



MD Support Centre Magazine

Spring / Summer 2025

Reclaiming life through
wheelchair tennis



Limitless Travel
takes on fundraising
challenge



Mobility and
volunteering with
Keith and Pam

Plus:

- Mia makes a splash
- Accessible holidays
- In remembrance of Gurjinder Birdi
- Adapting to Change
- and more..!



Making fashion
accessible





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Pack your picnic baskets for our

Summer Get-Together

Saturday 28 June | 12 - 4 pm |
Coventry HQ

In lieu of an Open Day this year, we're holding a relaxed summer get-together to socialise and have fun.

So please join us for a relaxed afternoon of fun, food, and (hopefully) sunshine. Bring a picnic, a blanket, and your family or friends and enjoy plenty of good company and laughs.

We can't wait to see you there!

Scan here to learn more or go to
mdsupportcentre.org/events





A Note from our CEO Sarah-Ann Moore

Welcome to the Spring / Summer edition of the MD Support Centre magazine!

As always, in this edition of the magazine, we have personal stories from our amazing service user community – of fundraising efforts, sporting exploits, and volunteering impact – as well as all the usual updates on our Centre and therapies.

With Wimbledon approaching, my thoughts usually turn to all things tennis, and I loved reading about Sarah Bard's wheelchair tennis journey (p4). Equally impressive are our amazing service users who are volunteering to improve the experience of people with disabilities, whether to improve the accessibility of fashion (p14) or public spaces (p16) for those in wheelchairs.

At MD Support Centre we always love hearing and sharing the experiences of our amazing service user and wider community. If you have a story to tell, please contact us at communications@mdsupportcentre.org. You could help others to feel less alone, shine a light on our work, or even unlock vital funding for our charity.

As you may have heard, sadly this will be my last MD Support Centre magazine as I am leaving the Charity at the end of June. The last five years have passed in the blink of an eye, and I am deeply privileged to have

contributed to the journey of this great charity.

We have grown and changed enormously over the last five years, expanding our satellite clinic network, moving into a new home at Westwood House, growing our therapy team, and, most importantly, being able to offer more support to more people with MD. I will leave with lots of fond memories and the knowledge that our small but mighty team will continue to do great things for our service user community.

Of course, although I will be leaving my role as CEO, I will be continuing to support the Charity! In particular, I will be returning in September to join service user Donna, and physiotherapist Lynn, on our 300-mile London to Paris cycling challenge:

www.totalgiving.co.uk/mypage/sarahannmoore.

Thank you for all of your support, and I hope that you enjoy this issue of our magazine.

With thanks and best wishes,



A word from Ruth Hereford, Chair of Trustees

Sarah has been an important part of the team since her appointment in 2020, which marked the first step in our five-year

Transforming Access to Therapies strategy and project, supported by funding from The National Lottery.

Over the past five years, she has supported the development of our charity and led the delivery of this project with dedication and care. Her work has helped us grow tremendously, and we are truly thankful for her substantial contribution and ongoing commitment.

The recruitment process for her successor is now underway. In the meantime, we remain focused on delivering the specialised therapies and support that help you maintain your independence and quality of life. Your continued input as service users is vital in shaping the development of the Centre.

As we look to the future, a key priority in 2025 will be internal consolidation following the rapid growth of recent years. This will allow us to strengthen our foundations, enhance sustainability, and prepare for the next stage of our journey.

On behalf of everyone at MD Support Centre we will miss Sarah and wish her all the best. Please join us at our summer get-together on Saturday 28 June to say farewell.

Reclaiming life through wheelchair tennis

Sarah Bard shares her experiences of growing up with CMT and how discovering disability sport changed her life.

I grew up in a village just outside London. My dad was a vicar. My childhood was filled with singing in church and selling raffle tickets at fetes. I was born with Charcot-Marie-Tooth (CMT) disease, a neuromuscular condition that wasn't well understood at the time.

I had to manage it as best I could. Doctors told me my chronic pain was mostly psychosomatic until I was 27, when I finally saw a specialist in London familiar with my type of CMT. I honestly don't remember ever being completely pain-free. I've had multiple operations, both as a child and an adult. Knowing my mobility would decline, I travelled as much as I could once I was old enough – often funding trips by singing.



Accepting change

On my 30th birthday, I was leaving a hotel in Nottingham when I fell down the stairs and fractured my ankle. I didn't want to miss my party, so my cousin and uncle carried me to the venue. My friends and family thought I was making a grand entrance – I guess I was. I spent the night with my foot propped up while everyone came over to see me. I felt like Birthday Santa. (I went straight to A&E once the party ended.)

After I came home from the hospital, reality hit hard. My condition had been progressing throughout my 20s, and I'd already damaged the ligaments in my other ankle. I'd just started using a stick, and now my 'good' ankle was broken. I suddenly had no working feet to carry my weight and found myself using a wheelchair. Because my hands are also affected, I couldn't push myself around or even open the heavy doors to leave my flat. I became housebound. Going from being an independent, sports car-driving woman to relying on others to get out of the house was a massive shock.

