessment in 2021, this was held on the phone due to Covid restrictions. The result was that that person was given the lower rate, as she could communicate well over the telephone, although she had a higher level of needs.

Recommendation: The Department for Work and Pensions should ensure that assessors have some areas of specialisms when carrying out assessments, for example, in cardiovascular diseases, and that they have specific guidance to follow on assessing people with heart conditions.

Recommendation: The Department for Work and Pensions should consider introducing a system whereby a person living with a progressive condition cannot be awarded a lower rate following reassessment for PIP.

A lack of awareness of cardiomyopathy from assessors and decision-makers was cited as another issue by the focus group participants. One member of the focus group told us that she appealed her PIP decision twice and finally went to tribunal. She was initially awarded 0 points for mobility, but finally received 20 points for mobility at the tribunal.

Another participant explained that she found the assessment irrelevant for a person with cardiomyopathy of working age; it was aimed more at older people experiencing mobility issues.

Recommendation: The Department for Work and Pensions should ensure that assessors have some areas of specialisms when carrying out assessments, for example, in cardiovascular diseases, and that there is specific guidance on PIP decision-making with people affected by heart diseases.

Eligibility

The timescales for the process of confirming eligibility, or the qualifying period, were described as lengthy by the focus group participants. The financial impact of this could be profound for people with cardiomyopathy: people with cardiomyopathy involved in our research explained that they have been forced into ill-health retirement or struggle to find a suitable role, which means they are dependent on savings, the income of a partner, or family, or their pension in order to meet their cost-of-living needs.

As with many conditions, the impact on people living with cardiomyopathy will differ greatly, even for people with the same condition and similar symptoms. There is a danger by making eligibility condition-specific that people with cardiomyopathy would be ineligible for PIP. This would be compounded when you consider that some people with cardiomyopathy are initially misdiagnosed, and face long waiting lists for diagnostic tests and for a cardiologist appointment. Taking this into account, we recommend that eligibility is based on needs, rather than on condition.

Recommendation: The Department for Work and Pensions bases eligibility for PIP on a person's needs, not on their diagnosis, taking into account progressive condition, and a person's needs will increase over time.

It is important to note that cardiomyopathy is a progressive illness, currently with no cure, and a person's needs will only increase over time. However, the progression of cardiomyopathy is unpredictable and dependent on the individual. We recommend that there is recognition in PIP eligibility that some conditions, such as cardiomyopathy, are progressive, but unpredictable in their progression, and that the qualifying period needs to reflect this fact.

Recommendation: The Department for Work and Pensions recognises that some conditions are progressive and a person's needs will increase over time, and this is reflected in the eligibility criteria.

Furthermore, there are wide discrepancies in the length of awards given to people with cardiomyopathy. In the focus group, this varied between one and five years. Whilst we reiterate that every person will experience cardiomyopathy in their own way, and the eligibility needs to be based on needs, it is also important to remember that cardiomyopathy worsens over time and a person will not get better, unless they have a heart transplant (which is rare). In our focus groups, some people with cardiomyopathy explained the undue stress of reassessment on an annual or biannual basis. Again, 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.

Recommendation: The Department for Work and Pensions must ensure that the length of PIP awards take into account a person's needs at initial assessment, that the condition will worsen, and the prognosis from a person's cardiologist.

People with cardiomyopathy in our focus groups told us that they use their PIP for a variety of reasons. The extra costs that people with cardiomyopathy face are often related to goods and services, as they are for additional aids or physical adaptations. In our focus groups, people with cardiomyopathy most often reported using their PIP to pay for travel, such as taxis and for utility bills, or a cleaner. The focus group participants also use their PIP payments for health and wellbeing reasons, such as to pay for art classes and good quality food, which enables them to have a better quality of life. One participant receives the PIP higher component for mobility and uses this for the Motability scheme. She described how having a car has allowed her to, not only drive to work, but also go to exercise classes and socialise with friends, which have all had a positive impact on her overall wellbeing and quality of life.

By removing the option for payments directly to people with cardiomyopathy, you remove their autonomy to choose how best to use the payments to meet their individual needs. This curtailment of choice is a contradiction to other common practices and person-centred approaches, such as direct payments for social care. Moreover, a voucher system or similar could not possibly cover the wide variety of uses people use PIP for. Therefore, removing direct payments will necessarily have a negative impact on recipients.

Recommendation: The Department for Work and Pensions continues to pay PIP into an individual's bank account to empower individuals to make choices which will best meet their own needs.

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