



MD Support Centre Magazine

Autumn/Winter Edition 2024



Abbie scores
goal for deaf
awareness



Donna turns
pedal power
into pounds

Plus:

- Kerry's experience as a new service user
- Ruth joins forces for change
- We talk volunteering with James

Sanah's adventure
away from the
everyday



Sarah's insights
from MoveWell



Contents

Page 3 - Welcome from our CEO Sarah Ann Moore

Page 4 - Away from the everyday with an outdoor adventure

Page 6 - Therapy update

Page 7 - Footy fan Abbie scores goal for deaf awareness

Page 9 - Fundraising update

Page 11 - Turning pedal power into pounds

Page 13 - Insights from MoveWell

Page 14 - "For the first time, I felt heard." *Kerry's story.*

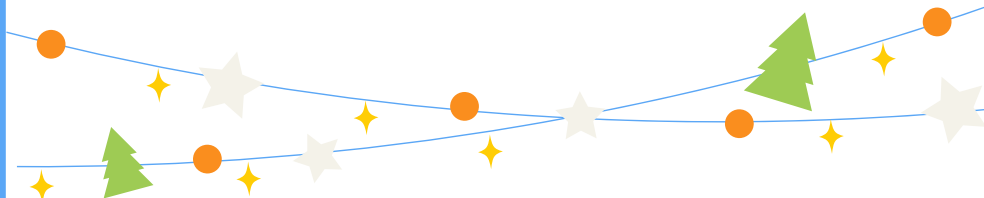
Page 16 - Joining forces for change with Ruth Hereford

Page 17 - James Mackay volunteer profile

Page 18 - Class and clinic schedules

Page 19 - Upcoming events

Page 20 - Keep in Touch



MD Support Centre Christmas social

**Get into the festive spirit at our annual
Christmas social event!**

**Wednesday 4 December | 3.00 - 5.45pm
MD Support Centre, Coventry**

**Join us for some festive cheer, share a glass of
non-alcoholic mulled wine and enjoy the festive
bakery at our annual Christmas social. We'll
toast another year of fantastic support and draw
the results for our Christmas raffle!**

Register here

<https://bit.ly/MDSCxmassoc24>



A Note from our CEO Sarah-Ann Moore

Welcome to the Autumn/ Winter edition of the MD Support Centre magazine!

We are delighted to share in this edition some fantastic stories from around our service user and wider community – of adventure holiday exploits, fundraising challenges, and volunteer efforts – as well as updates on our Centre, therapies, and new equipment. I was personally so inspired by Donna's London to Paris cycling challenge (p10) that I'm excited to share I have signed up to join her on the 300-mile journey to raise funds for our charity!

If any of these stories resonate personally with you, or you have a story of your own to tell, we'd love to hear from you. You can also find additional service user content on our MDSC Blog page mdsupportcentre.org/blogs.

Since our last magazine in Spring/ Summer, MD Support Centre has been busy continuing to develop our team and services – including welcoming new team members (Therapy Assistant, Suki and Communications Officer, Helen), piloting a new satellite clinic location at the MoveWell Centre at the University of Birmingham (see p12), and launching our Adapting to Change peer support group.

For more news and information about what we have been up to and for details of future events take a look at our website mdsupportcentre.org.

The upcoming festive season is a time for sharing thanks and goodwill, and we have much to be grateful for as a charity with the kindness, generosity, and enthusiasm of our amazing community of staff, volunteers, service users, carers, funders and partners.

Thank you for your continued support and I hope that you enjoy this issue of our magazine!



Away from the everyday with an outdoor adventure

by Paula Irish

When artist Sanah Rauf was invited to return to the Calvert Trust on Exmoor for a second adventure holiday with Spinal Muscular Atrophy UK, she didn't need asking twice.

On her first trip to the accessible activity centre in 2023, Sanah had the opportunity to try archery and also zip wiring - but confesses to having been a little apprehensive about whizzing along a suspended cable and so only did it once on that occasion.

However, returning this summer for another long weekend with the charity, Sanah says the zip wire was her favourite activity: "I did it five times! Although I was a bit scared last year, this time it was a case of 'let's go!' – I just like the feeling of it, flying through air. I'm quite outdoorsy any way but zip wiring makes you feel alive, like 'wow I just did that!' It's really exhilarating."