For a few years, my life shrank. I rarely left the city except for medical appointments. I gained four stones and struggled with my mental health. About eight years ago, things changed. My friend Eric suggested we attend a Paralympic 'come and try' event. I tried a few sports, but wheelchair tennis was the one that clicked. It was so difficult – pushing the chair, tracking the ball, intercepting it, and hitting it back. It felt impossible, and I loved it. I was invited to beginner sessions at Nottingham Tennis Centre.

Gaining confidence - the perfect win

Eventually, I raised money for a Tri-Ride, a powered add-on for my wheelchair that gave me back some independence. I got funding for a court chair and started entering competitions as a novice player. Winning my first match was an incredible feeling. It wasn't just about the win – it was about proving to myself that I could still compete. More importantly, my first tournament was the first time I was in a room full of people with disabilities. We all had different conditions and ways of managing, and everyone had tips to share. The players were so kind, and I learned so much. We didn't always talk about our disabilities, but we constantly picked up advice from one another. That community has really helped me move forward.

One of the things I love about wheelchair tennis is that although there are standard techniques, we each get there in our own way. I'll never have strong hands or wrists, so I tape them up and use sweatbands for support. I can't grip my wheels well because my fingers are weak, so I wear gloves and tacky bandages. One day I might have to tape the racket to my hand, but for now, I can hold it in my glove and generate power from my core. All of this has come from other players' tips, trial and error, and coaching.

As I improved and moved to the Women's Open category, my confidence grew, my health improved, and my mindset shifted. I lost all the weight I'd gained after my fall. My disease continues to progress, and I'll always need support for daily tasks, but my fitness keeps improving. I have neuropathy in my hands and feet, but with support, my core strength continues to develop. One of my consultants even said I was 'defying the textbooks.'

The perfect pairing – physiotherapy and sports

Being referred to the MD Support Centre has been a real gift. After an assessment, I was told I'd managed to achieve more than many people at my stage of the disease, thanks to the tennis. Dan Foley, my physiotherapist at the Centre, has been genuinely brilliant (though don't tell him I said that!). I've learned more from him about my condition than I ever had before.

He explained that not only are my feet deformed and some nerves trapped, but many of my peripheral nerves are misfiring and interpreting everything as pain. He's given me exercises to improve my balance, flexibility and pain management, and he helps with recovery after training or tournaments. He explains what's going on in my body with humour and interesting facts thrown in. I feel really lucky to be under the Centre's care. They've been so generous with their time, and Dan just seems to know what I need and how to help.

As you've probably gathered, I'd encourage everyone to try disability sport. There are so many options – and you don't even need to be a regular wheelchair user to play wheelchair tennis. It has quite literally changed my life. It gives me goals, helps me live better with my disability, and introduces me to a whole range of people I can learn from. Thanks to wheelchair sport, I'm building muscle where I can and slowing muscle loss where I can't.

I'll keep pushing myself and hitting my targets. As long as I'm improving as a player – and as a person – I'll be doing it.



Do you have a story to share? If so, we want to hear from you!

We're always looking for inspiring stories, updates, and experiences to feature in our magazine, website, social media, and blog. Whether it's a personal journey, a recent achievement, or how the MD Support Centre has made a difference in your life, we'd love to help you share it.

Your story could help others feel less alone, inspire others to make a change, raise awareness about our work, and even help secure funding for the charity.

Email communications@mdsupportcentre.org and let's tell your story together.

Therapists share expertise at international events

Lynn and Ulrike will be representing the MD Support Centre at FSHD Connect in Amsterdam in June. Hosted by FSHD Europe in collaboration with the FSHD Society, it's the first European networking event for people living with FSHD and their families.

They'll be leading exercise classes and giving a talk – an exciting chance to showcase our therapy team's expertise and raise awareness of our work on an international stage.

In April, Ulrike also gave a webinar for FSHD University, focusing on how to reduce overuse in certain muscles and improve function in those that are underworking, tailored specifically to people with FSHD.

June Kinoshita of the FSHD Society described it as "A great overview of how each individual needs to think about approaching understanding their body and their exercises."

You can [watch Ulrike's presentation](#) on the FSHD University YouTube channel.



L-R: Lynn and Ulrike with physiotherapists Siobhan and Chandni

Keep moving between therapy appointments

Did you know you can continue working on your strength, mobility, and fitness between therapy appointments?

Independent exercise with Suki

With support from Therapy Assistant, Suki, can access our Shapemaster, THERA-Trainer Tigo and GripAble in a safe, supportive environment. These sessions are designed help you stay active, manage your condition, and maintain the progress you've made in therapy. Suki will be on hand throughout your session to assist with equipment and tailor exercises to your goals.

Interested in getting started? Speak to your treating therapist to find out if independent exercise is right for you.

Join an online class

Don't forget we run a series of drop-in exercise classes to help you boost your health and fitness at home. Sessions include seated and standing cardio, yoga, and breathing and mindfulness.

