

PERT
Patient Emergency Response Team
(Plan) (2021)
Call PERT if your patient meets ONE OR MORE of
the following criteria

- Respiratory Rate ≥ 22 or ≤ 10
- Systolic BP ≤ 90 (unless noted for patient)
- Heart Rate ≥ 130 or ≤ 50
- Oxygen Saturation $\leq 92\%$ (on 2L O₂)
- Change in consciousness (GCS) or altered level of consciousness ≤ 14 GCS
- Urine output ≤ 0.5 ml/kg/h (if catheterised)
- Risk of an acute bleed or fall
- Blood Sugar ≥ 11 (or ≤ 4 if hypoglycaemic)
- ≥ 3 or ≤ 3 (or ≤ 3 if hypotensive)
- The RCPH (unless noted for patient)

A Manifesto for Cardiomyopathy in 2024

We're Cardiomyopathy UK

We are the specialist national charity for people affected by cardiomyopathy, a condition that affects the heart muscle. **What we do:**



We raise awareness of the condition so that more people know the signs and symptoms and can be diagnosed early.



We campaign to improve access to quality treatment that meets the needs of people with cardiomyopathy.



We promote clinical research to advance the development of new treatments and provide hope for the future.



We support people affected by cardiomyopathy, every step of the way, so that nobody has to face cardiomyopathy alone.

Every two years, we survey the cardiomyopathy community in the UK to gain insights into their experiences of health and care services in relation to their condition. The data in this manifesto is from our most recent [State of Cardiomyopathy Care 2023 report](#).

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.

There is currently no cure for cardiomyopathy, but with an early diagnosis and the right treatments and support, people with cardiomyopathy can live full and active lives. Early diagnosis of cardiomyopathy can reduce the risk of sudden cardiac death. It means that people can receive the treatments and care they need sooner.

What we're calling for:

Early detection and diagnosis

4

Mental health support for people living with long-term conditions

5

Access to specialised care, treatment and drugs

6

Reduce heart failure deaths by 25% in 25 years

7

Investment in life sciences

8



1. Early detection and diagnosis

Many people experience delays in getting a diagnosis of cardiomyopathy.

Our research found that:

GPs struggle to recognise the symptoms of cardiomyopathy:

53% of people who first went to their GP with cardiomyopathy symptoms were diagnosed initially with a non-heart related condition.

As a member of the [Global Heart Hub](#), we call for:



GPs to 'think heart': Increased awareness of the signs and symptoms of cardiomyopathy amongst GPs to make timely referrals to cardiologists.



Know the history: GPs to ask, and record, a detailed family cardiac and medical history (given cardiomyopathy can be genetic).



2. Mental health support for people living with long-term conditions

The wellbeing needs of people with cardiomyopathy are not being met.

Our research found that:

It can be mentally tough to live with cardiomyopathy:

Over 50% of respondents to our survey felt that they struggled to cope emotionally over the last 6 months due to their cardiomyopathy.

It's not easy to access mental health support:

46% of people felt having access to counselling and therapy would help their emotional wellbeing. However, only 9% of people with cardiomyopathy had been offered mental health support as part of their care.

As a member of the Long-Term Conditions - Mental Health Coalition, we want to see:



Integrated mental and physical health care: The Government and NHS to centre mental and physical health care integration within their plans for improving the health service so that people living with long term physical health conditions (including advanced serious illnesses) receive person centred mental health care.

3. Access to specialised care, treatment and drugs

Having access to quality information at the point of diagnosis can make a big difference, but this is not always provided.

Our research found that:

Information on cardiomyopathy is not always provided:

38% of respondents received a diagnosis letter without any further information about their condition.

Information on lifestyle choices is also lacking:

Few care plans contained information on wellbeing support (9%), nutrition (6%) or accessing cardiac rehabilitation (12%). All of these issues are important to people with cardiomyopathy.

As a member of both the [Specialised Healthcare Alliance and Genetic Alliance UK](#), we call for:



A tailored package of care and support: All people diagnosed with cardiomyopathy to have access to an integrated package of care appropriate to the needs of patients, covering the following areas: emotional and mental health support, sexual health and family planning clinics, prescription of tailored exercise, information on welfare rights and nutritional support.

4. Reduce heart failure deaths by 25% in 25 years

Cardiomyopathy is one of the causes of heart failure. Heart failure prevalence is set to double by 2040 and takes up 2% of the entire NHS budget.

We have joined the [25 in 25 campaign](#) which calls for:



A reduction in heart failure deaths by 25% in 25 years: The 25 in 25 Collaborative brings together health and social care professionals, public health, local government and community groups to identify trends in local population health and inform future community planning and resource allocation.



5. Investment in life sciences

In England alone, nearly:

1 in 5

are projected to be living with major illness by 2040. Research can unlock new ways to prevent, diagnose and treat disease.

As a member of the [Association of Medical Research Charities](#), we want to see:



Strong and sustainable government backing for life sciences:

A collaborative approach between government, charities and industry to accelerate access to innovation, improve health outcomes for everyone, reduce the burden on the NHS, and cement the UK's position as a world-leader in research.



Research in the NHS should meaningfully involve people across the UK:

The NHS should ensure that clinical research is representative by involving people from all UK communities and regions, and covering all conditions and disease areas. Cardiomyopathy UK recently partnered with the James Lind Alliance on a Cardiomyopathy priority setting partnership, a process to decide on the 10 priority research questions, as decided by people affected by cardiomyopathy and healthcare professionals.

Find out more about the cardiomyopathy future research priorities:



www.cardiomyopathy.org/future-research