MUSCULAR DYSTROPHY UK
OUR MUSCLES MATTER

A world without limits

Our ten-year strategy to 2035

Muscles matter.
We need them to walk, eat, smile, breathe – to live.

But over 110,000 people in the UK live with a muscle wasting condition which gradually damages the way their muscles work. And over time stops them from living everyday life. In some cases, lives will be cut short.

That's why for over 60 years we've been funding groundbreaking research and providing life-changing support for people living with a muscle wasting condition. During this time advances have been made that were once unthinkable. Ten years ago, there were no treatments available specifically for muscle wasting conditions. Today, there are eight. That's progress – but it's not enough.

People living with a muscle wasting condition, and their family and friends, still face huge challenges from delays in diagnosis to a lack of tailored support, limited treatment options to accessibility issues. This is not acceptable. The time for change is now.

We've developed a bold ten-year ambition to transform the lives of people with muscle wasting conditions. We're setting a clear, long-term direction for the future — one that's powered by purpose, backed by evidence, and shaped by the voices of those we are here to support. Our ten-year roadmap will ensure that, even in a fast-changing and unpredictable world, we remain focused on delivering lasting change.

> This strategy is our boldest yet — a ten-year ambition to transform the lives of people living with muscle wasting conditions. Our vision is clear, a world without limits for people with muscle wasting conditions, and we won't stop until we achieve it. But we can't do it alone. We need everyone — supporters, healthcare professionals, scientists, policymakers — to stand with us.
>
> **The time for change is now. Join us.**
>
> **Andy Fletcher,** Chief Executive

Our vision is clear: a world without limits for people living with muscle wasting conditions.

To realise this vision, over the next decade we'll be focussing all our energy and efforts on achieving four key strategic goals.

Strategic goal one:
Transforming diagnosis

We will help speed up and improve the accuracy of diagnosis.

Strategic goal two:
No one faces their journey alone

We will reach everyone with information and support at the point of their diagnosis and be there for them at every stage of their journey.

Strategic goal three:
New treatments, universal support

We will help accelerate the development of new treatments for every condition and ensure quicker and easier access to specialist support when and where people need it.

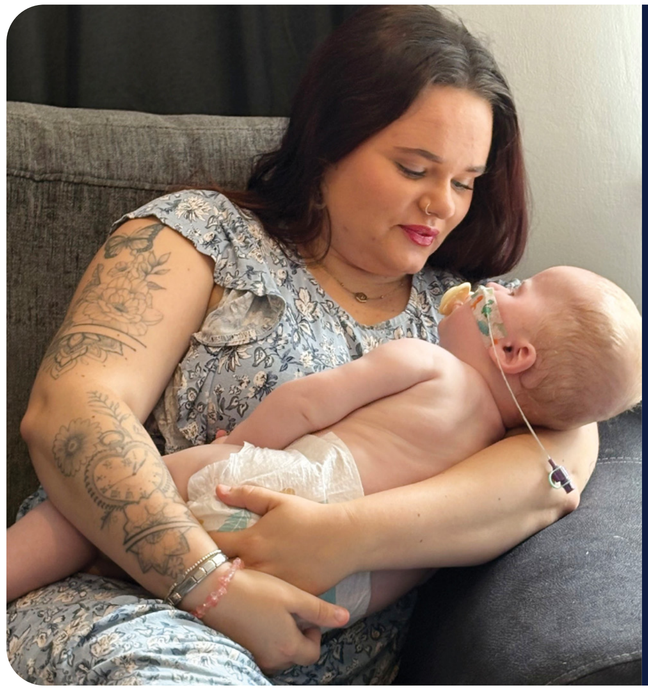
Strategic goal four:
Living your life to the full

We will campaign for a more equal and accessible world and support more people to live independently with better physical and mental health.

Strategic goal one:
Transforming diagnosis

Why this is important

Half of those living with a muscle wasting condition report being misdiagnosed. More than two thirds wait over a year for a diagnosis. And nearly half wait more than five years. Misdiagnosis and delays to diagnosis mean people can miss out on vital treatment and support and feel more alone with their condition. For some conditions, newborn screening can transform lives by providing treatment before symptoms even start.



> **Newborn screening would have changed our lives because with SMA it's a deteriorating disease. If Chester had had newborn screening, then he'd have gone on to the medication and the damage wouldn't have been to this extent. He would have lived everything to its fullest. Whereas now the future is so uncertain. It's quite scary.**
>
> **Kasey mother of Chester,** one, living with SMA

Our ambition

We will help speed up and improve the accuracy of diagnosis so that by 2035, no one will wait longer than six months to be diagnosed.