Head to mdsupportcentre.org/online-services for our current class schedule.



Limitless Travel marks 10 years with huge fundraising challenge

Accessible travel trailblazers, Limitless Travel, are celebrating a major milestone in 2025: ten years of breaking barriers in travel. To mark the occasion, the team is taking on ten ambitious challenges to raise £10,000 for MD Support Centre.

The campaign launched on 31 May with a team climb of Mount Snowdon. Other events taking place include a 100 km cycle in one day, Everest Base Camp treks, virtual mountain walking missions, and more. The campaign is a company-wide effort, with staff, families, and supporters united in raising awareness and funds. The goal is to raise £10,000 for our specialist physical therapies and wellbeing support.

Limitless Travel was founded by Angus Drummond, who lives with muscular dystrophy. It provides fully accessible holidays to over 100 destinations worldwide. The company also specialise in individual and group holidays with tailored care and support options to enable disabled travellers to enjoy their holidays.



Angus explains that he feels a personal connection to our charity, as he has been receiving physiotherapy at our Coventry Centre that help him stay active. He said: “Muscular Dystrophy Support Centre is a cause very close to my own heart and is a fantastic charity in terms of the support and information it provides. To offer this service free of charge is amazing but requires funding and support. I’m delighted we’re able to support them with this. I love the shared synergy between MD Support Centre and Limitless – both are organisations focused on empowering individuals, increasing independence, and ensuring we’re able to have the best possible experiences.”

Ruth Hereford, Chair of MD Support Centre’s Board of Trustees, said, “We’re thrilled and grateful to Angus and the Limitless Travel team for choosing our charity as part of their 10th birthday celebrations. Support like this is vital for small regional charities like ours. As one of only two UK charities providing proactive therapies for people with MD like Angus and myself, MD Support Centre is proud to share Limitless’ commitment to person-centred support that helps people stay independent and live well.”

Diagnosed with muscular dystrophy in his twenties, Angus was told his mobility would decline and he would most likely need to use a wheelchair. He decided to travel the world while he still could. So, he left his job, packed a backpack, and journeyed across 35 countries with his wife.

“I didn’t want to let muscular dystrophy change my sense of adventure. While travelling, I found the support that I needed didn’t exist, and I knew that I had to do something to make a change. I wanted to create a world where, regardless of disability, people could travel without stress, hassle, or fear.”

Since it was founded, Limitless Travel has enabled thousands of people to enjoy holidays around the world. MD Support Centre user, Emily, is about to embark on her fourth holiday with Limitless. She told us, “The therapies and support I’ve gotten from MD Support Centre and Limitless Travel have opened up the world for me and enabled me to live more confidently and actively as my disease progresses. With fellow service users Debbie and Louise, I’m even about to fly for the first time on my fourth trip with Limitless!”

Debbie echoes Emily’s sentiments, saying: “With a diagnosis of Spinal muscular atrophy, I have attended the MD Support Centre for the past 10 years. The treatment I receive is excellent and has enabled me to experience a better

quality of life. Without their expertise, things would be much different. The positivity given and recommendation last year about Limitless Travel meant I went on my first holiday with them, and it certainly won't be my last! The Limitless team of carers, tour managers and staff are fantastic, nothing was too much trouble. Holidays will no longer be a thing of the past – I can't wait for my next one. I'm delighted to hear that Limitless Travel are celebrating their 10th anniversary and are marking the occasion with a fabulous fundraising effort for MD Support Centre."

We are incredibly grateful to Angus and the Limitless Travel team for choosing to mark their milestone year by supporting our charity. Please join us in cheering them on in their fundraising efforts.

To find out more about travelling with Limitless Travel, go to www.limitlesstravel.org.

If you'd like to support their fundraising efforts, visit their JustGiving page at www.justgiving.com/page/limitless-travel.



Mia makes a splash for MD Support Centre

A school project took a heart-warming turn when nine-year-old Mia decided to raise vital funds for MD Support Centre by challenging herself to swim 3,000 metres in under two hours. She reveals that she decided to swim in aid of the MD Support Centre as "her mum has MD, and she wanted to do something good."

Mia's mum Tomomi was diagnosed with Limb-Girdle Muscular Dystrophy some time ago, having recognised the signs after seeing her brother go through similar experiences. She has been coming to the MD Support Centre for two years and says she is grateful for all that the Centre and physiotherapists do for her.

