



The Adaptability Issue

Summer Edition 2024



Paul - Out & About with Omeo



Navigating Care Support with Diana

Leanne - Inspiring Independence at our Open Day

Also inside this issue:

- New Adapting to Change Group
- Safe & Well Visits
- Service User Survey Results



And New Horizons for Bhavesh

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MD SUPPORT CENTRE OPEN DAY

29.06.24
REGISTER NOW

29TH JUNE 2024
10.30AM - 5PM
FINHAM PARK 2,
TORRINGTON AVE,
COVENTRY, CV4 9WT



Register here
<https://bit.ly/MDSCodininvite24>



Yes we will have the Insta Wall returning!
Make sure to check it out!



A Note from our CEO Sarah-Ann Moore

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

The theme of this issue is “Adaptability”, and in this edition you will find stories from our service users sharing how they have adapted to changes and transitions through their personal journey with MD – whether that is getting used to new assistive equipment or dealing with the emotional aspects of changes in mobility. We are also delighted as a charity to introduce our new “Adapting to Change” peer support group, led by a starting group of service users with the support of our Chair of Trustees and lead physios. This new group will be meeting regularly and available to any service user/carer who would like to share their own experiences of adapting to change, or to seek the advice of others in a caring and supportive peer environment. See the article later in this issue about this group.

As ever, if our magazine topic is of further interest to you, please also look at our MDSC Blog page for additional service user content

<https://mdsupportcentre.org/blogs/>

Since our last magazine in January, MDSC have been busy continuing to develop our team and services – including recruiting new physiotherapists and reception staff, planning for our Daventry Satellite Clinic Launch in May, and preparing for our biggest event of the year, our Open Day in Coventry at Finham Park 2 School on Saturday 29th June. Last year’s Open Day was a huge success and had a real impact for many of our service users – you can read on p21 how last year’s panel discussion on transitions inspired our service user Bhavesh to make changes in his life, and also led to the creation of our Adapting to Change group. This year’s Open Day promises to be another bumper event with opportunities to meet our team, socialise with other service users, and connect with other organisations of interest. We will be sharing more information about the line-up in coming days so please look out for details and don’t forget to register to join us at <https://bit.ly/MDSCodinvite24>

Thank you as always to our Service User Content Editor, Emily Bonner, for her hard work on this magazine, to all of our contributors, and to our hardworking team of staff, therapists, and volunteers. I always describe our charity as “small but mighty”- working enthusiastically and tirelessly to do more for more people with MD. We can only do what we do with the kindness, support and generosity of our amazing community of service users, carers, funders, and partners.

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



Therapy Update

Recent months have been busy as ever for our therapy team with exciting developments in our Centre, and at our satellite clinics:

Daventry Satellite Launch

On Tuesday May 21st we were delighted to formally launch our Daventry Satellite Clinic at the Reach for Health Centre (Stefen Hill, Stefen Hill Ground, Western Ave, Daventry NN11 4UD). After piloting the clinic for many months and gathering feedback, it was great to invite new and prospective service users to join us for a coffee and a slice of cake to celebrate the launch of the site. We were pleased to introduce our “new” physiotherapist Kate Andrejevas who will be running the clinic. Many of you may recognise Kate as she previously worked with MDSC in Coventry. We are delighted to welcome her back to the charity and are pleased to share that with her help our new Daventry satellite clinic will be operating every Tuesday (an extra 2 clinic days per month).



Recruitment



In addition to Kate, we have been delighted to add new Physiotherapist Tzoulia Petsi to the team. Tzoulia is an experienced physiotherapist who has worked in a variety of clinical settings, including providing hydrotherapy. She currently works Tuesday-Friday at our Coventry Centre, enabling us to offer 3 more clinic days there per week.

We have also welcomed Allyson Brown to our Reception and Administration team. Allyson started volunteering with us at the beginning of the year and is now working 3 days per week on reception.

We are continuing to recruit for paid and volunteer roles across all of our teams, including to work alongside our Chair of Trustees on IT and infrastructure development.

New "On-Demand" Exercise Classes

Our physio team have been working hard to prepare new pre-recorded exercise classes for our website so that service users can have the flexibility of being able to take part in more sessions "on-demand". We have added 5 new pre-recorded MDSC exercise classes (themed around stretching, balance, yoga, cardio, seated and standing) on our Service User Resources page (<https://mdsupportcentre.org/service-user-resources/>).