The support of SMA UK enabled 21 adults living with the condition to enjoy a break with the Calvert Trust last year, which it named Resonate 2023. This year saw both previous and new attendees at Resonate 2024 benefiting from a confidence-boosting weekend away together.



Action packed

As an MD Support Centre service user and an ambassador for SMA UK, Sanah is keen to raise awareness about the opportunities available for those living with muscular dystrophy conditions.

SMA UK aims to connect people and provide information, emotional support and practical guidance. For 27-year-old Sanah from Wolverhampton, the Resonate 2024 trip was a chance to not only meet old and new friends in the SMA community but also make memories with her family.

Accompanying Sanah on the holiday were her two sisters, one of whom also has SMA, and a carer.

As part of the SMA UK-supported long weekend, participants enjoyed sociable breakfasts and evening meals together and an action-packed schedule of morning and afternoon activities.

In addition to zip wiring, Sanah chose to take part in kayaking, biking, abseiling, and a crate stacking team challenge which sees participants hoisted above an ever-growing tower. Other activities at Calvert Exmoor include horse riding, swimming, bushcraft, climbing and rafting.

Access all areas

"It's what you CAN do that counts," is the ethos at the centre in North Devon, which provides fully accessible accommodation and activities that are designed to be both exciting and inclusive, allowing participants of all abilities to push their limits and try new things.

Calvert Trust Exmoor provides holidays for people with physical, learning, behavioural, sensory or multiple complex disabilities, with facilities for families, schools and groups that include ceiling and manual hoists, ramps, accessible bathrooms and electric profiling beds.

For activities, the kit ranges from a specialist abseiling wheelchair and optional seating for canoeing to an adapted carriage for wheelchair users in the equestrian centre.

It all adds up to visitors being inspired to take part in outdoor adventures they've often never had the opportunity to try before, enabling an escape from the everyday to relax in fresh air and on the water – or simply enjoy an adrenaline rush!

Life skills

For the SMA UK community, it's also a chance to boost life skills such as independence, teamwork and determination, while sharing experiences, learning from each other and having fun.

Sanah, who visits our Tipton satellite clinic and also our Birmingham and Coventry physio and osteo therapy services, says: "The trips are so good for your confidence. I felt on top of the world when I came home, it makes you feel really energised.

"You get up early and do an activity before lunch, and another one straight after. So it's 'go, go, go' but you have the energy to do it because it's so exciting and all the instructors are really professional, friendly and welcoming.

"I would 120 per cent recommend the Calvert Trust to other service users, I'd encourage people to give it a go. It's one of the best things I've ever done!"

Discover all the holidays and activities offered by [Calvert Exmoor](#) and visit [SMA UK](#) to find out more about the charity's support for people living with Spinal Muscular Atrophy.



Therapy Update

Balo brings greater access to physical therapies

We're pleased to share that, in October, we added a new Balo from THERA-trainer to our exercise equipment, thanks to a grant from Awards for All.

The Balo is a dynamic standing frame designed to improve balance while working core muscles in a fall-safe environment. It supports users into a standing position, allowing them to take part in exercises that build muscle strength and improve stability. This new addition means we can provide a greater range of treatments and exercises to our service users.



Independent exercise with Suki



MD Support Centre now offers independent exercise sessions between therapy appointments, allowing you greater opportunities to use the Shapemaster and THERA-Trainer Tigo bike.

With guidance from our new Therapy Assistant, Suki, these sessions help maintain muscle strength, cardiovascular fitness, and flexibility, supporting better balance, mobility, and independence. Speak to your treating physiotherapist to find out more.

Cancellations reminder

Appointments cancelled at the last minute (less than 48 hours notice) usually cannot be refilled, and each one costs us around £100. **We had 99 late cancellations and "no shows" last quarter – costing our small charity as much as £9,900!**

By cancelling, you not only miss out on your therapy but also another service user on our waiting list who could have booked your appointment is being denied vital therapies too.

So please support us and be considerate to your fellow service users – only cancel if absolutely necessary and please give us as much notice as possible so that your appointment is not wasted.

Footy fan Abbie scores goal for deaf awareness with Northampton Town



Abbie with the Northampton Town Football Club - credit Pete Norton

Players at Northampton Town Football Club have been taught British Sign Language for goal celebrations thanks to lifelong fan and MD Support Centre service user Abbie Davies.