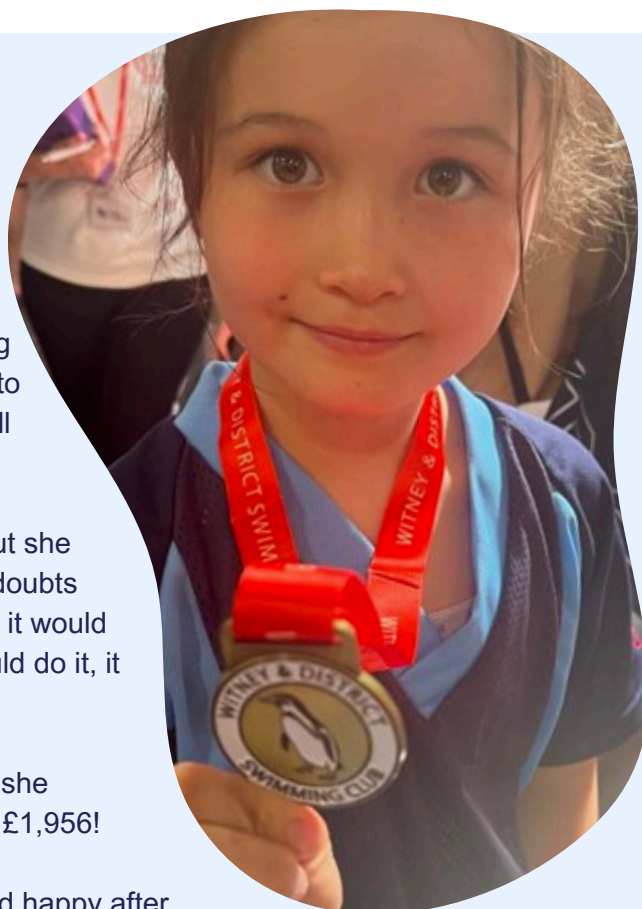
Mia has been an active swimmer since she was three years old, but she had never done a long challenge like this one before. There were doubts whether she could finish the distance in the time frame, or whether it would all be too much. But her coaches were confident that if anyone could do it, it would be Mia.

And they were right – not only did Mia complete the 3,000m swim, she smashed it, finishing in under 60 minutes and raising an incredible £1,956!

Mia confirms it was a hard challenge but says, "I felt very proud and happy after completing it!"

Her family, friends, and swim team are all bursting with pride – and Mia has already inspired others. Her cousins in Japan are now thinking about taking on a similar challenge.

Mia's advice to other young fundraisers? "It is hard, but keep going! You will make it!"





Fundraising update

Thank you!

We would love to say a huge thank you to everyone who has donated to our charity. We could not do the work we do without your support. Here are a few people who have supported us recently.

David Salt - held his annual quiz night, raising £652.

Reg King - hosted a charity golf day at South Staffordshire Golf Course. Reg raised £402.

Nancy and Simon - Held a party, complete with dancers and fire eaters, to celebrate an anniversary and birthday, donating £200 to our charity. They said: "Since Nancy was diagnosed with a long term condition similar to Muscular Dystrophy a referral was made to the MD Support Centre who were kind enough to take her on for physiotherapy to aid her wellbeing. Taher, Mani and Grace have been marvellous. Thus we decided to ask for donations in lieu of gifts and naturally the MD Support Centre were to be a beneficiary. Due to our friends' generosity we have been so pleased to give something back in the process. Keep up the fantastic work."

Andy Collins - held his second skittles night and a golf day at Ullesthorpe Golf Club to raise funds.



Many thanks to **The Rowleys Partnership Ltd** and **Arnold Clarke Community Fund** for their recent donations. The backing of community-focused organisations like these help us to continue providing our much-needed therapies and support.



Do you or your family work for organisations that support charities? Could you connect us so that we may possibly benefit from any charitable activities they undertake? We are also launching a Corporate Fundraising Pack soon to help you spread the word about us. Contact fundraising@mdsupportcentre.org to find out more.

Riders take training up a gear for London to Paris ride

Training is going well for our trio of intrepid cyclists as the countdown quickens to their epic London to Paris bike ride. Donna Scarrott, Lynn Ward and Sarah Ann Moore are taking on the journey in September to raise funds for our work. At time of writing, they have collectively raised £3,759. Find out more and sponsor them at bit.ly/MDSCLondonParis.

Donna is also holding a 12-hour cycle event on 7 June at the Village Inn in Beoley. Riders will cycle continuously from 12pm to 12am. There will also be a coffee morning from 10am and family fun activities throughout the day.



Huge thanks to...

Collection boxes

Everyone who has taken our collection boxes to their local pub, newsagent or small business. Not only do we raise funds for our charity, but we also raise awareness of MD and what the MD Support Centre does. If you would like to take a collection box to a business, please contact Nina or Vicki.

Trusts and foundations

Enormous thanks to all the Charitable Trusts and Foundations who support us throughout the year with grants to fund our work. We really could not deliver our service without this financial support.

Corporate friends

Could your company support our charity? Maybe they run a charity of the year scheme, or employee matched donations. If you think your company could help, let us know who to contact and we can do the rest.

Individual giving

Thanks to those who donate regularly via direct debit. The power of regular giving goes far beyond the pounds and pennies. For us, it means stability – knowing what's coming in each month helps us plan ahead, grow our services, and make a bigger impact over time.

Carol shares why she signed up to become a regular giver:

“My son who has FSHD has been receiving on going support and physiotherapy from the MD Support Centre for 10 years. Knowing how valuable this has been for us and enabling others to gain access to this support network by supporting this charity by donating a small amount by direct debit each month is our small way of saying thank you.”