We are also continuing to develop this area of our website to signpost new and useful resources from other organisations, so do please check it out.



Aquatic Therapy Exercise Classes



Our physios are excited to trial a 6-week block of group aquatic therapy exercise classes again this summer at the Xcel Centre in Coventry. We will be offering 30-minute group sessions on Tuesdays at 1:15pm and 2pm for 6 weeks (23rd July 2024 to 27th August 2024). The cost will be £60 (£10 per session for a block of 6 sessions). If you are interested in attending or would like more information, please speak with your therapist.

We recognise that, because these classes will be taking place in a swimming pool environment rather than a heated hydrotherapy pool, unfortunately they will not be suitable for everyone but we are continuing our tireless search for hydrotherapy facilities and hope to be able to offer other options soon.

Check out our latest in-person clinic and online class schedule. If you would like to book an appointment at any of our locations, join a class online, or would like more information regarding our services, please contact reception on 02476 100770 or by email at reception@mdsupportcentre.org.

Online Class Schedule



TUESDAY

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

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

Theraband optionally required.

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. Attendants will need to be able to get themselves on/off the floor at home and have had a face to face session in advance to teach Pilates core principles.

THURSDAY - AM

10.30am - Drop in Standing/Seating 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*

THURSDAY - PM

2:20pm - Seated Exercise - with Chandni

Seated exercise class. Working on upper and lower body range of movement, cardiovascular, core stability and stretches. *Floor mat required.*

5.15pm - Drop in Seated Yoga Class - with Rewati

45 min class consisting of stretching and relaxation using Yoga techniques. The aim is to enhance relaxation of muscles and body and learn breathing control. Warm up focuses on on breathing control, followed by chair based stretches, ending with a cool down promoting relaxation and mindfulness. *No equipment needed.*

FRIDAY

2pm - Drop in Breathing Class - 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.



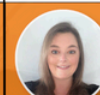
Dan



Ulrike



Lynn



Siobhan



Chandni



Rewati



France



Fundraising Update

Hi everyone, I am Nina, the Engagement and Fundraising Officer. I have been with MD Support Centre for 4 years now and what a journey it has been!

You might have seen me hiding behind my laptop in the office, creating the newest social media posts or events schedule. However, you might know me better from our online and in person coffee mornings and events and being the person asking you for a photo or quote whilst you have your session with your physio. I also look after all the service users that decide to organise and run a fundraising event or fundraising challenge for us, such as the golf days, quiz nights and marathons!

I love hearing all your stories and if you fancy sharing over a cup of tea, or if you have an idea for your own fundraising event or challenge, why not come and find me or contact me at nina.hanks@mdsupportcentre.org. I look forward to hearing from you!



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. Whether you have made a donation in the Centre or a satellite, donated online or organised your own fundraising event, it all matters. Thank you!

Special thank you to Fady and Imogen, who ran the Birmingham half marathon in memory of Fady's late father Rafik. Complete non-runners (by their own admission), they managed to complete the half marathon and raised a fantastic £1,153





Colin, partner of Service User Kaye, walked an astonishing 3 million steps in 8 months and raised £700! Thank you so much!

Service User Andy held his annual golf day, and what a brilliant day it was. The sun was shining on the teams playing and he raised a total of £764. Thank you so much Andy!



Trustee David hosted his annual quiz night. Everyone enjoyed a lovely evening with good food and some tricky questions. £505 was raised! Thank you so much David!

The MD Support Centre Easter raffle was a great success again this year and we raised a total of £168. Thank you to everyone who contributed to the raffle and bought tickets.

We're also incredibly grateful to those who have thought of us recently with in-memoriam donations. We really appreciate the gesture at such a difficult time. If anyone is thinking of supporting us in this way, please see our new in-memoriam and legacy giving pages on our website for information to help with this.

Our Year as the Lord Mayor's Charity



Our time as the Coventry Lord Mayor's Charity has come to an end, but we would like to thank the Lord Mayor Jaswant Singh Birdi, Lady Mayoress Krishna and their Council team for their support over the last 12 months. Choosing us was critical in raising awareness of our small charity. We were honoured to have been chosen alongside other local charities - the Coventry Resource Centre for the Blind, and University Hospitals Coventry and Warwickshire Charity.

It has been a fantastic year.

Thank You !

