MD Support Centre Magazine

Spring - Summer 2026

Travels with Scoot

How a portable travel scooter opened up a world of independence

A measure of independence

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Plus

- Emotional wellbeing and counselling support
- Choosing mobility aids
- Benefits application tips
- Support from SMA UK and CMT UK

...and more!

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Join the summer fun at our

Summer social

11 July | 11am - 2pm
at our Coventry centre

Join service users, carers, families, volunteers, and staff for a relaxed afternoon of fun, friendship, and celebration at the Muscular Dystrophy Support Centre.

Drop in to catch up with friends, meet new people, enjoy refreshments, take part in crafts and activities, join an exercise taster session led by Abbas, and try our hand therapy equipment with Suki.

We'll be joined by special guests including Wenman Healthcare and Bradley's Promise, and we'll be celebrating the achievements, milestones, and memories from the year so far. So bring your loved ones, bring a picnic, and celebrate the summer with us.

We'd appreciate it if you could let us know you're coming so we can plan for numbers and send you a reminder closer to the day.

Go to bit.ly/mdsc-summer for more information.

A note from our CEO, Zoe Richardson

Welcome to this latest edition of the MD Support Centre magazine.

For those who may not know me yet, I joined the charity as CEO August last year. Over the past few months, I have had the privilege of meeting many of our service users, families, supporters, volunteers and partners. One thing has stood out above everything else: the extraordinary resilience, determination and positivity within our community.

This edition focuses on something that sits at the heart of everything we do at MD Support Centre – wellbeing and living well with muscular dystrophy. While we know that living with a neuromuscular condition can bring challenges, we also know that wellbeing is about far more than managing a condition. It is about maintaining independence, staying connected, looking after your physical and mental health, finding joy in everyday experiences, and continuing to pursue the things that matter most to you.

Throughout these pages, you will find inspiring examples of exactly that. You'll read about the importance of movement, breathing and self-care, discover ways to support your health and wellbeing, and learn more about the services available through the Centre.

You will also meet some remarkable members of our community. We celebrate the achievement of one service user who completed the London Marathon, demonstrating incredible commitment and determination. We also share the story of travelling independently on holiday with a mobility scooter – a reminder that with planning, confidence and the right support, new adventures remain possible.

These stories are important because they remind us that living with muscular dystrophy is not defined solely by limitations. It is also about ambitions, achievements, relationships, experiences and possibilities.

As we continue to grow and develop the charity, our focus remains on helping people live as well as possible for as long as possible. Whether that is through specialist therapies, peer support, wellbeing activities, information and advice, or simply creating opportunities for people to connect, everything we do is driven by that goal.

Thank you for being part of the MD Support Centre community. Whether you are a service user, family member, volunteer, supporter, fundraiser or partner, your involvement helps make this charity what it is.

I hope you enjoy this edition and find something within it that informs, inspires or encourages you.
Warm wishes,

Zoe

Travels with Scoot

How a portable travel scooter opened up a world of independence

Paul Craddock shares how finding the right travel scooter helped him continue to explore new places with greater confidence and freedom.

By the time I hit 65, the progression of my limb girdle dystrophy was creating severe limitations to the distance I could walk, and hills were near impossible. Having always been a keen traveller, I decided to invest in a mobility scooter that was sturdy but could be broken into four pieces to fit into the car. I chose the Sterling Sapphire 2 from Sunrise Medical, a great scooter, but it soon became clear that it was quite an effort to take it apart and put it together, plus, it completely filled the boot of our large car, leaving no room for a small suitcase.

My wife and I are keen travellers and are fortunate enough to afford holidays abroad, so I decided to invest in something far more portable and aircraft-friendly. Meet Scoot! Scoot is my lightweight, folding travel scooter that has opened up the world and allows me to easily travel anywhere (within reason) that I like. He is a Genie from Monarch Mobility, and folds in a way that is much more boot-friendly than similar travel scooters that fold flat.

Weighing in at just 19 kilos, Scoot can be lifted into the boot of the car or any taxi. It is powered by a removable lithium battery and folds down to the size of a suitcase. When folded, he can be wheeled around just like a suitcase.

Ready for action

Scoot lives in the back of my car, where I have a little lifting device installed so I can get him in and out unaided. Whether it’s a weekend away, visiting relations, or going to the shops, Scoot is always with me and ready for action. The battery should last for about 7km on the flat, which is 10,000 of my wife’s steps; however, we now carry a spare battery in a backpack slung over the seat backrest.

Scoot has also been in countless taxis, two cruise ships, loads of aircraft, two smallish boats and two tuk-tuks. Battered and bashed, he is well travelled and has carried me for many, many miles around too many places to list here, but including USA, Costa Rica, South America, Norway, France, Poland and just last week, Sri Lanka. I tend to be apprehensive before each trip about how I will manage, but somehow it all works out.