If you would like to join Carol by donating to us in this way please head to mdsupportcentre.org/donate.

Other ways to help



Sign up to Easyfundraising to raise funds for us when you shop online. When you shop with over 8,000 retailers via Easyfundraising, the retailer sends our organisation a free donation at no additional cost.

[Sign up here.](#)



Hold an in-celebration fundraiser! Instead of presents for a birthday or anniversary, ask people to make a donation instead.

You can even [set up a birthday fundraiser on Facebook!](#)

As a small charity with huge ambition, we're grateful for any support you can give to help us deliver vital services to our growing community.

Got a fundraising idea or fancy a challenge? We'll support you every step of the way. Get in touch with Nina at our HQ or visit mdsupportcentre.org/fundraising.

“You’ll be amazed how it can open up your world.”

How Pam and Keith are opening up their world through mobility aids and volunteering.

When Pam was diagnosed with FSH muscular dystrophy at the age of 60, she decided it wasn’t going to control her life. Now 75, she reflects on the past 15 years with ownership and determination. “It has to live with me, not the other way around,” she says. For Pam, maintaining control over what she can and can’t do has been crucial to her positive mindset.

Pam’s husband, Keith, has long understood the importance of balancing independence and support. Having grown up helping his father manage multiple sclerosis, he says, “From a young age we had to work together as a family. That’s stayed with me.”

Empowerment and proactivity

Pam and Keith have developed a philosophy that centres on empowerment. Pam is open to asking for help when she truly needs it and encourages others to be proactive about exploring mobility tools and aids. “People used to tell us they were struggling, and we’d ask, ‘Have you tried a stick? Or a three-wheeler?’ And they’d say, ‘Oh, I’m not ready for that.’ But if you used it, you could do more,” she says.

One of Keith’s favourite memories is of Pam on top of Mount Snowdon, gazing out across the view after scaling the mountain in her mobility scooter. “If Pam hadn’t been willing to try that scooter, she’d never have seen this view,” he says. For them, mobility aids aren’t a symbol of limitation - they’re a key to freedom.

Their belief in trying new things and encouraging others to do the same has extended to fellow holidaymakers. On one trip, they lent Pam’s scooter to a woman with Parkinson’s. “Her husband told us, ‘I’m so glad she tried this now, she won’t hesitate when she needs it,’” Pam recalls. That woman now owns a scooter of her own.

Beyond mobility, Pam and Keith find fulfilment through volunteering. A visit to a National Trust property sparked a conversation with staff about joining their volunteer team, and the couple has been involved ever since.

Keith serves as a house guide, while Pam works on the



welcome team. “You log in, choose your shifts, and do as much or as little as you want,” Keith explains. The flexibility allows them to contribute at their own pace. In return, they receive a volunteer pass and discounts, but more importantly, a sense of belonging.

Community belonging

Volunteering has also brought Pam and Keith into a supportive and inclusive community. “They work with you and value your input,” says Pam, who has even been asked for feedback on access improvements. “They’ve never made me feel like I was just ticking a box - they genuinely care about making things work for everyone.”

Keith agrees, adding, “The staff and other volunteers are so welcoming. You’re part of a team that wants you there. They give you the time to learn the ropes and encourage you to share your ideas.”

The variety of roles available means there’s something for everyone, regardless of mobility or experience. From greeting visitors and supporting events to guiding tours or helping behind the scenes, there are plenty of ways to get involved.

Many National Trust properties have also made significant efforts to improve accessibility. Visitors will

find mobility parking, accessible toilets, step-free routes, hearing loops, and volunteer-driven buggy services for getting around the grounds.

Some historic houses offer virtual or touchscreen tours for rooms that aren't physically accessible, ensuring that no one misses out on the experience.

Just try

For those not ready to volunteer, Pam and Keith recommend simply visiting National Trust sites to explore what's on offer. "You don't have to do it all at once, says Pam. "Just go and enjoy a place. Take your time. Try a new aid if it helps you get further."

They're clear in their message: just try.

"Don't sit at home thinking, 'What can I do?'" says Pam. "Get out, try something new. Use a stick. Try a scooter. Visit a place. Volunteer. You'll be amazed how it can open up your world."

Keith nods: "We can't recommend it enough. It's made such a difference to our lives."

We are always looking for people to join our volunteering team at MD Support Centre. Please contact getintouch@mdsupportcentre if you're interested in getting involved.

Accessible holidays



Inclusive destinations and support schemes enable more people to enjoy a well-earned break. In addition to Limitless Travel, here are some options available to disabled holidaymakers that have been recommended by our service users.

The Bond Hotel – Blackpool

On Blackpool's South Shore, **The Bond Hotel** is the UK's largest fully accessible hotel, with over 40 years' experience in hosting guests with disabilities. It has 62 accessible rooms with profiling beds, wet-room showers, ceiling hoists, and emergency call systems. Guests can enjoy live evening entertainment, a licensed bar, and home-cooked meals for all diets. The hotel, which is close to popular tourist attractions, also offers door-to-door transport to support guests with their journeys.