Corporate

Are you in employment? Does your (or a partner/family member's) company have any charity initiatives, perhaps matched giving, payroll giving, grant programmes or charity of the year schemes? If so, please let us know so we can work together to get MDSC on the list of charities they support.



Did you know?...

In centre and at some satellite clinics we have our Paya machines. These are tap and go devices to make it quick and easy to donate. When giving, if you can take a few minutes to enter your details using the QR code on-screen or printout, we can claim an additional 25% in Gift Aid on your donation, securing even more money for our charity.

Events

Are you free on Saturday 29th June? Why not come to our Open Day and volunteer for a few hours or the day.

The day runs from 10.30am to 5pm at Finham Park 2, Torrington Ave, Coventry, CV4 9WT. We are looking for happy helpers to man our tea and coffee stations, advise people where to park, for photography and AV support and to just chat to attendees. If you are interested, please contact Nina at nina.hanks@mdsupportcentre.org.



Upcoming Events

Coffee Morning in Coventry

Join us at our Coventry HQ for an informal catch up with fellow service users.

10.30am - 12.30pm

In Person

 **Wednesday 24 July**

Steering Group Meeting

Join in and help us shape the future of our Charity!

10.30am - 12.30pm

Online

 **Wednesday 24 July**



Service User Survey Results

Our 2024 Annual Service User Survey will be out soon so watch this space!



CEO Sarah Ann Moore shares key findings and feedback from our 2023 questionnaire

We are excited to share the results of our Annual Service User Survey 2023! Thank you to everyone who took part in the survey and shared feedback on the services that the Charity provides.

Special thanks to our volunteer Richard Wilson RGN BA(Hons) MA(Econ) MSc, formerly Health Services Research Project Manager and Information Governance Manager in the School of Health and Related Research, University of Sheffield, who kindly donated his extensive skills and experience to collate the results into the formal report that you can read [here](#).

We are delighted that the survey results continue to demonstrate the enormous impact that we are having on the health, well-being and quality of life of our service users and carers. Key findings include:

- 77% of survey respondents said MDSC had helped them understand and manage their condition, 75% stated that their motivation was improved and 76% indicated that the MDSC assisted them to live well with MD
- 75% said that our support – online and face to face – helps them maintain their emotional wellbeing, and 79% said our support helps them build their physical resilience
- 89% were in agreement that our support helped keep their joints flexible, and 82% said it helped maintain muscle strength.
- 77% said our support prevented or reduced falls, and 73% indicated that their therapy helped to keep them out of hospital and reduced their reliance on other healthcare services.
- 76% said our support helped slow the deterioration of their condition, and 73% said that therapy support helped them manage pain.

Our team have really enjoyed reading through all of the lovely feedback and comments that so many respondents provided. We have also spent time reflecting on some of the great ideas and constructive feedback that came through, such as:

- Making more services available at satellite clinic locations
- Selecting music to make the environment in-Centre calmer and more relaxing
- Forging links with local taxi firms to help service users to get to us
- Implementing online booking for appointments
- Considering a monthly subscription to enable use of equipment

As we continue to work on our strategy for the coming years, we will provide updates on the positive changes that we can make in these areas.

All of the feedback that we receive is incredibly valuable in helping us to better shape our services, aligning what we do to what our service users want.

Feedback is also critical to demonstrate the impact that we are having and it enables us to access vital funding to keep the Charity going.

If you have any thoughts that you would like to share on any aspect of what we do at MD Support Centre, please do not hesitate to contact us at feedback@mdsupportcentre.org, and of course, we hope that you will take part in our next Annual Service User Survey which is due to be issued in **July**!

Navigating the Journey Towards Care Support

by Paula Irish

Former IT consultant Diana Wright has managed transitions throughout her life alongside the progressive muscle-wasting condition Charcot-Marie-Tooth.

Born in Khartoum, Sudan, in 1955, her mother's concerns that she was a 'floppy' baby were dismissed by doctors. But when she started missing the usual physical milestones like running, the family returned to the UK seeking a diagnosis.

Great Ormond Street Hospital believed it to be a neurological condition. It wasn't until Diana was around 30 years old, however, that the National Hospital for Neurology and Neurosurgery in London genetically diagnosed CMT1a.

Diana was able to walk with crutches and pedal a tricycle, then as movement became more difficult, switched to a manual wheelchair during her secondary education years.