When booking air travel, you need to request special assistance and inform the airline that you will be using a scooter (same for a powered wheelchair). They will want to know the weight, dimensions and battery details. The battery must be removable as it cannot go in the hold. You also need to select hotels carefully, making sure there is stairless access and, of course, an elevator.

At the airport, I usually drive right to the jetway, where we remove the battery and fold the scooter so it goes in the hold with the pushchairs and wheelchairs. If it's steps access to the plane, the airports all have a thing called an 'Ambi lift', which elevates you to a separate aircraft door. I can still just about walk to my seat, but a special narrow wheelchair is available to those who can't.

Travel is still possible

I won't deny that there are challenges in scooting around places with a lack of dropped kerbs or even pavements. I couldn't do it without my wife there to help, although it's heartwarming as strangers always offer to help. Also, I look a bit ridiculous as the scooter is very small for my 6ft body, but hey-ho, I look ridiculous when trying to walk anyway! Another issue is cobbled streets, as the small, solid wheels bump alarmingly and uncomfortable over the cobbles.

Now aged 70, my walking and balance have further deteriorated, and I find myself needing to use the scooter inside hotels and venues, like theatres. I will drive to within a few dozen steps of where we will be sitting, then, with stick in one hand and wife on the other, hobble to my seat.

MD disrupts lives and stops you from doing many things. But if you are lucky enough to afford it, travel is still possible with the help of a powerchair or scooter - plus some careful planning.

The Sterling Sapphire in the foreground with Scoot in the boot and crane ready for use.

Scoot tucked into the corner of the boot

My wife, Scoot and I on a rope bridge in the jungles of Costa Rica

A measure of independence:

equipment to have a shower on my own

By Sheila Hawkins

I broke my leg in 2019 and, when I was discharged from hospital with my leg in plaster, I was also provided with a wheeled commode/shower chair and a care package that included two carers every morning to help me have a shower and get dressed.

Here it is enjoying a breath of fresh air in the back garden!

As my leg healed and became less painful, I reached a point where the only help I needed was someone to hold the chair steady while I transferred from my powerchair into the plastic shower chair, as the brakes weren't reliable. Even in hospital, I'd been able to wash myself, so I never needed help actually taking a shower.

Once I was able to bear weight on my broken leg, my NHS care package came to an end, although I could no longer walk into or stand up in the shower. I knew I wasn't eligible for means-tested benefits as I was working, mostly from home, on a reasonable salary.

It would have been possible to purchase a care package, but I was advised this would cost at least £20 per day, which seemed a lot for someone to hold the chair steady while I transferred in and out of a plastic chair with dodgy brakes. In addition, although I had a nominal time when the carers would arrive, in practice it varied considerably and was sometimes over an hour late, often because they had dealt with an emergency for a previous client.

My partner, Paul, and I decided that he would assist me with transfers in and out of the shower chair, and we'd spend the money on something else, like regularly going out for a nice dinner.

This arrangement continued for several years and was generally OK, except that if one of us wanted to be up and out early, we both had to get up and get on early. I also had a home hairdresser and always wanted to wash my hair after she'd cut it, which meant Paul had to hang around while I had my hair cut.

Seeking independence

After the pandemic, when it became possible to travel again, we stayed in various hotels and realised that some, including Premier Inn, had good fixed shower seats. These allowed me to transfer independently and have a shower on my own. It also meant I could go away with a couple of close friends for girls' weekends, which I always enjoyed.

I started looking around for a shower seat that I could buy and install in our bathroom. Premier Inn wouldn't tell me where they sourced their shower seats and it's very difficult to get a sense online of what works.

I went to my local CareCo, who referred me to Pochin's. They didn't sell shower seats either, but they did give me the name of a plumber who could install them.

I eventually bought a Savannah seat and the plumber came round to install it. We both quickly realised that it wasn't safe for me to transfer from my powerchair into the seat because my banana board had no grip on the hard, curved plastic surface.

Finding the right equipment

I then discovered that the plumber had previously worked for a company that installed accessible bathrooms for Leicester City Council. He told me that the shower seat they always installed was the AKW 4000 series, which is available in different colours and sizes.

So I looked at their website, decided what I wanted, and the plumber sourced and installed it for me last September. It cost £420, including installation. **It means I can now shower at a time that suits me and have the confidence of knowing I can prepare to face the world independently each morning.**

In the meantime, if anyone wants an unused height-adjustable Savannah shower seat, it's free to a good home. It's unsuitable for anyone who uses a transfer board, but if you just want to be able to sit in the shower, it's fine. Message me via the Muscular Dystrophy Support Centre.

You can find the AKW 400 shower seat recommended by Sheila at akw-ltd.co.uk.