Unlocking adventure with the Calvert Trust

The Calvert Trust offers inclusive adventure holidays at its three fully accessible activity centres located in **Exmoor**, **Kielder** (Northumberland), and the **Lake District**. Led by fully qualified and experienced instructors, activities include canoeing, climbing, horse riding, and zip-wiring - all adapted to individual needs. The Calvert Trust also runs bursary schemes to help with costs.

Financial help for accessible travel

- **The 3H Foundation** – holiday grants of £250–£550 for low-income disabled individuals and their families.
- **Revitalise** – accessible respite holidays with 24-hour care at centres in Chigwell, Southampton, and Southport.
- **Disability Aid Trust** – helps cover the costs of carers or helpers needed for holiday support.
- **Holidays with Help** – fully supported group holidays with trained helpers and on-site medical support.
- **The Jumbulance Trust** – group holidays in the UK and Europe with specially adapted vehicles for those with severe disabilities.
- **Disability Grants** and **Turn2us** offer searchable databases to find grants.

Know of a great accessible holiday spot or financial support?

We'd love to hear about it! Share your recommendations with us at communications@mdsupportcentre.org.

More than yarn: building belonging at Knitter Natter

Clair McHale knows the power of a good natter – and a pair of needles or a crochet hook. What began as a personal passion has now blossomed into a welcoming community at the MD Support Centre, where the monthly Knitter Natter group offers a space to connect over creativity and shared experiences.

The idea came when Clair brought a crocheted item into the Centre to sell. She says: “We got talking about craft groups and someone suggested I start one here. I was unsure at first because I’d lost a lot of confidence over time. But I’m really glad I did.”

Since launching in January, the Knitter Natter club has grown into a welcoming creative hub. “People come from all different areas,” she says. “I’ve met some lovely people I wouldn’t have met had this not happened.”



She understands that stepping into something new can be hard. “People have to overcome the barrier of meeting new people. And if it’s something you don’t know how to do, you think you can’t learn. But just be patient. You will.”

More than a craft group

There’s no pressure to be an expert or even to pick up the needles. “It’s a nice, relaxed environment,” Clair says. “You can learn, bring your own work, or just join us for a drink and a bit of a chat. Come and go as you like. It feels inclusive. Everyone joins in and gets chatting. It’s a proper mix.”

As a former hairdressing teacher, Clair enjoys helping people learn new skills. She says, “It gives me an immense amount of satisfaction. Like with Nina – I showed her how to crochet she picked it up really quickly. The pride she had in herself... It gives you pride too.”

A place to feel normal

What sets the group apart, Clair says, is the sense of shared understanding. “One thing I love about it is that we’re all in the same boat,” she says. “From the first week, I felt relaxed. It wasn’t like wheeling in somewhere and having everyone look at you, everything needing to be moved, and feeling different to everyone else.”

“Some people don’t know how to speak to you. They’re worried they’ll offend you. But here, it’s different. You’re not the odd one out. You’re not awkward. We’ve all got issues, but they don’t have to be discussed or singled out because for us, it’s normal.”

“When you’re in your chair, or if you’ve got an issue with mobility, you rarely feel normal. That’s something you lose the ability to feel in most places. But here, you do.”

Knitter Natter meets on the last Thursday of every month, between 1–3pm, at the MD Support Centre’s Coventry HQ. Visit mdsupportcentre.org.uk/events to book your spot.

Making fashion accessible

Sheila Hawkins is on a mission to make clothing more inclusive and accessible for disabled people. She writes:

What do you wear in your wheelchair?

When I started using a wheelchair in 2019, I realised how many practical issues there are when it comes to dressing and undressing. Some clothes were simply impossible to wear while seated. Around the same time, I began a Foundation Degree in Fashion and Footwear Design. That got me thinking about how the fashion industry could better serve people with limited mobility.

I launched a survey at the MD Support Centre's 2023 Open Day to explore the challenges people with limited mobility face when choosing and buying clothes. With support from the Centre, Muscular Dystrophy UK, and Spierziekten Netherlands, I gathered 100 responses. I didn't ask why people had limited mobility, so the results reflect a range of conditions beyond muscular dystrophy.

The results sent a clear message

The results confirmed what I suspected: finding stylish, accessible clothing that works well in a wheelchair is difficult, and sometimes impossible.

"We don't have to be dowdy just because we are disabled."

"Find a modern winter coat where I sit comfortably in my wheelchair."

I asked about practical issues like fastenings, pocket placement, collars, and the overall shopping experience. 65% of respondents said they couldn't use 'accessible' changing rooms, and nearly a quarter had given up on in-store shopping altogether, opting to buy online. I published the findings in an academic paper in March 2024, followed by a visual version. Both are available at [**Advice on clothing - Pod NMD**](#).

There are some specialist adaptive fashion brands, but the clear message from the survey was that people want to wear the same styles as their peers.

"Need adapted clothing, not exclusively for old people, and some key fashion pieces."