With her parents encouraging self-reliance, after getting a local council job as a trainee computer programmer, Diana moved into a rented ground floor flat in the family's home village of Harpenden at the age of 21 and says:

"I was independent and driving myself to work in Luton in a blue three-wheeler 'Noddy Car' from the Department of Health and Social Security."



Diana's early years of walking with crutches and her tricycle

A subsequent work move to Barclaycard for 20 years saw Diana buying a detached house in Northamptonshire, where she was still able to transfer to and from a wheelchair, and social services put in a stairlift.

But by 2003, it was all becoming more difficult and the risks were increasing.

"I could see the writing on the wall," recalls Diana.

"I wasn't safe to do the standing and was finding it incredibly difficult to do transfers onto the stairlift. It took a huge effort and I needed to make my life easier."

Thinking Ahead

Diana moved to a bungalow in Flore for 20 years until 2023, during which time she says it became increasingly harder to bear her own weight:

"I had to think about getting a hoist in readiness for the day I wasn't able to do it.

"I didn't want an accident to happen because that can completely ruin your life and that of your family, who have their own lives to lead, so I got a ceiling hoist that allowed me to self-hoist and still physically do the transfers by myself.

"But it was taking me longer and longer to do this and to get dressed, or have a shower, so I began to think about the need for care."

Never unemployed, Diana's career had included gaining a BSc Hons Degree in Computing and IT Software Development, and with a good salary, she had savings.

As such Diana did not qualify for social care help with day-to-day living - and had to fund this herself – but was able to use Access to Work for a Personal Assistant (PA) to support her continued employment, including for driving.



Clinical Need

Diana took early retirement in 2007 and following the onset of respiratory failure in 2015, now needs overnight ventilation support.

Without the physical functionality to don her own mask or sit up in bed, Diana has an NHS personal health budget and a contribution from social services for personal care.

This provides 77 hours a week of support which Diana uses to employ a two PAs on a three-day rotation, providing a sleep-in role from 10pm-8am. Diana then pays them to continue their shift to provide day support and housekeeping.

Based on her own experiences, Diana has the following insights:

- You will not get social care support if your savings and income are above the means tested threshold, so it is necessary to plan for this. If you have no savings you will be more able to access social care. · Each local council has criteria for accessing social care and what councils offer can be a postcode lottery. You may have to pay towards your care and the more money you have, the more you'll be expected to pay.
- Clinical medical needs – such as Diana's need for support with breathing, risk of choking/aspiration – and the need for personal help with toileting – score highly.
- Ask your multidisciplinary team rather than your GP for help with writing your application for continuing healthcare. It was only when The National Hospital for Neurology and Neurosurgery wrote the application for Continuing Healthcare to Northamptonshire NHS that things started to move forward for Diana.
- Social care is reluctantly given and may not be the standard you want, so be prepared to pay for the quality of care you would like.
- When recruiting a carer, it's important that the individual is companionable but it's necessary to remember that you are an employer and the carer is an employee, so there is still a line to be drawn in the relationship.

Acceptance of Care

- Employing carers directly - rather than using an agency - enables you to establish your preferences for care and routines.
- If moving home becomes a necessity, health and social care budgets need to move with you, along with your care package and GP records – plan for this and don't assume it will all happen smoothly or automatically!

Diana and her sister built a home together last year to meet both their needs, with Diana living in an annexe with a large bedroom and bathroom each equipped with ceiling hoist, while her sister is in the main house. This practical solution enables them to see each other more easily as they grow older and for Diana to see lots of her nephews and nieces and their children.

Diana adds:

"My sister is not my carer though because it would strain and potentially ruin the relationship. Too often the NHS and society think family can step in and do the things they should be doing. But as a person with a disability, I don't want to be in the position where I'm having to call on my family to look after me."

Now aged 68 and retired, Diana is happy in her own company but misses the spontaneity of when she was able to live independently without carers.

"You do have to meticulously manage your life," she explains. "Gone are the days of getting out of bed when you wake up because you have to tell your PA when to come in to work. And I feel that I can't be myself anymore because there is always someone in the background, whether that's when I go out in the community, or in a family setting. It's also frustrating when people engage with the PA and not me."

"Accepting the need for care is a hard thing to do - and you do mourn for the life you had - but you have to come to terms with it."



"What I would say to people is don't leave it too late to make the big decision about needing care – or wait for the life changing event - because that might mean the outcome is not as good as if you had planned and put in place what you need."