Savannah seat

AKW 4000 seat

Partner spotlight: **Wenman Healthcare**

Wenman Healthcare demonstrating a transfer aid at MD Support Centre

Since 2024, we've been proud to partner with Wenman Healthcare to help connect our service users with expert mobility equipment advice and support.

Based in Barford, Warwickshire, Wenman Healthcare is a family-run business that has been helping people maintain their independence since 1983. With more than 40 years of experience, they are trusted by individuals, families, carers, and healthcare professionals to provide expert advice, information, and high-quality mobility solutions for disabled and older people.

After starting out by supplying wheelchairs for the Whizz-Kidz charity, Wenman has grown to offer a wide range of mobility and daily living equipment. Their products include wheelchairs, mobility scooters, specialist seating, riser recliner chairs, profiling beds, hoists, walking aids, bathroom equipment, and home adaptations.

The Wenman team has received training from Muscular Dystrophy Support Centre at our Coventry Centre and understands the unique challenges faced by people living with muscular dystrophy and related neuromuscular conditions. They work closely with each individual to understand their needs and identify equipment that can support their independence, comfort, and quality of life.

Importantly, their support doesn't end once equipment has been purchased. They continue to provide ongoing advice and assistance to ensure equipment remains suitable as needs change over time.

Wenman Healthcare takes a personalised approach, working with people to understand their individual needs and circumstances. Through showroom demonstrations, home assessments, equipment trials, servicing, repairs, and ongoing support, they aim to ensure that every customer receives the right solution for their individual circumstances.

As well as supplying equipment, Wenman Healthcare provides information and advice for people living with neuromuscular conditions. Their team can offer guidance on aids and equipment that may support independence, comfort, and day-to-day living. Their website also features a variety of helpful resources.

As a valued partner of Muscular Dystrophy Support Centre, Wenman Healthcare also supports our work through a donation scheme. When Muscular Dystrophy Support Centre service users or carers make a mobility equipment purchase of more than £250 and mention the Centre, Wenman Healthcare will make a donation to the charity.

So, if you're considering purchasing mobility equipment, please remember to mention the Muscular Dystrophy Support Centre, even if you are buying something unrelated to MD. Not only will you receive tailored expert advice and support, but your purchase will also help us continue to provide vital services for people living with neuromuscular conditions.

We're also delighted that members of the Wenman Healthcare team will be joining us at our Summer Social. They will be bringing along a selection of aids and equipment for visitors to see firsthand, providing a great opportunity to ask questions, explore different options, and find out more about the support available.

Wenman Healthcare will also be delivering a Wellbeing Hub session on choosing mobility equipment to help maintain independence. The session will offer practical guidance on selecting equipment that suits individual needs and lifestyles, with further details to be announced soon.

To find out more about the support they can offer, go to wenmanhealthcare.co.uk

Share your thoughts!

What’s your must-have aid or piece of equipment?

The right piece of equipment can make a huge difference to everyday life, whether it's a mobility aid, bathroom adaptation, kitchen gadget, travel accessory or something completely unexpected.

We're looking for recommendations from people in our community. What equipment has helped you maintain your independence, save energy, or make daily tasks easier?

Tell us what it is, why you chose it, and the difference it has made. Your recommendation could be featured in a future issue of the magazine.

Email communications@mdsupportcentre to get involved.

Working together to support emotional wellbeing

At the Muscular Dystrophy Support Centre, we know that wellbeing is about much more than physical health. Living with a neuromuscular condition can bring changes and challenges that affect every aspect of life, including emotional wellbeing.

That's why we're pleased to be working with **Emotional Respite**, a specialist counselling service founded by Helen Rutherford, who lives with Spinal Muscular Atrophy. Through her own experiences, Helen recognised the importance of accessible emotional support for disabled people, people living with long-term health conditions, carers, and family members.

Like us, Emotional Respite believes that support works best when people feel understood. Their team of qualified counsellors combine professional expertise with lived experience of disability, illness, and caring responsibilities, bringing a unique perspective to the support they provide.

Find out more about Emotional Respite at www.emotionalrespite.co.uk. Your therapist can also refer you for support - speak to our team to find out more.

We're delighted to be welcoming Emotional Respite to our Wellbeing Hub on 7 July, where they will lead a session exploring how to live well and manage mental health and change when living with a progressive condition.

The session will provide an opportunity to reflect on the emotional impact of change, discuss strategies for maintaining wellbeing, and learn more about the support available. As with all our Wellbeing Hubs, we hope it will be a welcoming space where people can learn, connect, and share experiences. Find out more at bit.ly/emotional-respite-tix.

All of Emotional Respite's services are delivered online, helping to make support more accessible for people who may find travelling difficult or who prefer to access help from home.

We look forward to working together and continuing conversations about the importance of emotional wellbeing within our community.

Welfare benefits

Adam's Top Tips!

We recently held a Wellbeing Hub on applying for welfare benefits, led by benefits adviser Adam Booth. Here are Adam's top tips to support your application.

