Cardiomyopathy UK
the heart muscle charity

# Parliamentary briefing: Reducing premature deaths from heart disease and stroke

**Westminster Hall debate | Thursday 2 July 2026, 1.30pm**
Led by Paul Foster MP (Labour, South Ribble)

Briefing prepared by **Cardiomyopathy UK**, the specialist national charity for people affected by cardiomyopathy.

Cardiomyopathy UK warmly welcomes this debate and the Government's ambition to reduce premature deaths from heart disease and stroke by 25% by 2035.

Cardiomyopathy is a disease of the heart muscle affecting around **1 in 250 people in the UK** (an estimated 246,000 people) and is one of the leading causes of heart failure. It is also the leading cause of heart transplant in the UK, accounting for around half of all transplants in patients older than 1 year. Yet because its cause is most often genetic rather than lifestyle-related, there is a real risk it is overlooked as the Government develops its plans.

This briefing sets out how the forthcoming Modern Service Framework (MSF) for cardiovascular disease – and the wider 25% ambition – can deliver for people with cardiomyopathy. It is informed by the findings in *Living with cardiomyopathy*, our 2025 state of the nation report on the experiences and insights of over 1,300 people affected by cardiomyopathy across the UK.

## Our key asks for this debate

- Publish the Modern Service Framework for cardiovascular disease without further delay and ensure it explicitly includes inherited and non-preventable conditions such as cardiomyopathy – not just high-prevalence, lifestyle-related conditions.
- Drive earlier diagnosis through increased GP awareness, family-history recording, and timely, equitable access to genetic testing.
- Provide holistic, person-centred care – including care plans, mental health support and cardiac rehabilitation – for everyone with cardiomyopathy.
- Guarantee equitable access to treatment, continuity of care and investment in research, so where you live no longer determines the level of care you receive.

## Why cardiomyopathy must be central to the 25% ambition

Cardiovascular disease (CVD) remains one of the UK's biggest killers, responsible for over 170,000 deaths a year and, for the first time in over half a century, premature deaths from CVD are rising again.

Cardiomyopathy sits squarely within this challenge: it is a major cause of heart failure, contributes to the wider cost of CVD (estimated at around £29 billion a year, with £12 billion in direct healthcare costs) and affects people of all ages, including children and those of working age.

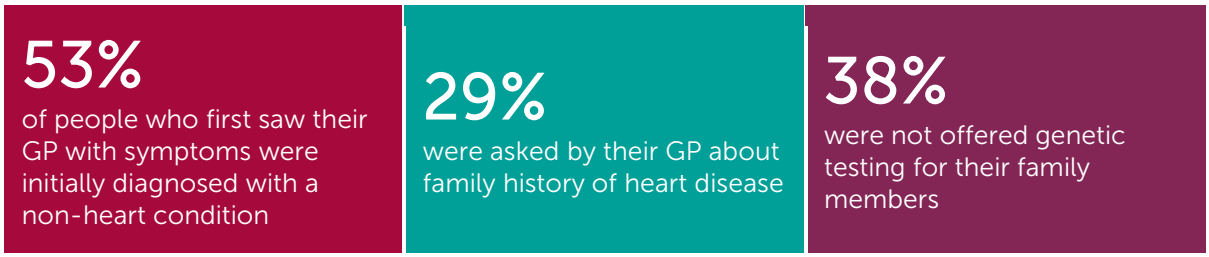
The success of the 2000 National Service Framework for coronary heart disease (which helped deliver a 40% fall in premature CVD deaths), show what clear national standards can achieve. The MSF is a once-in-a-generation opportunity to repeat that successful delivery against the Government's manifesto commitment to tackle the UK's biggest killers – but only if it reflects the **full spectrum of cardiovascular conditions**. As our state of the nation report highlights, the framework must not focus exclusively on lifestyle-related conditions and overlook rarer or genetically driven diseases.

## The Modern Service Framework – a defining moment

On the parliamentary record on 24 June 2026, the Government stated that "the Modern Service Framework will soon be published". With priorities still to be confirmed, this debate is a critical opportunity for Members to shape its ambition and to press for publication. While the MSF covers cardiovascular care in England,

the burden of CVD is felt across all four nations, and the principles below are relevant UK-wide.

## Priority 1: Early diagnosis and timely access to genetic testing




Statistics taken from *Living with Cardiomyopathy,* Cardiomyopathy UK's state of the nation report (2025)

Too many people face delayed diagnosis, often only after a cardiac event. Symptoms are missed or mistaken for other conditions – particularly in women – and family history is not consistently recorded. Access to echocardiography, a key diagnostic test, is also under strain: in 2022, 37% of patients waited over six weeks for an echocardiogram, up from just 4% in 2020. Genetic testing, which is central to diagnosing and managing inherited cardiomyopathy, also remains inconsistent, with regional and ethnic variation in who is offered it.