ADAPTING TO CHANGE



Introducing our new Adapting to Change group

Formed by Chair of Trustees Ruth Hereford along with Lead Physiotherapists Ulrike Uta and Lynn Ward, our new Adapting to Change group was born from our 2023 Open Day's Transition Panel whereby Ruth and service users John Goodman, Leanne Herbert and Tony Corbett answered questions about transitioning as their decrease in mobility progressed. It has been a long-held aim at MD Support Centre to form service-user peer groups for support and sharing.

Here we introduce you to some of the group.



The panel from our 2023 Open Day L-R Tony Corbett, John Goodman, Leanne Herbert, Ruth Hereford

From our Chair Ruth



For many years after diagnosis, I lived alone with my diagnosis and uncertainty about my future. My family and close friends knew but I avoided discussions or my own feelings about it. I'm not sure if I was afraid of meeting others with MD or if I was in denial about my MD despite dealing with the effects of progressive muscle weakness. Even after meeting others with my condition, I didn't actively engage with others for support or sharing experiences and info.

It was only after getting involved with MDSC (NMC Midlands) when it was formed that I began to see how much more could be done with support and sharing. Reflecting back on the years wasted in living alone with my MD, not adapting to changes more quickly and what I could have been doing and enjoying is what has inspired me to support others to live better for longer. Stories like Leanne and Bhavesh's recently posted on the [MDSC blog](#) and also on page 21 of this magazine show what is possible when we connect with others to share experiences and understanding.

Ruth Hereford

Initial Starting Group

We are an initial group of service users working on getting the group up and running but we invite our fellow service users to not only take part in sharing experiences but join us in developing the group.

Our initial group consists of:

John Goodman
Leanne Herbert
Neil Corfield
Mark Thompson
Tony Corbett
and Emily Bonner



"I am keen to learn from others about transitions and have been through a few with varying degrees of elegance. I find thinking and talking with others living with MD supportive, fun and informative. So I want to do more of it!"

Mark Thompson



"I understand only too well the battle between mind and body - sometimes it takes time for both to align!

In my case going from feet to wheels!

You often feel quite isolated despite knowing you are not alone when it comes to making these life changing decisions so I want to be able to support others from a firsthand experience of muscular dystrophy progression"

Emily Bonner

The group held its first on 12th June (in centre and online). To hear how it went and for more information about the group you can speak to members on 29th June at our Open Day where they will be hosting an informal social connect in our exhibition area. Alternatively, check out our website for details of the next meeting.



Paul - Out & About with Omeo

by Paula Irish

MD Support Centre service user Paul Dowling rediscovered a sense of independence and freedom after starting to use an Omeo. Omeo pairs innovative technology and compact design in a two-wheeled mobility chair with hands-free operation, a 0-degree turning circle and all terrain capability.

Having first heard about the Omeo from his mum and at MD Support Centre after it appeared on the TV show Dragon's Den, Paul acquired one in December 2023.

It has been transformational in enabling him to keep up with both work and family.

Sharing his story, Paul says:

"My condition was getting progressively worse and I knew I was going to need a wheelchair fairly soon, so I started researching what was out there. Up to that point I'd been using crutches for two years.

Mum had seen a Dragon's Den episode and said there was a really good product that would help me, then I came into MD Support Centre for a physio session, a day or so later, and I heard it was called an Omeo.

I started looking at the company's videos online and decided I was going to get one. It's only got two wheels so it's like a seated Segway – it's self-balancing with a gyroscope and you can go off road, on the beach, up and down hills!

Mum had seen a Dragon's Den episode and said there was a really good product that would help me



I've got two boys aged six and 12 who both play football and like to be out and about, and crutches were really limiting me, so I knew if I was getting a wheelchair, I wanted it to do what the Omeo can do. It's fantastic!

The top speed is 12mph and it can go 40 miles in a single charge. I'm able to go and watch my boys play football and go out with them on bike rides. I'm also a Villa fan and I'm able to go to a game with them again for the first time in ages.

With a travel cover and off-road wheel extras the Omeo came in at around £21,000. The company Adapt Ability UK have trial days when prospective customers can try it out for themselves, and the team suggested that support may be available to fund it through the government's Access to Work scheme. Mandy-Jayne of Accessibility Partners then helped me through the process of applying and made sure she was with me on the telephone call with the assessor, and that I was faithfully represented. If you are using it for work, a proportional amount of funding support is approved to help cover the costs.