1. ### Be honest and detailed

   Describe how your condition affects you most of the time, including pain, fatigue or distress

2. ### Link to criteria

   Assessment descriptors for many welfare benefits, particularly PIP, are available online. Review the ones relevant to your circumstances and tailor your answers accordingly.

3. ### Provide copies of evidence

   While some applications ask for your consent to contact your healthcare providers for evidence, they may not actually do this. It is crucial that you send copies of important evidence with your form.

4. ### Keep records

   Keep copies of all documents sent alongside forms, and take notes of phone calls for reference and follow-up.

5. ### Take your time

   During assessments ask for clarification if questions are unclear, and bring someone for support if needed.

To watch a replay of the session in full, go to mdsupportcentre.org/service-user-resources.

Jono goes the distance

In April, Jono Whitehead took on the challenge of completing London Marathon to raise funds for Muscular Dystrophy UK, completing the race in 7 hours 30 minutes. He shares his experiences with us.

Last year, when the London Marathon was on, I saw a couple of friends talking about it and then completing it. I remember thinking, "I could do that."

A week later, after watching loads of videos from people who had taken part, I decided I definitely wanted to give it a go. I knew my chances of getting a place through the ballot were pretty slim, so I got in touch with Muscular Dystrophy UK and was lucky enough to secure a charity place.

My brother joined me as a support runner, so we took on the challenge together.

Training in all weathers

Training started just before Christmas and lasted for around 19 weeks. It was hard work, not just because of the miles but because it felt like it rained almost every day. For two months, nearly every training session was either in the rain or after it had rained, which meant constantly dealing with wet wheels and getting soaked.

I won't pretend I loved every minute of training. Mostly, I was just tired. Looking back at my training plan, I didn't quite hit every distance I was supposed to, but I was consistent and stuck to the three sessions a week as much as I could.

The marathon itself was incredible. The thing I'll remember most isn't the distance. It's the atmosphere. For seven and a half hours, people were shouting my name. Everywhere we went there were crowds cheering, clapping and encouraging us. The support was unbelievable.

At one point I got a bit too excited by it all and nearly came out of my chair. I wasn't paying enough attention, hit a raised section of pavement where a bollard had been removed and my back wheels lifted off the ground. Thankfully, I managed to stay upright and carry on.

Crossing the finish line

Crossing the finish line felt great, although by that point we were completely exhausted. It wasn't a huge emotional moment. It was more a sense of relief and achievement. We'd done it. I've always tried to stay active. I regularly take part in parkruns, I cycle using a handbike attached to my wheelchair and I play wheelchair basketball.

Taking on a marathon was something completely different, though. It pushed me further than anything I've done before.

One of the things that made such a difference during training was the support I received from the team at the Muscular Dystrophy Support Centre. I had regular soft tissue treatment on my shoulders and back, and honestly, I couldn't have done it without that support.

The team understands the importance of helping people stay active, whatever that looks like. For some people, staying active means being able to cook a meal independently. For me, this time, it meant completing a marathon.

Alongside the challenge itself, I was also fundraising for Muscular Dystrophy UK. At the time of writing, I've raised £3,401 thanks to the generosity of friends, family, colleagues and supporters. I'm incredibly grateful to everyone who donated.

People often ask whether I'd do another marathon. The truth is, I'm not sure. It was an amazing experience, but it was also one of the toughest things I've ever done.

What I do know is that staying active matters. That doesn't have to mean taking on a marathon. For some people it might be a walk, a swim or a weekly exercise class. For others it might simply mean finding a way to keep doing the things they enjoy.

When I first watched those runners last year and thought, "I could do that," I had no idea where it would lead. Nineteen weeks of training, seven and a half hours on the course and £3,401 raised later, I'm proud that I gave it a go and saw it through to the finish.

It's something I'll remember for a very long time.

Share your story and you could be featured

We're always keen to share real stories in our magazine, website, social channels, and blog.

It could be your journey, a recent achievement, some advice or helpful tips for others, or how the MD Support Centre has supported you. Your story can help others feel connected, raise awareness, and even support future funding.

Email communications@mdsupportcentre.org to get involved.

Good news: More therapy appointments available

We're pleased to share that recent additions to our physiotherapy team have enabled us to increase the number of therapy appointments available across our services, helping more people access specialist support.

We now have increased availability in Coventry on Mondays and Fridays, along with additional clinics in Leicester, running one Monday and one Saturday every four weeks.

Our Tipton clinic schedule has also changed, with clinics now running every Tuesday, alongside alternating Wednesday and Thursday sessions.

From July, our MoveWell satellite service will also be open five days a week.

A top secret surprise for Uncle Saj

Akal's story

Last year, 11-year-old Akal Singh Sehra and his younger brother Naryan raised money for the Muscular Dystrophy Support Centre as part of a special surprise for their uncle Saj. Here, Akal shares the story in his own words.