Signs of progress

1.2 million people in the UK use wheelchairs some or all of the time - a sizeable market that the fashion industry could serve much better. Over the last year, I've worked to influence the industry, showing brands that they could boost profits by improving options for people with limited mobility. There are signs of progress: Primark has launched an adaptive range (not linked to my work), including wheelchair jeans - though the fastenings still need work! The survey really highlighted that people want choice and clothes that reflect their own personal style.

I created a workshop to help clothing designers understand the practical challenges faced by people with limited mobility. I've delivered it to students at Leicester College and hope to do the same at De Montfort University. I'd love to take it to the big fashion brands - but no luck so far.

I've had some media success, speaking on Radio Leicester and East Midlands Today about what people with limited mobility really want from fashion. I'm writing a case study for the International Journal of Sustainable Fashion & Textiles, showing how improving accessible changing rooms could boost in-store sales and reduce costly returns.

So, a huge thank you to everyone who took part in the survey, especially the person who said, "We don't have to be dowdy just because we're disabled." That quote has become the working title for my campaign. I'm also working on a wheelchair-friendly coat prototype, which I might bring along to an MDSC event for people to try on. And if you've had any positive experiences with finding and buying clothes, I'd love to hear them!

To connect with Sheila, please email communications@mdsupportcentre and we'll pass your details along.

In remembrance of Gurjinder Birdi



Our MD Support Centre team bid a sad farewell in late February to long-time friend and service user, Gurjinder Birdi. As one of the Centre's very first attendees, Gurjinder was a familiar face and a valued part of our community.

She found the ongoing therapy we provide incredibly helpful in managing the progressive effects of her condition. In those early days, she and her husband Parminder became not only friends but vital supporters of the Centre, especially at a time when our future was uncertain.

Alongside the British Asian Business Professionals Association and their family and friends, they organised events and fundraising efforts that provided critical financial support to help us stay open. Just as importantly, they offered unwavering encouragement, reminding us of the deep value our services bring to people's lives.

More recently, the Birdi family marked our 10th anniversary by hosting a celebratory dinner on our behalf. They also set up a memorial fund which raised an incredible £5,500 – a testament to the love and respect so many had for Gurjinder.

Throughout the years, Gurjinder was known for her radiant smile, gentle strength, and quiet determination. She faced challenges with grace and without complaint. She will be deeply missed by everyone who knew her, and we extend our heartfelt condolences to her family. We share in their loss and thank them for their thoughtfulness in supporting the Centre during this difficult time.



Gurjinder's family present a cheque in her memory

We've invited Gurjinder's daughters, Rasmeet and Bhavan, to share a few reflections about their mum below:

Our mum was diagnosed with Inclusion Body Myositis (IBM) around 17 years ago, after first being misdiagnosed. Even with a diagnosis like this, she wasn't phased. She continued to live her life in the most selfless and full way. Everyone who met our mum was instantly drawn to her - she was warm, humble and caring. On the 28th of February this year, our mum passed away following complications from pneumonia. We were heartbroken and are still trying to find our new "normal" as life goes on without her.

We knew there was no cure for Mum's condition, but thanks to the MD Support Centre, she was able to maintain her symptoms as well, and as long as she could. Our heartfelt thanks to all the staff who gave mum every ounce of their energy.

To all service users and their families - we see you, we know your struggle and we hope that the funds we raised go some way to helping you all. You have our utmost respect.

We will forever be friends of the MD Support Centre and will continue to show our support in whatever way we can.

Birmingham women leading the way in making spaces more accessible

Two inspiring women from the MD Support Centre community are helping to create more inclusive spaces for everyone, drawing from their own lived experiences to drive change in their local areas.

Over the past year, both Elizabeth Norman and Victoria Barr have been involved in projects that aim to improve access to the outdoors and public spaces for people with disabilities.

Improving Moseley Park

Elizabeth (pictured) took part in a community symposium held by Moseley Park and Pool, where residents gathered to explore how the park could become more accessible to disabled visitors. She spoke about the barriers many people face when trying to enjoy green spaces, sharing practical ideas based on her own experience.

Thanks to feedback from Elizabeth and others, the park has already made significant improvements, including the addition of an accessible toilet, new seating areas, and flatter, wheelchair-friendly pathways. Work continues on improving access for all.

Elizabeth also generously chose to donate her speaker fee from the event to MD Support Centre. She said, "I've no idea how I would be functioning without MD Support Centre," she said. "The therapy helps my joints and mobility. They've even taught my husband how to do some massage therapy at home. So I decided to donate my fee as a way of giving something back."

Making Kings Heath Accessible

Victoria Barr got involved in the Kings Heath Access for All project after spotting a Facebook post asking about accessibility on the High Street.

She said, "I knew I had valuable insight due to my own experiences as I experience the challenges of navigating the High Street and Birmingham daily. For many businesses, appropriate access for people with disabilities is an afterthought and it often does not concern them unless they have personal experiences.