Link to the debate: Earlier detection is the most direct route to preventing premature deaths and to tackling the inequalities highlighted. It also supports the Government's goal of narrowing the gap in healthy life expectancy between the richest and poorest areas of the UK.

## What we're asking for

- GP awareness and family history: integrated care boards (ICBs) should work with primary care networks, charities and professional bodies to train GPs to recognise the symptoms of cardiomyopathy and to record detailed family cardiac history.
- Best practice tariffs: the Department of Health and Social Care should introduce 'best practice tariffs' for timely genetic assessment and standardised referral to inherited cardiac conditions (ICC) centres, backed by investment in ICC centre capacity.
- Faster diagnosis: access to diagnostic services should be improved, including retaining and expanding the trained NHS echocardiography workforce.
- Targeted screening: the UK National Screening Committee should take forward a stratified, targeted screening programme focused on people with a known family history or other risk factors.

## Priority 2: Holistic and person-centred care


Statistics taken from *Living with Cardiomyopathy*, Cardiomyopathy UK's state of the nation report (2025)

Cardiomyopathy affects far more than just the heart. It also impacts mental health, the ability to exercise, relationships and the ability to work – half of those surveyed in our state of the nation report said their ability to work had been affected. Yet most people have no care plan, emotional support is rarely offered, and many feel abandoned between appointments. This is despite the fact that people with a care plan are more than twice as likely to report very good overall care.

Link to the debate: CVD is the fifth most common condition among working-age people who are economically inactive due to poor health. Holistic care that helps people stay well and in work supports both the 25% ambition and the Government's growth and economic-inactivity goals. There is also an opportunity to join up with the forthcoming Men's and Women's Health Strategies.

## What we're asking for

- Equal access via the MSF: the Department of Health and Social Care and ICBs should ensure the MSF gives people with ICCs such as cardiomyopathy equal access to specialist cardiac care, supported by integrated care plans and clear signposting to holistic support, including charity-led groups.
- Mental health support: NHS regions and ICBs should be supported to provide access to specialist mental health professionals within ICC services, in line with the European Society of Cardiology consensus on mental health and cardiovascular disease.
- Cardiac rehabilitation: clear commissioning guidance for ICC centres should be developed on the role of cardiac rehabilitation for people living with cardiomyopathy.

> *"I just got the diagnosis, was given pills and that's about it. I have never been advised of exercise, nutrition or any other everyday things that can affect my condition."*
> – MyInsight survey respondent*

*The state of the nation report used data collected in the national Cardiomyopathy UK MyInsight survey, featuring over 1,000 respondents with, or connected to, cardiomyopathy.

## Priority 3: Enhanced access to treatment and continuity of care

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| **81%** had not been offered the chance to take part in cardiomyopathy-related research | **22%** say the professionals involved in their care "definitely" work well together | **1 year** is how long some patients wait for access to approved medicines such as mavacamten |

Statistics taken from *Living with Cardiomyopathy*, Cardiomyopathy UK's state of the nation report (2025)

Access to effective treatment should not depend on where someone lives. Yet care is often fragmented across primary, secondary and specialist services, with patients left to coordinate their own care and re-tell their story. Medicines approved by NICE are not always added to local formularies in good time, creating a postcode lottery, and opportunities to take part in research are scarce – a missed chance to improve future care.

Link to the debate: This directly supports the Life Sciences Sector Plan's ambitions on innovation, technology and new treatments, and the debate's focus on research and innovation. Joined-up records and equitable prescribing also help close the geographic and ethnic inequalities at the heart of the 25% ambition.

## What we're asking for

- Single Patient Record: implementation of the Single Patient Record should be expedited to enable seamless information sharing across care settings.
- Access to treatments: work should be undertaken with ICBs, patient charities and industry to ensure newly approved cardiomyopathy treatments are not only accessible but actively prescribed, supported by the Single National Medicines Formulary pledged in the 10 Year Health Plan.
- Research and innovation: the Department of Health and Social Care and the Department for Science, Innovation and Technology should invest in clinical researchers and research in line with the James Lind Alliance priorities for cardiomyopathy.

## Questions Members may wish to raise

- When will the Government publish the Modern Service Framework for cardiovascular disease, and will it explicitly include inherited and non-preventable conditions such as cardiomyopathy?
- How will the Government ensure GPs are supported to recognise the symptoms of cardiomyopathy and to record family cardiac history, so that fewer people are diagnosed late?
- What steps is the Government taking to expand the echocardiography workforce and reduce diagnostic waits?

- How will the Single National Medicines Formulary and the Single Patient Record end the postcode lottery in access to approved cardiomyopathy treatments?

## Work with us

Cardiomyopathy UK is the only specialist national charity for people affected by cardiomyopathy. We provide support and information, campaign for better access to quality treatment, raise awareness of the signs and symptoms, and shape research to provide hope for the future.

We stand ready to work with parliamentarians, clinicians and the wider system to turn these recommendations into reality.
**Contact our policy team: policy@cardiomyopathy.org**