Fundraising for My Uncle Saj

Hello, my name is Akal Singh Sehra, and I'm 11 years old.

On 6 October 2025, me and my brother had the privilege of helping to raise money for the Muscular Dystrophy Support Centre at Caffeine & Machine in Stratford-upon-Avon. The event was organised for my Uncle Saj, who has been living with muscular dystrophy for a number of years.

Muscular dystrophy is when your muscles deteriorate over time. My Uncle Saj, who now uses a wheelchair, is such a nice person. He teaches me lots about cars and editing, and he is always smiling.

A top secret surprise

At the time, the event was top secret, so I couldn't tell anyone what was happening. Now I can finally share the full story.

The surprise was organised by the TV show Car SOS. They arranged for my uncle's old car, which he had owned for 30 years, to be repaired and restored before being revealed to him in a special surprise.

I was super nervous on the day, but also really excited for Uncle Saj. Me and my brother Naryan, who was five at the time, arrived early and collected our fundraising buckets before Uncle Saj got there. Luckily, my school let me have the day off because I was helping with the fundraising, so thank you to St Michael's CE High School.

We walked around speaking to people and asking for donations. If people didn't have cash, we gave them leaflets so they could donate online if they wanted to. Everyone was so generous and friendly. We were really nervous at first, but we ended up enjoying it a lot.

The big reveal

After a few hours, we had to hide because Uncle Saj was nearly there. My dad and Uncle Shan had helped organise the surprise, and we couldn't let him see us. We stayed inside the restaurant and even managed to carry on fundraising while we were hiding, with some of the staff making donations too.

When Uncle Saj arrived, everyone acted normal until it was finally time for the surprise. He was so shocked when we all came out. I think he was having the best time in the world. All I could think about was how happy he was, and that's what I really cared about. Him being happy means the world to me.

The biggest surprise of all was seeing his old car restored and back on the road. Because of his poor health, he never thought he would see it like that again. He was absolutely speechless. It was amazing to see him so happy and to realise that Car SOS had done all of this after my dad had written to them.

We carried on fundraising afterwards, and there was such a good atmosphere around the whole event. Everyone seemed happy, and it was a really feel-good day. By the end, me and Naryan felt proud that we had helped raise money for the Muscular Dystrophy Support Centre.

Altogether, we raised £435 on the day

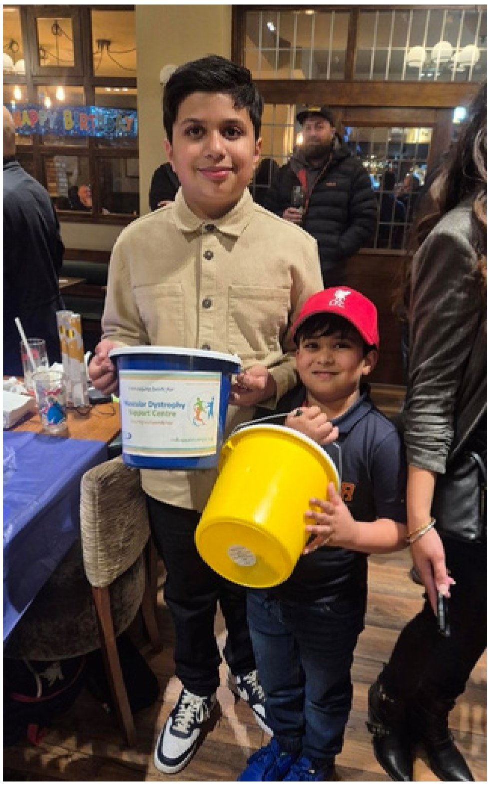
Seeing it on TV

The episode was shown on TV on 2 April during the Easter holidays. To celebrate, a big party was organised so everyone could watch it together. It brought back lots of great memories, and it was so nice seeing Uncle Saj on TV enjoying the surprise. He even wore a custom hoodie with his car on it.

As everyone was meeting up again, me and my brother decided it would be a good opportunity to do some more fundraising. We got our buckets out once again and raised even more money for the charity. I'm not sure exactly how much we raised that time, but I know it is going to a good cause.

It was an amazing experience, and I'm really proud that me and my brother were able to help raise money to support people living with muscular dystrophy.

Thank you for reading my story. I hope you enjoyed it.



Congratulations and thank you to Akal and Naryan from everyone at MD Support Centre!

Community connections:

REGISTERED CHARITY NUMBER 1112370
COMPANY NUMBER 05574584

CMTUK

Supporting people living with Charcot-Marie-Tooth

cmt.org.uk

What is CMT?

Charcot-Marie-Tooth disease (CMT) is a group of conditions that damage the peripheral nerves.

