

Our Manifesto for Muscles 2024

Over **110,000** people in the UK live with one of over 60 different muscle wasting and weakening conditions. That's nearly **1 in 600** people.

It's essential that the next Government tackles the barriers and challenges our community face so everyone can get the healthcare, support and treatments needed to feel good, mentally and physically.

Every day counts when you're living with in many cases a progressive, and sometimes life-limiting, muscle wasting and weakening condition. We're calling on all political parties and candidates to commit to making a real and lasting change.

We're calling on the next Government to deliver five key priorities for our community.

1. Improve access to NHS services and treatments

We're calling for faster, better, and more equitable access to NHS services and treatments. Our community of over 110,000 people living with muscle wasting and weakening conditions has a wide range of health needs, requiring multi-disciplinary care from a broad range of both specialist and community services, to provide coordinated, patient-centred care.

It's essential the next Government develops a sustainable funding settlement for the NHS, to ensure it's appropriately resourced to deliver specialist health services; to address gaps in the workforce and infrastructure; and to ensure an up-to-date service specification is in place to meet the needs of our community.

Everyone must be able to access the services and treatments they need, regardless of where they live.

Results from our community survey show:

- **Nearly 1 in 2 (45%) people with a muscle wasting and weakening condition do not feel in control of their physical healthcare**
- **1 in 4 people don't feel in control of their mental healthcare**

2. Ensure people affected by muscle wasting and weakening conditions can feel financially secure

Our community has been hit disproportionately hard by the cost-of-living crisis, and living with a muscle wasting and weakening condition comes with additional everyday costs. People face barriers to work, study, and to living independently. We're calling on the next Government to ensure our community can have financial security by reviewing disability benefit rates and carers allowance, and committing to fix Personal Independence Payments. Improvements are also needed to Access to Work, and it's essential that employers are held to account on providing reasonable adjustments.

Results from our community survey show:

- **1 in 4 people with a muscle wasting or weakening condition feel financially insecure**
- **70% of our community are worried about their financial situation**
- **1 in 4 people with a muscle wasting or weakening condition don't feel they have the opportunity to work or study if they'd like to**

3. Ensure people living with a muscle wasting and weakening condition can get a timely diagnosis

Early access to treatment, care and support is essential for people living with a progressive muscle wasting and weakening condition. Being seen by the right specialists as soon as possible is key to ensuring better health outcomes for our community.

Newborn screening is vital for early diagnosis, and as new treatments that can transform the lives of people with muscle wasting and weakening conditions become available, we're calling for the process to add conditions to the NHS newborn screening programme to be sped up.

For older children and adults developing muscle wasting and weakening conditions, it's essential they're put on the right pathway to receive a timely, accurate diagnosis, to lead to earlier treatment and improved outcomes.

Results from our community survey show:

- **Over 2 in 3 people waited longer than a year for their diagnosis**
- **For the majority (55%) of people, it took four or more meetings with healthcare professionals to get a diagnosis**

4. Increase knowledge of muscle wasting and weakening conditions among non-neuromuscular specialist healthcare professionals.

A lack of understanding among non-neuromuscular specialist healthcare professionals about muscle wasting and weakening conditions can be frustrating and harmful to our community. It leaves families at a loss, unsure where to turn when health professionals don't understand their condition, and in emergencies, this can be life-threatening. We're calling on the next Government to promote ongoing professional development and upskilling of all health professionals around rare diseases and muscle wasting and weakening conditions.

5. Maintain the UK's position as a world leading centre for research excellence

The next Parliament will be a critical time for research and development into muscle wasting and weakening conditions. The UK has a valued reputation for research to develop life-changing and life-extending therapies and treatments, with a pipeline for new treatments that was unthinkable just decades ago. It's vital the UK retains this status, attracting and nurturing the best research talent by boosting clinical trial capacity and ensuring researchers in UK muscle centres have the time and resources they need to conduct clinical trials.

We're calling on the next Government to create a regulatory environment incentivising innovation, balanced with an equitable healthcare system, ensuring critical new treatments are accessible to those who need them. The appraisal processes for new treatments needs to reflect that rare conditions should not be assessed in the same way as more common conditions, recognising their unique nature.

Prospective parliamentary candidates can show their support by emailing: campaigns@muscular dystrophyuk.org

More details about our community survey cited in this manifesto: [How you're shaping our work - Muscular Dystrophy UK](#)