"Even when you plan ahead phoning venues to ensure they're accessible, you still arrive to find a step no one mentioned or a broken lift. Not only is this awkward, but



it can feel like you're making a scene, having to leave and change long-anticipated plans."

Victoria joined a focus group where she helped identify accessibility needs in the area, spoke to businesses and encouraged them to make changes. She has also helped secure funding for improvements in the high street, including ramps, doorbells and hearing loops.

"What surprised me was that some businesses had ramps available but didn't promote that they had a portable ramp for wheelchair users to access their shops. This meant that no one was aware of it, and they were possibly losing out on trade."

The group has given grants to make changes and produced a brochure to raise awareness. Victoria said, "We want people to start thinking about accessibility and hopefully start a conversation which will improve the experience of navigating a day out for everyone.

"This project has been immensely rewarding. Not only was I part of improving accessibility in my area, but I also got to meet lots of new people. I found it satisfying talking to businesses that didn't really understand the varying needs and improving their mindset and awareness.

"I would encourage everyone to talk to your local businesses. If you can't access a venue or there are things you can see that could be improved then talk to the owner or person and share your thoughts."

For more information on the Kings Heath Access for All project visit www.enjoykingsheath.com.

Supporting life transitions with the Adapting to Change group

Our Adapting to Change group is a peer-led space where people come together to share experiences, advice and encouragement. It was created to support people through the many transitions that come with living with muscular dystrophy.

Led by a small team of volunteers, the group meets quarterly to explore real-life transitions and decisions. Each session focuses on a theme chosen by members, shaped by the needs and voices of our community.

The first discussion took place at our 2023 Open Day, facilitated by Co-Lead Physiotherapists Lynn and Ulrike. Focusing on changing mobility needs, they spoke to people about the emotional and practical process of accepting new mobility equipment. Mark Thompson, who now helps lead the group, says, "Sometimes you talk to someone in the Centre and think, 'I wish we had more time to ask questions and hear more stories.' That first session felt like an extension of those conversations and showed how valuable it is when people open up and speak honestly."

Lynn says, "I remember working in Leicester a few weeks later and one of the attendees told me he'd gone out and bought a wheelchair as a direct result of that session. That really showed me the impact it had."

Going from strength to strength

Since then, the group has centred each session around a particular theme. So far, they have covered holidays, accessing care, and transport. A member of the core group opens the discussion by sharing their personal story, which triggers a wider conversation. People have the opportunity to share their experiences, ask questions, or listen and absorb the information.

A session on travel and holidays featured stories of how mobility aids and care support can transform trips. Mark says, "I remember one particularly moving story about how using a wheelchair on a family holiday meant the whole family had a wonderful time. Whereas the previous year, they'd really struggled, looking after Dad. Now, Dad could do his own thing without needing to be pushed."

Another session focused on planning and arranging care. Attendees shared practical tips and talked openly about how they had come to accept help while still maintaining independence. It highlighted the differences in how services are delivered across regions, particularly around access to carers and local authority support. Lynn says,



Members of the Adapting to Change group

"Sometimes just hearing that someone else was able to access support gives people confidence to ask the right questions and keep asking until they get a fair answer."

The most recent session covered transport and Motability, with members exchanging experiences of applying for accessible vehicles and making adaptations to their vehicles.

Mark says that hearing from others has had a direct impact on his own life. "I applied for Access to Work after someone in the group said how much it helped them. Now I'm hoping it will help me stay in work for longer."

A different kind of support

From a professional perspective, the sessions have been just as valuable. Lynn says, "It's given me insight I wouldn't get anywhere else. Hearing people's honest, first-hand experiences helps me better support others. I come away with ideas, real-life examples, and the confidence to say to someone else: 'Here's what you might try.'"

The peer-led nature of the group is key to its success. "The support you get from professionals is important," says Mark, "but the support you get from someone who has lived it is of a different order."

Another strength lies in the mix of participants: some confident in sharing advice, others just starting their journeys. "Some people listen with their cameras off and mics muted, and that's fine," says Lynn. "By the end they're often asking questions or coming back for the next one. It's not about being at the same stage. It's about people meeting each other where they are."

Adapting to Change meets quarterly in-person and online. For details on upcoming sessions, visit mdsupportcentre.org/events. You can also visit our blog page to read Emily's reflections on the group.



Dates for your diary

June

Fri 6	Breathing and More	Online
Thurs 26	Knitter Natter	Coventry HQ
Sat 28	Summer Get-together	Coventry HQ

July

Friday 4	Breathing and More	Online
Weds 16	Focus Group	Online
Thurs 31	Knitter Natter	Coventry HQ

For details of all upcoming events,
go to mdsupportcentre.org/events

Keep in touch

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

Find us on social media



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[@mdsupportctr](https://www.instagram.com/mdsupportctr)



linkedin.com/company/muscular-dystrophy-support-centre

Join Our Social Group!

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

Would you like to contribute? We are always on the lookout for content for our magazine and blog and we'd love to hear from you if you have a story to share or an exciting experience you'd like to tell the world about.

Please email communications@mdsupportcentre.org if you have a story to share.