These nerves run from the spinal cord to the extremities and are responsible for passing on commands from the brain to the muscles in the arms and legs, and for passing information back to the brain about sensations, such as pain, heat, cold and touch.

Because of the nerve damage, people with CMT may find that their muscles particularly in their hands, arms, feet and lower legs become weaker over time, and the sense of feeling can become dull or numb in the same areas.

Rarer symptoms can include breathing problems, including sleep apnoea, scoliosis, hip dysplasia and vocal cord paralysis.

Can cause chronic pain and fatigue.

It is the focus of research in both genetic causes and possible treatments.

Hereditary Neuropathy with Pressure Palsy (HNPP) is a condition that is linked to CMT with comparable symptoms.

Who we are?

CMTUK is the UK's only national charity dedicated to supporting people living with CMT and related conditions.

What began as a small support group has grown into a thriving national community of people living with CMT, their families and carers, healthcare professionals, and researchers.

We are a membership-based organisation committed to improving lives, raising awareness, and connecting the CMT community across the UK — because nobody should face CMT alone.

UK CMT Research Database

Led by Professor Mary Reilly's team at the Centre for Neuromuscular Diseases, Queen Square, UCL, this database helps researchers understand how many people have CMT, what types they have, and how the condition affects daily life.

By registering, you can be kept updated on research opportunities, questionnaire studies, and potential new treatments.

Join the CMT Register

Why become a CMTUK member?

- Regular news
- Research updates
- Regular ComMenT magazine
- Dedicated Helpline
- Information Leaflets
- Guidance on benefits, orthotics, physiotherapy, and more
- Events and Conferences
- Access to online support groups and local meetups
- CMT Alert Card for medical appointments and emergencies
- CMT Kids(11-17yo) and Big Kids
- Information for Professionals

Donation based membership is available to everyone affected by CMT / HNPP in the UK.

How we support people with CMT

Information and resources

We provide reliable, accessible information about CMT, practical guidance for daily life, and regular updates on the latest research developments. Members also receive our ComMenT magazine and email updates packed with real-life stories and inspiration from across the community.

Support when you need it

You can call or email our friendly helpline team any time you need help. Whether you want to chat, ask about symptoms, or need advice for a carer, school, or employer, we are here for you. Members also receive a CMT Alert Card, handy for medical appointments or emergencies.

Practical guidance

Benefits and support systems can feel overwhelming. We help members navigate PIP, Attendance Allowance, Blue Badges, and more, so you do not have to figure it all out on your own.

Support for children and young people

We run camps, trips, and online communities just for young people with CMT. A safe space to make friends, have fun, and know they are not alone.

Events and Conferences

Our annual conference brings together CMT specialists, researchers, and the wider community for a day of talks, Q&As, and connection. We also run health and wellbeing days, regional support group meetups, online support meetings, children and family events, and awareness campaigns throughout the year.

Get involved

Become a member, join a support group, attend an event, volunteer your time, or fundraise for the community.
Every contribution makes a difference.

Whether you are newly diagnosed, have lived with CMT for many years, or support a loved one, there is a place for you within the CMTUK community.

cmt.org.uk

Join the CMT Register

Find us

/CMTUK2
@charcotmarietoothuk
/@CMTUnitedKingdom
linkedin.com/cmtuk

CMTUK Helpline ☎ 0300 323 6316

☎ Office: 01202 474203

✉ enquiries@cmt.org.uk

Community connections:

Spinal Muscular Atrophy (SMA) UK is a national charity dedicated to supporting everyone affected by SMA, a rare genetic condition that causes progressive muscle weakness. We work closely with individuals, families, and professionals to ensure that no one faces SMA alone.

Our support spans every stage of the journey. We provide personalised one-to-one support, practical advice, and emotional guidance through our Support Team. We offer grants to help families manage the additional costs of living with SMA, and we create opportunities for connection through events and peer support networks. Alongside this, we fund research, campaign for access to treatments and care, and work to raise awareness of SMA across the UK.

We also offer a wide range of trusted information and resources, including guides on diagnosis, care, education, and transitioning into adulthood. You can explore these at: https://smauk.org.uk/support-information/ and access practical information here: https://smauk.org.uk/living-with-sma/

Whether you are newly diagnosed, living with SMA, or supporting someone who is, SMA UK is here to provide expert information, compassionate support, and a strong community.

Support

Community Support – information about the support we offer is here: smauk.org.uk/support-information/support-for-you

Rareminds, free, confidential counselling for anyone affected by SMA 18+. Find more details and request support at: smauk.org.uk/support-information/support-for-you/counselling-service

We have information on many topics on **Living with SMA** here: smauk.org.uk/living-with-sma/

Our **resource hub** is here: smauk.org.uk/support-information/support-for-you/resource-hub

SMA UK Grants

Felix Grants

FG 1 is for support with accommodation and travel for any family attending an NHS appointment for treatment. (we are unable to offer this grant for private health appointments)

FG 2 is to support pieces of equipment (not supplied by statutory services) such as car seats, small aids, portable hoists and more. Our team is happy to talk through with you any application you're considering.