Cobblers' supporter Abbie is deaf and recalls how special it made her feel after former player Clarke Carlisle signed to her when she was an eight-year-old mascot: "Having that recognition that someone I looked up to and watched every week, knew how to communicate with me."

Inspired by seeing young fans of Chesterfield Town introducing their team with sign language, Abbie asked Northampton Town FC if she could help her own team go one better.

The club loved the idea as a way of supporting Shoe Army fans while raising awareness about British Sign Language (BSL) and invited Abbie to run a training day in April - teaching the players how to sign their initials and shirt number for this season's goal celebration GIFs, which are shared on social media every time the team scores. Season ticket holder Abbie lives just a stone's throw from the team's Sixfields ground in Northampton and also re-visits whenever the team gets new players to show them how to sign too. Other GIFs recorded by the team for match days include 'thank you for your support', the fans' chant 'Super Sammy Hoskins' and of course: 'GOAL!'

“

Abbie says: "I had a fun day teaching the players their initials and squad number as well as a few other signs. Practice makes perfect and like any language some players picked it up easier than others. Once they were on board with understanding why we were doing it, they were really intrigued and wanting to make sure they were getting it right. I hope that the younger fans will see their favourite player signing and think 'I want to do that as well'."

Aged 20, Abbie works part-time in administration and was introduced to supporting the Cobblers by her mum, with memories of going along to her first match aged just six.

Abbie has Facioscapulohumeral Muscular Dystrophy (FSH/FSHD) and having discovered MD Support Centre through our Daventry clinic, now visits Coventry every two weeks – or sometimes just once a month during the football season, saying: “It definitely helps me to manage aches and pains and it’s enabling me to keep what strength I do have so I don’t lose it as quickly.”

She hopes her ongoing initiative with Northampton Town FC will help to raise awareness about deafness and signing to help others living with impaired hearing to feel less isolated.

“It’s so important to understand that because deafness is a hidden disability, it often gets overlooked,” explains Abbie.

“When I was younger I went to a mainstream school so I was surrounded by people who could hear each other. I often had to ask people to repeat things. It can be hard, and sometimes you could think: ‘I don’t want to be deaf because I want to be included in that conversation.’



Northampton player, Jordan Willis, signing the letter W

“Some people will just pretend they understand and nod their head, because they don’t want to tell people they’re deaf, so I’m hoping the Northampton Town initiative is good for everyone, hearing fans as well. I can imagine a child seeing the players signing and wanting to do what their idol is doing. I’m hoping that by raising awareness it will help.”

As Cobblers team captain Jon Guthrie sums up: “The more goals we score, the more views the Goal GIFs will get and that will only be good news for everyone!”

With Northampton Town FC currently battling it out in League One, it’s all to play for! If you are interested in learning British Sign Language, please feel free to contact Abbie on daviesabbie20@gmail.com.

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

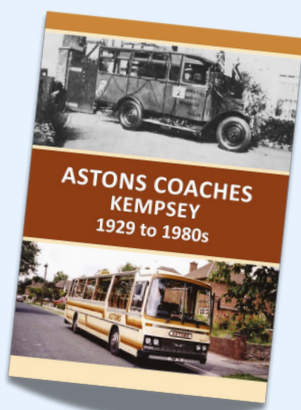
We are always on the lookout for content for our magazine and blog and we’d love to hear from you. If you have a story to share or an exciting experience you’d like to tell the world about, get in touch with us at communications@mdsupportcentre.org.



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.



Andy drives donations through book sales

When Astons of Kempsey Heritage Group published a book detailing the history of Astons Coaches, the authors decided to donate some of the profits from sales to charity. Andy Curtis, a direct descendant of the company's founders and key contributor to the book, was diagnosed with MD and receives support from MD Support Centre. In honour of Andy, the book's five co-authors selected MD Support Centre as their chosen charity.

The book features a collection of photographs, historical insights about the company, and personal stories from former employees.

Bowled over by fundraising success

Service User Andy Collins hosted a Skittles night complete with fish and chip supper. Everyone that attended had a great time playing some classic pub games while raising funds for MD Support Centre. The event was such a roaring success that he has organised another evening of fun for March 2025.



