

Here for you

Support for people with
muscle-wasting conditions



**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions





Making every day count

Muscular Dystrophy UK (MDUK) is here for anyone living with a muscle-wasting condition, right from the moment of diagnosis and beyond.

Here at MDUK, we drive change; we support high-quality research to find effective treatments and cures, and won't stop until we have found them for all muscle-wasting conditions.

We believe in building a world where there are no limits in life for people affected by such conditions, a world with improved standards of care and quality of life.

Because we understand the everyday challenges of living with muscle-wasting conditions, we're here to offer information, advice and support, advocacy, a network of local groups and an online community.

Learn about your condition

MDUK's work covers more than 60 rare and very rare, progressive muscle-weakening and wasting conditions, affecting around 110,000 people in the UK. We have info factsheets on the different, varied muscle-wasting conditions, practical advice and guidance, as well as informative videos on our YouTube channel.

Go to www.musculardystrophyuk.org/conditions to download these free factsheets from our website or call us on 0800 652 6352 and we'll send them to you.

Visit our YouTube channel at www.youtube.com/c/MuscularDystrophyUK/playlists

Inform healthcare professionals

As muscle-wasting conditions are very rare, affecting just one in every 600 people in the UK, many people – and even some healthcare professionals too – might not have heard about them. By carrying one of our condition-specific alert cards, which can fit in your purse or wallet, you will have the security of knowing you can easily inform healthcare professionals of specific, vital information about you and your condition.

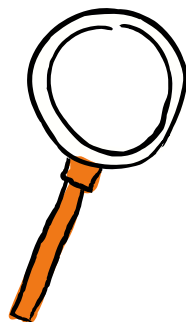
Find out more at www.muscular dystrophyuk.org/alert-cards

We have also developed online courses for healthcare professionals to ensure that your GPs and community teams have the skills they need to offer you the best possible support. To help promote these training modules to your local healthcare professionals, please get in touch and we can send you more info.

Find out more at www.muscular dystrophyuk.org/professionals/elearning-modules

Get what you're entitled to

Often people with muscle-wasting conditions will face higher costs because of their condition, but several benefits are available to help you manage these extra expenses. Our advocacy team is here to help you understand what financial support may be available to you and can help you with applications and appeals. They can also share information and advice about home adaptations, inclusive education and what care and services you may be entitled to.



“Personal Independence Payment (PIP) applications and assessments can be daunting, especially if you’re applying for the first time, but we’re all really experienced in supporting people with their applications. We want you to get the support you’re entitled to, and we can guide you to have the best chance at going through the process.” – MDUK helpline team member

Get in touch with our team on [0800 652 6352](tel:08006526352) or info@musculardystrophyuk.org

Get financial support for vital mobility equipment

MDUK provides information on adaptations and equipment you may require, as well as information on grants and financial assistance to help you pay towards their extra costs. Also, our own welfare trust – the Joseph Patrick Trust (JPT) – awards grants towards the cost of mobility aids to improve your quality of life. Find out more about our JPT grants and other information on this topic on our website.

Go to www.musculardystrophyuk.org/JPT-grants





Find services and support near you

MDUK works to ensure everyone living with muscle-wasting conditions in the UK has access to the specialist NHS care and support they need. Knowing what support is available, and making sense of the different services, can be confusing and overwhelming. Our online map of support will help you find specialist healthcare services or Muscle Clinics near you.

To see our map of the services and support near you, go to www.muscular dystrophyuk.org/support-in-your-area

Talk to us

We understand that a diagnosis of a muscle-wasting condition can change everything, and there are challenges when you live 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 support you. Whether you have just received a diagnosis, need some practical information or would just like to speak to someone who understands what you're going through, we can help.

We know there may be times when you are finding things difficult and you might not be sure what support or information you need. Our caring team are here to advise you and help you get the support you need.

It's also important to have support that is specific to you and the area you live in. Our regional teams across England, Scotland, Northern Ireland and Wales are on hand to assist you, wherever you're based in the UK.

You can find free, expert information, resources and support online, over the phone and within communities. When you want to know how to adapt your home, how to fill in that long PIP application form or what benefits you're entitled to, get in touch. If we can't help you, we can direct you to those who can. We're here for you every step of the way.

"You'll always find a warm, listening ear and someone who knows the ins and outs of the various processes." MDUK helpline team member

Call us on [0800 652 6352](tel:08006526352)



Speak 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 similar situations can really help. We can put you in touch with people who understand what you are going through and can give you guidance on things that have worked for them and services they have used.

“Talking to someone with a first-hand understanding of living with a muscle-wasting condition can make a huge difference.” Gemma Rose from Essex

Complete our form to start the process of meeting one of our peer support volunteers at www.musculardystrophyuk.org/peer-support-enquiry

Meet people in person or online

There are loads of opportunities for people with muscle-wasting conditions, and their families, to get together in person or online. Here are a few ways you can connect with others in the community:

Muscle groups: by getting together at our regional muscle groups, you can share experiences, and discuss local and national issues that affect you.

Go to www.musculardystrophyuk.org/support-in-your-area



Online support groups: there are several support groups, including one for parents on Facebook at www.facebook.com/groups/mdukparentsupportgroup and even more to explore on our website at www.musculardystrophyuk.org/support-groups

Events: at our conferences, virtual Muscles Matter seminars, information days and other events, you can hear about the latest research and ask leading researchers about their work, take part in workshops on practical topics, meet new people, or catch up with old friends.

Online forum: on TalkMD, you can meet, share experiences or ask other people living with muscle-wasting conditions how they dealt with a challenge you might be facing.

Visit <https://community.musculardystrophyuk.org>





World-class research

MDUK is working towards a future with effective treatments and ultimately cures for all muscle-wasting conditions. We know we can beat muscle-wasting conditions more quickly if we work together, so we're committed to supporting, funding and collaborating with researchers and clinicians to help them carry out the best quality research. To find out more about research into your condition, and what clinical trials are available, get in touch with our research team.

Get in touch with our team at research@musculardystrophyuk.org

Campaigns

We campaign to improve the quality of life of people living with muscle-wasting conditions, particularly advocating access to the specialist healthcare, welfare support and emerging treatments they need. We do this by bringing people living with first-hand experience together with healthcare professionals and decision-makers, and by making sure their voices are heard in parliaments across the UK.

Visit www.musculardystrophyuk.org/get-involved/campaign to find out more about our campaigns.

Fundraising

Throughout the year, we facilitate a range of fundraising events and opportunities, including skydives, runs, challenges and bake sales, to name just a few. Also, some people choose to set up a family fund or a fundraising group to raise awareness and funds within their local community to make a real difference to those living with muscle-wasting conditions. Family funds are an important part of MDUK's community, allowing you to restrict your income to research into a specific condition close to your heart and put some aside for any future welfare needs you may have, such as buying a wheelchair or making adaptations to your home.

Get in touch with your Regional Development Manager to find out more. Call us on [0300 012 0172](tel:03000120172)



If you'd like to support any of MDUK's work, please get in touch with us. We have loads of events you can take part in, or you may prefer simply to make a regular gift to the charity. We rely almost entirely on voluntary donations and legacies to fund our vital work. Together we're bringing forward the day when there are effective treatments available for all muscle-wasting conditions.

www.muscular dystrophyuk.org

Find out more

Freephone helpline: 0800 652 6352 (Mon to Fri)
info@muscular dystrophyuk.org

Research Team: research@muscular dystrophyuk.org

JPT: www.muscular dystrophyuk.org/JPT-grants

Support and services near you:
www.muscular dystrophyuk.org/get-support

Fundraising hotline: 0300 012 0172