SMArt Moves offers grants to support with the purchase of mobility equipment and can help with repairs, batteries, etc.

X8 Hire – the X8 is free to anyone who wishes to use it, just book hire dates into the on-line calendar.

The Wave Project – one free adapted surfing experience in locations across the UK.

Find more information and application forms at:
smauk.org.uk/support-information/sma-uk-grants-for-the-community

Connection

Community Connections - Find links to our WhatsApp community groups here:
smauk.org.uk/community-networks-voices/

Our events for this year are here:
smauk.org.uk/connect-with-the-community/community-meet-ups/

C**ommunity podcasts and webinars** can be found here:
smauk.org.uk/connect-with-the-community/community-podcasts-videos/

Find out more:

smauk.org.uk

A big thank you to CMT UK and SMA UK for helping us showcase some of the support available to people living with neuromuscular conditions.

The charities are part of a wider network of organisations supporting our community. From condition-specific charities such as FSHD UK to organisations like Emotional Respite, Pathfinders Alliance, and JPT Grants, there is a wealth of support, advice, and opportunities available.
In future editions, we'll continue exploring the organisations, services, and resources that can help people living with muscular dystrophy and related conditions thrive.

What's on

July

Wellbeing Hub: live well through change - get expert advice from Emotional Respite disability counselling service on exploring ways to live well through change. Online, 7 July, 6.30pm

Summer social - Join us at our Coventry centre for a fun summer social event. We'll have crafts, activities, exercise taster sessions, hand therapy demonstrations, and much more. Bring your loved ones, bring a picnic and join us for some summer fun. Coventry, 11 July, 11am

August

Wellbeing Hub: the stress container - hear from the Wolves Foundation about how to manage stress using the stress container model. Online, 6 August, 6.30pm

Adapting to Change Peer Support Group - Connect with others living with MD. Hear personal stories and advice on navigating the changes that come with muscular dystrophy. Online and in person, 12 August, 4.30pm

Focus group - join our CEO Zoe Richardson and have your say on the future of our charity. Online, 25 August, 6.30pm

September

Wellbeing Hub: sleep - expert information and advice on improving your sleep. Online, 10 September, 6.30pm

Adapting to Change follow-up - an opportunity to talk about how things have been since the last peer support session, discuss things you may have tried, and reconnect with others. Online, 6pm

Find details of all our events at bit.ly/MDSC-joinanevent

Did you know?

The difference between our Wellbeing Hubs and Adapting to Change Group

Our **Wellbeing Hubs** are online webinars led by external speakers who are experts in their field. Working with trusted partners, we bring you professional information, advice, and guidance on topics that support wellbeing, independence, and everyday life with a neuromuscular condition.

The **Adapting to Change Peer Support Group** offers something different. Led by people living with muscular dystrophy, it's an opportunity to connect with others who understand the day-to-day realities of living with a neuromuscular condition. Share experiences, exchange practical tips, and learn from the lived experiences of people who have faced similar challenges. While it's not a source of professional advice, it provides valuable peer support, understanding, and encouragement.

Stay strong with MD Support Centre

Online exercise classes

Seated exercise, Tuesday 2pm – led by Ulrike or Siobhan
Suitable for all levels, this gentle seated session focuses on upper and lower body movements, posture, and core stability, helping you build strength and confidence at your own pace.

Seated/standing mix, Thursday 10.30am – led by various therapists
An advanced class, this dynamic session combines standing and seated exercises, focusing on cardio, posture, balance, core strength, and range of movement.

Mind, Body and Movement, Thursday 5.15pm – led by Rewati
Unwind in a 45-minute session blending gentle stretching and deep relaxation through Yoga-inspired techniques Release tension, improve breath control, and cultivate a sense of calm.

Breathing and Mindfulness, every two weeks, Tuesdays / Wednesdays 2pm – led by France
Explore breathing techniques and exercises designed to enhance respiration and promote a more natural breathing rhythm. We also have limited in-person spots for these classes that must be booked in advance. Please check our website for upcoming dates.

Find details of all our online classes at mdsupportcentre.org/online-services

Experience the fun of our Aquatic Exercise classes

Join us this summer for our popular Aquatic Exercise classes - Tuesday afternoons at the Xcel Centre in Coventry from 21 July.

Experience the benefits on your mental and physical health as we guide you through a series of enjoyable activities that benefit your strength, flexibility, core stability, and heart and lung health.

Led by our specialist physiotherapists, you'll exercise alongside others living with muscular dystrophy in a dedicated pool session.

Speak to your physiotherapist to find out if it's suitable for you or call our Reception team to book!