Personal connection inspires charitable support

When Zicam Security Systems learned of employee Mark McGeown's connection to MD Support Centre, they immediately pledged their support to our charity. Mark, who is married to our Head of Reception, Vicki, put MD Support Centre forward as a charity in honour of the couple's son, Jonathan.

Jonathan was diagnosed with MD as a child and began attending the centre after leaving college. After he passed away, Vicki began volunteering as a receptionist and sees her work here as a tribute to Jonathan. Since hearing of Mark and Vicki's deeply personal connection, the company made a monetary donation, signposted to our donate page through their newsletter and have given a £350 television as a prize in our Christmas raffle.



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.

Golf days

Trustees David Salt and Gary Evans and corporate supporter Paul Dowling through ABP Club hosted charitable golf days earlier in the year. We are incredibly grateful to them and their fellow golf enthusiasts for supporting our charity.

Corporate friends

Thanks to all our corporate partners who have donated generously to our Christmas raffle. Looking beyond Christmas, 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.

How you can get involved!



Shoppers using Easyfundraising have raised £168.19 for us to date.

Sign up here to earn donations for MDSC every time you shop.



Did you notice that October was free Wills month? It would be wonderful if you could consider leaving a gift to MD Support Centre in your Will at any time of the year. Find out more at mdsupportcentre.org/gift-in-your-will/



Don't forget to get your Christmas cards and raffle tickets!

Cards are available in packs of five for £5 or ten for £8. Raffle tickets are £1 each or £5 for a strip and we have some amazing prizes including the TV donated by Zicam, football tickets, a professional photoshoot and more!

Come and see us in-centre or call us on 02476 100 770.

Anything you can do to support our work delivering a vital service to our growing community of service users is greatly appreciated. Go on, get involved today!
If you have an idea for a fundraising event or want to challenge yourself and raise funds for the MD Support centre, we can help you every step of the way.
Contact Nina at our HQ or go to mdsupportcentre.org/fundraising.

Turning pedal power into pounds

Join us in supporting Donna's London to Paris challenge!

by Paula Irish

An epic test of endurance will see service user Donna Scarrott cycling more than 300 miles from London to Paris in September 2025 to raise money for MD Support Centre.

Donna is determined to convert pedal power into pounds to support the vital work of the charity which has helped her to navigate life with Charcot Marie Tooth Disease (CMT).

She says: "It's also about challenging myself and keeping fit at the same time and I'm looking forward to meeting new people and the scenery along the way - and having that sense of achievement. When I see the Eiffel Tower, I can imagine myself getting quite emotional."

Donna has completed previous cycling challenges, but taking on this four-day ride across the English Channel will be her biggest adventure yet. She hopes people will be inspired to sponsor her – or sign up to join her on the road to Paris as part of an MD Support Centre team!

Rehabilitation

Donna was first motivated to get on a bike with support from the government's Cycle to Work scheme after adopting a positive mindset to support her recovery from major foot surgery in 2019 and then tough times working as a nurse through the pandemic.

A 52-mile cycling event in the New Forest was followed by a 97-mile charity ride from Evesham to Weston-Super-Mare in September 2023. Then in March 2024, Donna entered a Wessex Downs Cycle Ride of 36 miles before going into hospital for further operations at the start of summer.

When we catch up with Donna to find out more about her London to Paris challenge, she has only just re-visited her allotment for the first time in months and returned to work as a Senior Sister at Worcestershire Acute Hospitals NHS Trust, where she is also chair of the Staff Disability Network.



Her latest operations involved major left foot reconstruction, and six weeks later, surgery to straighten the toes on her right foot: "I was in plaster for three months and because I had both feet done this time I had to accept care support, which was quite hard for me because as nurse I'm usually the one giving care, not receiving it."

Top team

Her passion for now getting into training for the London to Paris challenge in aid of MD Support Centre reflects the essential role played by the therapy team in helping Donna before and after surgery, and with her ongoing journey living and working with CMT.

“She says: “Their support has been invaluable, not just to me but to other members of my family living with the same condition. I have a challenging career as a nurse, which I have worked so hard for over the years. This has become more challenging with the progression of my CMT. The help and support of the friendly team at MDSC allow me to stay stronger for longer and enable me to maintain my independence and ability to continue in a job I love so much.”

"It's not just the physical therapies that have had the greatest impact on my journey so far, but the staff themselves provide so much more. A friendly smile, a chat over a cup of tea as I discuss my worries and concerns, a hug when needed, and all the practical, emotional and mental support they provide, sometimes without even realising it.