I work as an operations director in a multimedia company and when I was going out for meetings previously, I had started to have falls which were embarrassing and a risk. The Omeo has enabled me to go out on client visits again."

Paul is happy for people to get in touch with any questions if they would like to find out more, email: dowlipa@sky.com

Further information

Omeo Technology: Find out more about the innovative Omeo design -
www.omeotechnology.com

Adapt Ability UK: Information, testimonials and blogs, book a trial or place an order -
www.myadaptability.co.uk

Accessibility Partners: Support with access to work funding and adjustments in the workplace - www.accessibilitypartners.co.uk

You can also check out our Employability Wellness Hub video on our You Tube channel! The session was led by MJ pictured right and is a gem of information and advice
[Click Here](#)



Mandy-Jayne (MJ) Lane of Accessibility Partners

Safe & Well

by Emily Bonner

First off - if you aren't a member of our Social Group on Facebook do consider joining (link below) - sometimes invaluable information is shared between service users and in this case, there was no exception.



<https://bit.ly/MDSCsocial>

Back in April a service user posted about a dramatic event whereby her smoke alarm was screaming every 45 seconds! Can you imagine, those things are deafening at the best of times. After 3hrs, 2 batteries and 2 phone calls later it transpired her alarm was malfunctioning and she was told by a friend that she should have called the local fire service to change the battery. Once the watch commander rocked up to change the batteries and check the alarm a further conversation about evacuating at night in the event of a fire ensued.

It's a worrying thought is it not and I'm sure has crossed many of our minds, especially as we are more vulnerable at night when asleep anyway but coupled with mobility issues and the extra time it can take to just get out of bed.

The service user in question was later reassured by promise of 4 engines, a crew of 20 and a big sledgehammer!

So, in their words:

- If you can't change your smoke alarm battery or reset it, call the fire station.
- If you want fire advice and to let them know you exist, give them a call too! *

*This service is typically called a Safe and Well visit. You can ask your OT for a referral or alternatively search for your local fire service's Safe and Well and request them to visit you.

In my personal experience a Safe and Well visit is very 'belt and braces'. For example, things like charging your wheelchair outside and not overnight isn't exactly plausible.



I also learnt firefighters are the worst for not following their own advice! I was told of a firefighter who had a house fire due to an indoor sauna, and the chap who visited me told me of a suspect smell coming from his kitchen which he later discovered was the block extension overheating because he'd plugged both his washer and dryer into the same one! He now carries it around with him to show people what not to do!

Things I learned:

- Get an extra smoke alarm! I got an extra smoke alarm (totalling 3 in a small one bed bungalow) I was assured I'd hear them!
- Don't overload extension cables and use high powered items like kettles, hair dryers and portable hobs directly into wall sockets
- If I were trapped in the bedroom at night closing the door would give me an extra 20 mins
- If I can get out do so before calling the emergency services (to save time) this would involve throwing myself to the floor and attempting to crawl...
- Consider getting alarms connected to a call centre
- Ask for extra sockets to facilitate my electric bed (currently all 4 bed plugs are plugged into in one extension lead) ...
- Don't do what the fire officer does, but do as he says!

Here's a link to the West Midlands Fire Service website (with links for Staffs, Warks fire services etc. too) -

<https://www.wmfs.net/our-services/safe-and-well/>

FEELING GREEN FINGERED?

Did you know you can apply for grants to help make your garden accessible!

Check out

[Home - Gardening With Disabilities Trust](#)

Individuals can apply for small grants to help with their gardening needs such as raised beds and accessible pathways



INSPIRING INDEPENDENCE AT OUR OPEN DAY

by Paula Irish

When Leanne Herbert shared her journey towards full time wheelchair use at our Open Day in 2023, it inspired fellow MD Support Centre service user Bhavesh Tailor to reconsider using a powered wheelchair to support his independence.



As part of her role at De Montfort University, Leanne co-chairs the Staff Disability and Wellbeing Network, as well as delivering training on disability and mental health awareness.

Invited to speak at MD Support Centre's Open Day, Leanne shared her own experiences on the topic, which she said, "resonated with so many people".

Leanne has been a wheelchair user for more than 15 years but confessed that, in the period prior to this, using a chair had "never really entered my head". However, days out had started to become uncomfortable and stressful due to multiple falls and, on one occasion, resulted in a trip to hospital and missing a friend's wedding.