Share your holiday recommendations

Have you discovered a great accessible holiday destination? We'd love to hear about it.

Finding reliable information about accessible travel can be challenging. That's why we're looking for people living with muscular dystrophy and related neuromuscular conditions to share their experiences of holidays, short breaks, and days out that have worked well for them.

Whether you've enjoyed an accessible UK staycation, a relaxing cruise, a city break, or an adventure further afield, your recommendations could help others plan their next trip with confidence.

We're particularly interested in hearing about:

- Accessible accommodation
- Transport and travel experiences
- Attractions and activities
- Wheelchair access and mobility support
- Helpful facilities or services
- Tips you wish you'd known before you travelled

We'll use your experiences to create a feature on accessible holiday destinations in an upcoming edition of our magazine, and we hope this will be the start of a valuable community resource that helps people discover accessible places to visit.

If you'd like to share your recommendations, please get in touch with us at [contact details] and tell us a little about where you went and what made it accessible for you.

Your experience could inspire someone else's next adventure.

Thank you for your support

Every day, we see the difference that support from our community makes.

Thank you to everyone who supports our work, whether by making a regular donation, giving after a therapy appointment, organising a fundraising event, taking out a collection tin, shopping through fundraising schemes, buying from our shop, or helping to spread the word about what we do.

Every act of support helps us continue providing therapies, wellbeing services, and practical support for people living with muscular dystrophy.

We're especially grateful to those who choose to support us at significant moments in their lives, whether by fundraising at a celebration, donating in memory of a loved one, or leaving a gift in their Will. These thoughtful gestures help ensure our support is here for future generations.

The Muscular Dystrophy Support Centre exists because of the generosity of people who care about our community. To everyone who supports us in any way, thank you. Your kindness and commitment make a lasting difference to the lives of the people and families we support.

Your connections can make a difference

At the Muscular Dystrophy Support Centre, we are incredibly grateful for the generosity of the individuals, businesses, trusts and foundations that support our work. Sometimes, however, those opportunities come from the people who know us best – our service users and families.

Recently, one of our service users, Rob, approached us with a wonderful opportunity. Rob is also a trustee of a small, local charitable foundation and suggested that they might be interested in supporting the Centre's work. Following an application from us, the foundation very kindly awarded us a grant of £2,000 to support our work in Birmingham.

That funding will help us continue providing the vital support, advice and services to people living with muscular dystrophy and related neuromuscular conditions. As costs rise, independent charities like us need all the help we can get.

Rob's story is a great reminder that everyone has connections that could open doors for us. You may work for a company that has a workplace giving programme, know someone involved with a local trust or foundation, be a member of a community group, or volunteer with an organisation that supports good causes.

Many businesses offer grants, sponsorships, match-funding schemes or charity partnerships. Likewise, there are thousands of charitable trusts and foundations across the UK that rely on recommendations from people within their local communities.

If you know of a business, trust, foundation, community group or workplace that may be interested in supporting the Muscular Dystrophy Support Centre, we would love to hear from you. An introduction, recommendation, or simply pointing us in the right direction could help us secure funding that enables us to continue supporting you, your family, and others living with muscular dystrophy.

You don't need to make the ask yourself – Jamie, our Head of Fundraising and Income Generation can do that. Often all it takes is a connection.

If you think you may be able to help, please email fundraising@mdsupportcentre.org or pop your head into the Coventry office and ask for Jamie. Together, we can make sure everyone with MD gets the support they need.

Thank you to Rob for helping make this possible and for demonstrating how every connection can have an impact.

Stay connected

To hear about our fundraising, events and other news, sign up to our newsletters at bit.ly/MDSCsubscribe

Find us on social media

mdsupportcentre

@mdsupportctr

muscular-dystrophy-support-centre

Join our vibrant Facebook group as a way to connect with other service users, share ideas and support, and to ask questions. It's also the perfect place to chat with people who understand.

www.facebook.com/groups/mdscsocial

Fundraising opportunities

If you'd like to support our charity, here are some ways you can help.

- Sign up to become a regular giver
- Hold a fundraising event
- Make a one-off donation
- Take a collection tin to a local shop or pub
- Take on a challenge
- Shop to donate using Give as You Like or Easy Fundraising
- Ask for donations in lieu of gifts
- Fundraise on social media
- Donate after your therapy
- In-memory collection
- Leave a gift in your Will
- Become a corporate supporter or ask your employer if they support charities

For more information or support on fundraising for MD Support Centre, go to mdsupportcentre.org/donate or email fundraising@mdsupportcentre.org

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Thank you for reading! Our next magazine will be published in November/December 2026.
To contribute, contact communications@mdsupportcentre.org

mdsupportcentre.org

02476 100770 | getintouch@mdsupportcentre.org

MD Support Centre is a working name of NMC Midlands Ltd. Charity no. 1148855