"Now I feel it's time to give back to the charity so that they can reach further to support the lives of other individuals with neuromuscular conditions which cause progressive muscle-wasting."

Training plan

Although some people take on the London to Paris challenge using electric bikes to help take the strain, for Donna these are too heavy to balance, so she is planning to complete her incredible journey under her own steam on a light-weight carbon fibre road bike.

Now walking again, Donna says she feels steadier than before and is getting stronger by the day. She is swimming to rebuild her strength and has rejoined a gym, where she is getting back in the saddle. To avoid cycling in the cold and icy conditions of winter, she also now has her own indoor bike with a screen, workouts and even Google maps, so she can ride virtually from London to Paris, complete with variable resistance to simulate hills.

Donna is confident that by September 2025, her training will have put her on track to be celebrating the successful completion of her challenge at the Eiffel Tower.: "The longest day on the London to Paris ride is 103 miles, just over what I've done before so I know it's achievable.

"The organisers, Discover Adventure, have also sent me a 15-week training plan, although I'm going to spread this over a longer period from November through to when we go next year. I've already started fundraising and would love it if people would support me – and join me!"

Community effort

Donna lives in Redditch and has already raised nearly £200 with a fundraising 'street party' with live music, which in unseasonal weather moved into the local pub, The Village Inn. Other ideas include a bingo evening, and also supporting Donna are the Cider Mill and Ambassador pubs in Evesham.

The London to Paris ride is open to cyclists of all levels who are able to train for it and Donna invites anyone living with or affected by muscular dystrophy, family and friends and keen cyclists to join her in pedalling to raise money for MD Support Centre.

"If anybody would like to join me on the ride – service users or friends or family if they are unable to – it would be great if people could register by the end of December. We could do some training and leisurely bike rides together to get to know one another.

“Let's make this ride unforgettable! Together, we can conquer the miles and make a lasting impact for people living with muscular dystrophy.”

Support Donna

Get in touch: donna.scarrott@hotmail.com

Sponsor her: [click here to visit her fundraising page.](#)



Fundraising fact file

The challenge: Cycle from London to Paris

Organiser: Discover Adventure

Date: Wednesday 10 - Sunday 14 September 2025

Route: London to Paris

Distance: 300 miles (approx.)

Registration fee: £149 then £250 payable to the organisers ten weeks before the event

What's covered: Return ferry or Eurostar, four nights' hotel accommodation, meals, Discover Adventure crew and vehicle support throughout, route information, training plans

Fundraising Target: £1,400

**Click here to
sign up**

Insights from MoveWell

Sarah's story

When we began trialling a new clinic location at the MoveWell Centre in Birmingham, Sarah Rennie was the first service user through the door. Here she shares her insights from her first appointment. Sarah writes:

I live in Birmingham city centre, so the Birmingham satellite clinics have been very helpful and massively reduced my travel time as a non-car owner. I've really enjoyed the Bournville Gardens site as the location was easier and you're always guaranteed a warm welcome and a Murray mint from the older residents!

However, I jumped at the chance to be the first service user as part of the trial at Birmingham University, particularly as it's well connected for public transport and has more of a younger vibe.



Modern and spacious

As the weather was shocking, I lazily got a taxi. The building entrance is all level access which is great for many people, but tricky for taxi ramps that need a high kerb. There are low kerbs by the North Gate (across the road from the MoveWell Centre) and a high kerb at the bus stop – right outside. This, incidentally, is the nearest bus stop too! There is, of course, car park provision immediately outside, including several Blue Badge bays. I travelled back by train via Birmingham University station – I used the new entrance with the massive zig-zag ramp, but disabled passengers can enter via the exit opposite the QE hospital if necessary.

Inside, the building is modern and spacious. I appreciated having a private room for my appointment, as it can be awkward with just the screens in the Bournville Garden gym. It was very quiet when I went last week but term time hadn't yet started. Hopefully, there will be opportunities to work more closely with the University's physiotherapy students as the relationship between the University and the MDSC develops.

Opportunities to develop

After my appointment, I went to check out the Changing Places WC. There are two facilities on the campus but the one I used was in the Main Library which is about a 10-15 minute walk from the MoveWell Centre. It's just to the right as you enter (signposted) and if you get to the reception desk or turnstiles you've gone too far! The facility is very modern and well-maintained, with a Geberit WC. There's also a high-quality Changing Places in University station too.

