

**MUSCULAR
DYSTROPHY**
UK | OUR MUSCLES
MATTER

We're here for you

Providing life-changing support for people
living with a muscle wasting condition



Who we are

We're the leading charity for more than 110,000 children and adults in the UK living with one of over 60 muscle wasting and weakening conditions.

We're here for everyone living with a condition as well as those around them. From the point of diagnosis to living the best life possible.

- We share expert advice and support to live well now.
- We fund groundbreaking research to understand the different conditions better and lead us to new treatments.
- We work with the NHS towards universal access to specialist healthcare.
- Together, we campaign for people's rights, better understanding, accessibility, and access to treatments.



How we can support you

Talk to us

We know being diagnosed with a muscle wasting condition can change everything, and there are challenges you'll face living with a progressive condition. Having access to the right information and advice can make all the difference. Our Information, Advocacy and Care Team are here to talk to you.

Whether you've just received a diagnosis, need some practical information or just want someone who understands what you're going through. We can help.

Sometimes, you might not know what support or information you need. Our caring team can help you with this, wherever you're based in the UK.

When you want to know how to adapt your home, how to fill in that long benefit application form or what benefits you're entitled to, we're here for you. And if we can't help, we'll direct you to someone who can.

Our helpline: [0800 652 6352](tel:08006526352)

Email: info@muscular dystrophyuk.org



Get what you're entitled to

You can often face higher costs than others when you live with a muscle wasting condition, for things like electricity to charge your wheelchair. There are benefits available to help you manage these extra costs. Our advocacy team is here to help you understand what financial support might be available and to help you write applications and appeal should your application not be successful.

“Personal Independence Payment (PIP) applications and assessments can be daunting, especially if you're applying for the first time. We're all really experienced in supporting people with their applications.” ~ Helpline staff member

Financial support for your mobility equipment

Through our welfare fund, the Joseph Patrick Trust (JPT), we provide grants towards the cost of essential powered mobility equipment to improve your quality of life. For over 30 years, we've awarded more than 6,000 grants, totalling more than £6million. We also signpost and share general information on other grants and financial support towards other such costs.



Talk to others in a similar situation

Having a muscle wasting condition often means adjusting to a new and unexpected reality, but meeting other people in a similar situation can really help. We can put you in touch with people who understand what you're going through and can give you guidance on things that have worked for them and services they have used.

Our peer support volunteers provide you with one-to-one support. We'll match you with someone who has had a similar experience to you. They can provide you with informal emotional support and advice over the phone or by email.

"Talking to someone with a first-hand understanding of living with a muscle wasting condition can make a huge difference."

~ Gemma



Meet people in person or online

Our Muscle Groups

Our welcoming groups provide information and support and an opportunity to meet other people living with a muscle wasting condition in your community. Online or in person, the groups are an opportunity for you to share experiences, discuss local and national issues and hear about the support available for you.

Our online support groups

We run online support groups for people affected by a muscle wasting condition on a variety of different online platforms. This includes WhatsApp support groups for different age groups and conditions.

Our events

We hold conferences, virtual information seminars, information days and other events, where you can learn more about your condition, hear about the latest research, and ask leading researchers and clinicians about their work. Our Information days provide guidance and support in condition management and practical information to help you to live well and independently. You can also take part in workshops on practical topics, meet new people and connect with others who've been through something similar.



Find out more about your condition

We have information fact sheets for a number of muscle wasting and weakening conditions. These offer you practical advice and guidance. We also produce information videos on our YouTube channel and share stories from other people living with a muscle wasting condition.

Alerting your healthcare professionals about your condition

Muscle wasting conditions are rare, affecting just one in every 600 people in the UK. This means some healthcare professionals may not have heard about your condition.

We've created 12 condition specific alert cards with information to share with a healthcare professional to help them treat you. They can be kept in your purse or wallet, giving you the security that you carry important information about your condition with you.

Training healthcare professionals about your condition

We provide online training courses on muscle wasting and weakening conditions for healthcare professionals, such as GPs and community teams, to make sure they have the right skills to offer you the best possible support. Tell your healthcare professional to get in touch with us and we can send them more information.





Get involved

We believe in the power of community. That the whole is greater than the sum of its parts. Because the more of us who come together, the greater the impact we'll be able to make. Whether you'd like to fundraise or volunteer, there are lots of ways you can get involved.

Some people choose to set up a family fund or a fundraising group to raise awareness and funds within their local community. Family funds are an important part of our community. They allow you to restrict the money you raise for research into a specific condition and put aside some funds for future welfare needs you may have, such as buying a wheelchair or making adaptations to your home.

Sign up to our monthly e-newsletter and hear about our latest news, campaigns, research and ways you can support us.

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#MusclesMatter

<https://www.muscular dystrophyuk.org/>

Our helpline: 0800 652 6352 Email: info@muscular dystrophyuk.org

www.muscular dystrophyuk.org

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