How we will do it – our priorities for the first three years:

- We will **campaign** for better newborn screening for relevant muscle wasting conditions.
- We will **invest in research** to explore how we can improve diagnosis and better understand the prevalence of people with muscle wasting conditions.
- We will **educate** thousands of healthcare professionals responsible for identifying potential muscle wasting conditions for timely referral.

Strategic goal two:
No one faces their journey alone

Why this is important

Being diagnosed with a muscle wasting condition can be devastating. It can be frightening. It can be lonely and isolating. Getting the right support at the point of diagnosis can be crucial in living well with a condition both physically and mentally. Yet too many people face this journey alone.

> **I received my diagnosis by letter, three lines long, saying we'll be in touch to have an appointment in a few weeks. That was it. I was shocked. I knew there was a problem, but to just receive a letter with no details, nothing.**
>
> **Stewart** living with Inclusion Body Myositis

Our ambition

We will reach every person with a muscle wasting condition by 2035, so no one faces their journey alone.

How we will do it – our priorities for the first three years:

- We will develop a **new diagnosis referral service,** with tailored support materials for people newly diagnosed with a muscle wasting condition.
- We will develop a programme of **in reach into neuromuscular centres** and clinics, developing staff and volunteers to offer direct and peer support.
- We will **significantly increase awareness** of muscle wasting conditions and the charity so more people can access support when they need it.

Strategic goal three: **New treatments, universal support**

Why this is important

There is no cure for any muscle wasting condition. But for the first time there are new treatments being developed which can slow the progression or reduce the impact of some conditions. However, too often people can't access these treatments because of a lack of capacity in the NHS. While some areas of the UK have specialist clinical support, a stark postcode lottery exists. This means some people miss out on vital care and support to help them live well with their condition.

> **It feels like the network of support from healthcare professionals has got smaller and smaller. That safety net really has just gone. We feel frightened when we have illnesses or new symptoms come up because it's just so hard to get advice or it's a six month wait till your next appointment.**
>
> **Charlotte,** lives with muscular dystrophy

Our ambition

We will help accelerate the development of new treatments so that by 2035 they will be available everywhere. And everyone will be able to access specialist support when and where they need it.

How we will do it – our priorities for the first three years:

- We will **fund groundbreaking research** into new treatments and better understanding of muscle wasting conditions.
- We will **campaign and influence the NHS** across the UK to end the postcode lottery and ensure there is capacity in the system to treat and support those who need it.
- We will **support the growth of neuromuscular services and workforce** through education and quality improvement.

Strategic goal four: **Living your life to the full**

Why this is important

Living with a muscle wasting condition affects every part of life — and the impact goes far beyond the physical. It can be exhausting, isolating, and overwhelming, taking a serious toll on both mental and physical health. But the challenges don't stop there. Society too often shuts people out — with barriers in transport, housing, education, and work that make independent living harder than it should ever be.

> **The biggest challenge is integrating Vinny with the community because there are many obstacles. Like accessible transport, and everything has to be pre-planned as the chances are places won't be accessible.**
>
> **Satish,** Vinny's father. Vinny lives with Duchenne muscular dystrophy

Our ambition

We will campaign for a more equal and accessible world and directly support every person who needs it by 2035 to live independently with better physical and mental health.

How we will do it – our priorities for the first three years:

- We will **significantly grow our direct services** and review our existing model of support to reach more people with practical and emotional support.
- We will **campaign for a more just and inclusive society** with accessible services and state support to live a full life.
- We will **grow our community** of people affected by muscle wasting conditions to improve self-advocacy and peer support.

Making it happen – developing our organisation

A great fundraising organisation

To achieve these goals we will strive to be a great fundraising organisation where everyone plays their part. We will double our income by 2035 to £15 million.

Better use of data and technology

We will harness technology and improve how we collect and utilise data to ensure we reach more people and deliver more impact. This includes developing the UK's leading evidence base for the numbers, prevalence and experience of people living with a muscle wasting condition.

Raising awareness and understanding

We will increase awareness and understanding of muscle wasting conditions and the charity to grow our community, increase our impact and raise more money.

A great place to work

We will invest in our team of staff and volunteers to ensure that we have the talent and skills to deliver more impact and ensure we are an inclusive place to work where everyone belongs.

Join us

This is an ambitious strategy, and while we're passionate about delivering it, we can't do this alone. The transformation starts right here, right now. And you can be part of it.

Donate

Donate today and help change the future of muscle wasting conditions.

Volunteer

Join our incredible team of volunteers and experience the joy of making a difference.

Sign up to our monthly e-newsletter

Keep up to date with the latest news, campaigns, research and ways you can support us.

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