There are plenty of coffee shops and places grab some lunch around campus after the MDSC physios have given us a workout. Maybe even a pint in the student bar...

I'm really excited about potential opportunities that could develop as a result of the new site and encourage any service users to give it a whirl!

Do you want to try out the MoveWell pilot clinic? [Contact us](#) to enquire about booking an appointment.

For the first time, I felt heard.

Kerry's story

Kerry lives with a rare form of muscular dystrophy (FHL1). After struggling to find therapists with experience of her condition, she was referred to MD Support Centre where she found a caring community as well as physical support. She shares her experiences of coming to MD Support Centre for the first time.

Exercising, easy right? As easy and simple as putting on your Lycra outfit, sweat bands and saying 'okay let's do this' with Olivia Newton-John's 'Let's get physical' playing in the background.

However, how realistic is that for many disabled people? Especially if you're unable to do any physical exercise or be at one with nature on a long walk.

It's hard to find a professional such as a physiotherapist who has a real understanding of Muscular Dystrophy and how it affects every part of your body inside and out – you can feel lost, unheard and unimportant. Sent home with a fact sheet of exercises and stretches to do, with no follow up or even asked if you're able to continue the fact sheet of exercises at home!

For those who don't know, the form of Muscular Dystrophy I have is a rare progressive muscle-wasting condition. Those of us with MD will continue to lose muscle strength over time and with exertion. The disease doesn't stop or decide to take a holiday. Slowly but surely over the years, some of the actions I used to be able to do, like stepping into the shower, standing by myself with help, walking and getting dressed, will become either no longer safe on my own, extremely difficult or stop all together.

I'd heard of the Muscular Dystrophy Support Centre a few years back from friends, who always spoke highly of their work with people with MD. At that point in my life, it was so far out of my reach, being an hour away from home with no way to get there. It wasn't until I got my WAV (Wheelchair Accessible Vehicle) that the thought of being able to access something that could help keep my muscles moving wasn't just a pipe dream anymore.

The referral was in. A date was set for my induction to the service. I was secretly excited. But those lingering thoughts in the back of my head were hard not to listen to. Am I expecting too much? Could this be just another service that will send me wheeling away with yet more fact sheets?



L-R: Ruth Hereford (Chair of Trustees), Sarah Ann Moore (CEO), Kerry Thompson, and Taher Dhuliawala (Clinical Services Manager)



The feeling I had coming away from MD Support Centre, however, was nothing more than relief and for the first time I felt heard.

I was lucky enough to have my induction with Taher, the Clinical Services Manager. I didn't have to explain or constantly repeat myself as to how muscular dystrophy affects my body, or what I can and can't do.

It was a breath of fresh air to just talk to someone who wasn't telling me what they thought I needed. For the first time I was asked what I needed and so was my husband. For years no-one has cared about my husband and everything that he does or watches me go through. My husband was given a few tips that would help him when getting me in and out of bed.

As crazy as this sounds, I now live for my monthly sessions with the physio team and osteopath, to be pulled, stretched and massaged. Bring on the pain, I can totally handle it although my face might tell a different story!

All the tension and tightness in my muscles, neck and shoulders is gone. I can breathe better, as in my lungs feel more open. After a session - I am ready to take a siesta. But in the same sentence, I feel refreshed.



I've been a few times now and it's hard not to fall in love with each and every one that works at MD Support Centre – it's not just a service, it's a family that cares!

Kerry is an award-winning blogger and campaigner on a mission to change people's perspectives about disability and make the world a more inclusive place. You can read more about Kerry's experiences and work on her blog: [My Life, Kerry's Way](#).

Service user resources

Carer Card

If you provide support to a spouse, partner, parent, child, relative, friend, or neighbour you may benefit from a Carers Card.



CARERS CARD UK

Available to all paid and unpaid carers (including those receiving carers' allowance) the card provides access to online discounts, carer identification, personal support, a wellbeing hub, carer circle tool and more.

Find out more at www.carerscarduk.co.uk.

Did you know we have resources and helpful links on our website, including recordings of our previous Wellness Hubs and online exercise videos to follow along with at home? And, we're regularly adding more!