"I knew that even though I'd rather be up on two legs, using a chair would be much safer," she explained, and that the added safety would make it easier to visit places and, ultimately, "lead to more freedom".

Despite this realisation, Leanne found the prospect of using a wheelchair a difficult decision to make - even considering using a mobility scooter as an alternative. She remembers Claire Lomas MBE - a motivational speaker, campaigner and former event rider - describing choosing her first wheelchair as a question of: "Do you hate this chair a little less than that one?" It was a quote which helped to humanise the process for Leanne.

Freedom

Leanne secured an Access to Work government grant to support her changing needs in the workplace. This currently funds equipment for her such as a wheelchair, and workplace adaptations, including a pillar lift to reach lecterns. Since 2017 it has also funded an assistant to help Leanne with personal care, and with physical tasks such as using the photocopier.

In 2009 Leanne began to use a wheelchair full time and in 2011 transitioned to a powered chair. She explained one of the drawbacks of this change was that transfers were more difficult: "I did become more reliant on people". However, as she points out, it is impossible to know: "Is it because I'm using the wheelchair, or just the natural progression of MD?"

The hardest adjustment, she says, is "realising the freedom a wheelchair will give you over anything else". Having once attended a job interview with sticks and finding it a struggle, Leanne described how - mid-way through the interview - she said to the panel: "Sometimes I use a wheelchair, is that a problem?" The panel were very supportive, and she reflects: "I do think now the interview would have gone better had I just gone in my wheelchair."

Leanne doesn't downplay the mental toll of transitioning to a wheelchair: "It takes some getting used to, and is hard, but in time a wheelchair becomes part of your life."

In the end, the problems Leanne experienced while trying to navigate the world without a wheelchair were more limiting: "My chair always used to be in the back of the car. Now I think 'if it makes my life easier, I'll do whatever it takes'. I'd rather that than still be walking and not be able to work or enjoy a day out."



The message from Leanne is a simple one – don't fight it. The magnitude of deciding to transition to a wheelchair cannot be underestimated. However, if the alternative is avoiding going out, or a constant worry of falling, she would urge people: "Do not stop living."

New horizons



Bhavesh is also from Leicestershire and works full-time from home as a planning coordinator for a water services company. Referred to MD Support Centre from a yearly hospital appointment, he finds the regular therapies at our Leicester satellite clinic ease the tension in his calves, shoulders and neck from sitting at a desk five days a week.

He says: "The talk by Leanne caught my attention because of the way she sold the benefits of using a wheelchair full time. It made me think about it for myself and my family because I just had a manual wheelchair and going out to places was getting difficult, as my wife had to push me around and I wasn't able to have any independence.

It opened my eyes and I thought maybe it's the right time for me to switch to a powered wheelchair.

I didn't do it before because I was a bit hesitant about using a wheelchair on a permanent basis, as I worried it would make my legs weaker and stiffer: that was the downside and the fear I had about it. But I wanted to be more mobile and I bumped into a lady in a wheelchair who lives near me in the same village and she also explained the benefits, so I decided to make enquiries."

Bhavesh is in his 50s and says his decision was also influenced by looking ahead to the long term, with a view to making life easier not only for himself but also for his wife, who is in her late 40s, and their son who is a medical student and living at home while at university.

He enthusiastically describes getting his first powered wheelchair in October 2023 and says he hasn't looked back since. With an NHS referral from his GP and putting half towards the cost personally, he was able to choose a practical, lightweight and foldable wheelchair suitable for using inside as well as outside of the house, and which his wife is able to lift in and out of the car.

It is ideal for getting into town or shopping - which now doesn't need his wife to attach a wheelchair to a supermarket trolley and push both - and the couple are looking forward to holidays.

Bhavesh says: "My condition can be frustrating but you have to jump that hurdle and be positive. My world had started to shrink and I couldn't go anywhere on my own. But now I can sit in my wheelchair and go to the local shop and come back, and that goes a long way for me and my wife. I can also go out by myself with my friends to a restaurant or on a boys' night out.

"There are so many benefits in having a powered wheelchair, it's been amazing. It's brought back my independence and now if we're shopping, my wife can go and do whatever she wants to do, while I'm able to wander off somewhere else doing my bits. It's really boosted my confidence and it's easier for her too. She has to find me now in Tesco's and sometimes even has to ring me on my mobile phone to ask: 'Where are you?!'"

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