Take a look at our website: mdsupportcentre.org/service-user-resources.

If you know of a resource that you think would be useful to other service users, please let us know! Get in touch with communications@mdsupportcentre.org.

Joining forces for change

Ruth Hereford's journey with MD and the West Midlands Secure Data Environment



Living with a rare form of MD since her teens, Ruth Hereford knows first-hand the challenges of navigating a condition that's both complex and widely misunderstood. Now, as Chair of the MD Support Centre's Board of Trustees and a passionate advocate for research, she's working to change that for others.

"If you want to see a change, you must be part of that change. If you think things aren't the way you want them to be, get involved and participate," says Ruth. And Ruth is living this advice through her role on the Patient and Public Advisory Group (PPAG) for the West Midlands Secure Data Environment (SDE).

Diagnosed with a rare form of MD at 18, Ruth spent years feeling isolated by the lack of resources. Now, through her work with PPAG, she's helping advance research into MD and advocating for greater understanding and support for those affected by the condition. Ruth is one of 12 members of the public that support the programme's decision-making.

The West Midlands SDE plays a critical role in gathering data on MD, which Ruth describes as "very little understood." By securely collecting anonymised health data, the SDE offers a powerful tool to researchers aiming to unlock new insights into neuromuscular conditions.

She said: "There is very little data out there about MD. There are around 30 different kinds of MD and the knowledge for each type can be quite specialist. The West Midlands SDE provides a means of being able to gather data, so that conditions like muscular dystrophy can be studied and can be better understood, so that better support can be developed."

For Ruth, the prospect of future treatments has only recently become a possibility, as such data-driven research shines a light on new avenues. "I just thought I was on my own for the longest time," she says, "and it's only now that I see a light that there's a possibility of a treatment in my lifetime. And that treatment can't happen without anonymised health data."

The SDE ensures all patient data is stored and analysed within a secure, controlled environment. For Ruth, this approach provides peace of mind. "Before hearing about SDEs and how they work, I would have had concerns about my personal data being used," she adds. "But the measures in place to de-identify and protect our data reassure and give me confidence."

Ruth hopes that the collective power of anonymised data will enhance research into MD and ultimately improve the quality of life for many. "Working here at the MD Support Centre, we see a lot of people come in where they feel without hope," she shares. "This type of anonymised health data will help to change that."

If you are interested in joining Ruth on the PPAG, more information is available on the [West Midlands SDE website](#).

Whatever you bring to the table, your skills are valuable.

Volunteer profile: James Mackay

James Mackay is a professional copywriter and the Founder & CEO of copywriting service Copychomp. He also volunteers with MD Support Centre, We spoke to James about why he chooses to support MD Support Centre.

Can you tell us a bit about yourself, your role at Copychomp, and your background?

I run a copywriting and design company that helps organisations define their message and communicate it clearly to their audience. Since 2019, Copychomp has been supporting clients with websites, emails, brochures and plenty of other bits and pieces. Any marketing content you can think of - we've probably done it!

How long have you been supporting MD Support Centre and why did you get involved?

I got involved just over a year ago when I met CEO Sarah in a networking session at our local tennis club. We got chatting about MDSC, the work they were doing and how they needed help giving their newsletter a refresh. One of my first clients at Copychomp was an EDI consultant called Toby Mildon, who had a rare neuromuscular condition called Spinal Muscular Atrophy. I really connected with Toby and his story – so I saw the chance to work with MDSC as a bit of a homage to him and his resilience.

What inspired you about our work?

Before I started working with MDSC, Sarah sent me over some of your old newsletters and magazines. Reading through the service user stories and seeing how people showed up for each other in the community was impactful and inspiring. It made me want to contribute to the great work the charity was doing – even if it was in a small way with some newsletter content every few months.

What kind of work do you do as a volunteer?

I write and design MD Support Centre's email newsletters to make sure they're as effective as possible when it comes to spreading the message about what the charity does. There are so many volunteers who do much more important work than me – but it's nice to know I'm playing my part. If one person gets something out of the newsletter that they wouldn't have done previously, I feel like I'm making a difference. It's rewarding – and I hope to continue my work with the charity long into the future.

What would you say to someone thinking of volunteering with MD Support Centre?

If you're already thinking about working with MD Support Centre, it sounds like you're the kind of person who naturally wants to do some good and make a positive impact on people. So, all I'd have to say is 'do it!' Whatever you bring to the table, your skills are valuable and there's someone out there who'll benefit from your involvement.

Feeling inspired? Contact us to find out about volunteering!



Class and clinic schedules

Current clinic schedule

COVENTRY

Physiotherapy:

- Monday to Thursday
- Every other Friday and Saturday

Osteopathy:

- Two Wednesdays and one Saturday per month
- One Friday a month

BIRMINGHAM - BOURNVILLE

Physiotherapy:

- Every Friday and every other Monday, Tuesday and Saturday

BIRMINGHAM - MOVEWELL

Physiotherapy:

- Every other Monday

TIPTON

Physiotherapy:

- Every other Tuesday and every Thursday

LEICESTER

Physiotherapy:

- Every other Saturday

Complimentary therapy:

- Saturdays by appointment

DAVENTRY

Physiotherapy:

- Every Tuesday

DROITWICH SPA

Osteopathy continues to be available with Jane at the clinic in Droitwich by appointment.

Online classes

TUESDAY

2pm - Drop-In Seated Exercise with Ulrike or Siobhan

Perfect for trying out an online class. Suitable for all levels as exercises can be adjusted to individual needs. A gentle seated exercise class working on upper and lower body exercises, posture and core stability. *Theraband optional.*

6pm - Floor Pilates with Lynn

Intermediate Level Pilates class. 20 mins standing warm up/balance work, followed by 40 mins matwork Pilates on the floor. *Theraband, Pilates ball, floor mat needed.*

6pm - Beginner Floor Pilates with Siobhan

Beginner Pilates class. Standing warm up followed by Pilates matwork exercises on the floor. *Attendees will need to be able to get themselves on and off the floor at home, and have had a face-to-face session in advance to teach Pilates core principles.*

THURSDAY

10.30am - Drop-in Standing/Seated Mix with various therapists

Perfect for trying an advanced online class. Mixture of standing and seated exercise class working with cardio, posture, balance, core and a range of movement exercises. *Theraband and ball needed*

5.15pm - Drop-in Seated Yoga Class with Rewati

A 45-min chair-based class consisting of stretching and relaxation using Yoga techniques. The aim is to enhance relaxation of muscles and body and learn breathing control. *No equipment needed.*

FRIDAY

2pm - Drop-in Breathing Class - Once a month with France

Breathing techniques and exercises to aid respiration and facilitate a more natural breathing pattern. Self-discovery of the art of breathing along with Mindfulness, which is being aware of the body and its most important function - breathing. *No equipment needed.*

If you would like to book an appointment at any of our locations, join a class online, or want more information about our services, please contact our reception on 02476 100770 or reception@mdsupportcentre.org.



Upcoming Events



December

Christmas social

Celebrate Christmas with MD Support Centre.
Join us at our Coventry HQ for some festive fun.

3.00 - 5.45pm

In person

 Wednesday 4 December

January

Online coffee morning

Join us online on the second Wednesday of each month for a social get-together and a chat over a cup of tea or coffee.

11.00am - 1.00pm

Online

 Wednesday 8 January

Coffee morning, Bournville

Get together with our MD community at our Bournville Gardens satellite clinic to socialise and meet others.

11.00am - 1.00pm

In person

 Tuesday 14 January

Wellness Hub

Join us for a session on nutrition, maintaining muscle mass, protein intake, dietary supplements and gut health.

6.00 - 8.00pm

Online

 Monday 13 January

February

Online coffee morning

Join us online on the second Wednesday of each month for a social get-together and a chat over a cup of tea or coffee.

11.00am - 1.00pm

Online

 Wednesday 12 February

Coffee morning, Tipton

Get together with our MD community at our Tipton satellite clinic to socialise and meet others.

11.00am - 1.00pm

In person

 Thursday 13 February



Keep in Touch



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www.facebook.com/mdsupportcentre/



Find us on LinkedIn here:
www.linkedin.com/company/muscular-dystrophy-support-centre

Sign up!

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

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.



CLICK HERE



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.

Do you have a creative hobby? Participate in sport? Or could you recommend a life changing piece of equipment or adaptation that would possibly benefit others?

Please reach out to Nina or Helen to share your ideas and contributions. Email nina.hanks@mdsupportcentre.org or helen.mccarroll@mdsupportcentre.org