



Kev's 7 in 7 in 7 challenge

MND community takes on 'Extra Mile'



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On the cover: Kevin Sinfield CBE on the final leg of his 7 in 7 challenge



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Welcome

from our Chief Executive

December proved a whirlwind end to my first year at the Association. It was a privilege to be invited to the International Alliance of ALS / MND Associations meeting to share some of the opportunities and challenges of the last 12 months and to talk about the vision for our growing organisation.

The following day I found myself in the presence of 1,300 of the greatest scientific minds in the world as we opened our 34th International Symposium on ALS/ MND in Basel, Switzerland. It was our first in-person Symposium since 2019 and there was such passion and energy as people collaborated, shared and created new partnerships.

There was a similar feeling of anticipation at the launch of the UK MND Research Institute at King's College London in November. The Institute was born out of a shared vision by people with MND, researchers and MND charities. It will provide a virtual hub for researchers and clinicians to share ideas, knowledge and expertise in the hope of finding the answers we all desperately want. Read more on page 21.

I raced back from the Symposium to cheer our patron Kevin Sinfield CBE over the finish line of his latest challenge which saw him run seven ultra marathons in seven cities in seven days. Each day he was joined on the 'Extra Mile' by people with and affected by MND, which was incredibly moving to see. Once again, Kev smashed his £777,777 fundraising target. You can read more and see photos on page 6-7.

On page 18-19 there's an exclusive behind the scenes peek of the Association's new television advert. The series of films featuring people with MND and their loved ones will be shown on ITV during *Coronation Street* ad breaks over the coming months. We hope they, and the accompanying publicity and social media activity, will inspire some of the six million Corrie viewers to support the MND community.

And talking of the MND community, as I write hundreds of you are involved in Fundraising Takes Over, our annual January push to raise money to fund the Association's work. There are some amazing photos and stories being shared on our socials channels – do take a look. And if you're inspired, our fundraising team would love to hear from you!

Finally for this issue, the Directors and I are planning a series of roadshows taking us the length and breadth of the nation this spring to meet branches, groups and volunteers. Do look out for more about these events in the coming months – we hope to see you there!

Tanya Curry, *Chief Executive*



International MND research and healthcare at the 34th International Symposium on ALS/MND



After three years of attending the event online, the MND research and healthcare community reunited in-person at the 34th International Symposium on ALS/MND in Basel, Switzerland.

From 6 – 8 December 2023, we welcomed one of our highest attendances, more than 1,300 delegates, including researchers, health and social care professionals and people living with and affected by MND. Another 350 delegates joined us online from across the globe.

The International Symposium is the largest event in the global MND/ALS

calendar, where research and healthcare professionals can hear about the latest research, share ideas and foster collaborations to drive us towards effective treatments and improved care for people living with MND.

Three sessions ran in parallel on each day, beginning early in the morning until late in the evening, meaning more than 100 talks were presented. The work presented showed the depth and breadth of MND research around the world. The topics covered included clinical trials, diagnostic markers and disease models through to clinical practice, cognitive



The Symposium is very powerful and it makes people feel they belong to this specific group of people. It's a way that you grow as a scientist and you cannot overestimate the contribution this event has made to the science."

**Professor Martin Turner,
Researcher**

change and improved care.

In the opening session, we heard from Dr Rui Costa from the Allen Institute, based in Seattle, in the Stephen Hawking Memorial Lecture. He discussed how his team is creating maps of the human brain to learn more about how we control movement. Knowing how these systems connect and function over our lifetime, will allow a greater understanding of how these systems go wrong in MND.

We were later joined by Dr Caroline Ingre from the Karolinska Institute in Sweden. She spoke about how the care for people with MND is not the same for people in





different countries. Access to clinical trials and educational resources drastically changes with location. Dr Ingre is looking at how to offer better access to all people affected by MND, regardless of where they live.

The clinical trials session was extremely popular with people lining the room to hear the latest updates. Professor Merit Cudkowicz showed the additional findings seen with the drug treatment, in people with a SOD1 mutation, accounting for around 2% of all MND cases. Professor Cudkowicz highlighted the long-term results from the VALOR trial which were consistent with the short-term results.

“
It's fantastic to see all areas, from biomedical to clinical research come together for a common goal.

Elise Kelleff, Early Career Researcher

The level of a marker of nerve damage, called neurofilament, remained low

when Tofersen was taken for a long period of time suggesting Tofersen continues to be effective long-term. This treatment, although applicable to only a small proportion of people with MND, has given hope and a sense of optimism to the whole community.

“
It's been really exciting. I've enjoyed every moment of it. I would absolutely recommend for other people living with MND to attend.

Rick Nelms, Patient Fellow

In the closing session we felt further optimism as encouraging results from another potential treatment for a rare genetic and aggressive form of MND, known as FUS-MND, were presented. All presentations demonstrated the increased pace of discovery and highlighted the volume of important research findings that are moving us closer to effective treatments.

Powered by eyes

The Association has partnered with a London-based wheelchair service to trial the use of eye gaze to independently drive a wheelchair.

An app called *Ability Drive* is loaded onto the control system of the wheelchair and viewed through the eye gaze communication device. The wheelchair user will see directional arrows on the screen. To move, the user will look at the arrow box to drive the chair in a specific direction. When the user wants to stop they will look away or close their eyes.

In December, our Wheelchair Support Service team presented the trial findings to the International Alliance of ALS/MND Associations (AHP) in Basel, Switzerland, highlighting the advantages and disadvantages of the technology. The study had been undertaken with two people who are living with MND and who are already competent eye gaze users, with no other accessible movement to operate a powerchair independently.

Through the trial, both users were able to operate their powerchairs affording them independent indoor mobility and reducing the need for carer support. The carer of one of those involved told Anne Buchanan, Care Improvement Co-ordinator: “After four years of loss, some independence is returned. It's hoped that this success will pave the way for future users who will gain even more as these wonderful technologies develop.”

While this technology offers great potential there are some limitations. The technology is very new which means it's very expensive. Eye gaze can also be difficult to use in direct sunlight, so this may affect its use outdoors. The integration of the wheelchair and eye gaze device is complex, and the *Ability Drive* system may not be compatible with the wheelchair or eye gaze device that's been provided by wheelchair services.



If you have any questions please contact wheelchairqueries@mndassociation.org for more information. Please note, eye gaze assisted driving will also require support from all relevant local community teams for effective assessment and provision.

Super Kev smashes 7 in 7 in 7 challenge... and he wasn't the only one who went the Extra Mile



“The MND community is a beautiful community and it needs all of us to keep fighting. The awareness we've generated this week has been enormous again in Rob's name. Fundraising is so important.”

Kev addresses supporters before the final leg of his 7 in 7 in 7 challenge

In December, in another epic feat of endurance, Association patron Kevin Sinfield CBE completed his fourth fundraising challenge to raise awareness and funds for MND, inspired by his friend and former team-mate Rob Burrow CBE.

Dubbed the 7 in 7 in 7 challenge, Kevin and the team ran 7 ultra marathons in 7 cities in 7 days, raising more than £1 million for the MND Association and four other MND charities.

Rugby league legend and fellow Association patron Rob joined the team for the start in Leeds, and from there Kevin moved on to Cardiff, Birmingham, Edinburgh, Dublin, Brighton, finishing on the Mall in London.

This time there was also a special twist – one mile of the 27.2 mile daily

route saw Kevin joined by members of the MND community. This 'Extra Mile' signified the extra lengths people go to support their friends and family who need help in tough times, and gave Kevin the opportunity to thank hundreds of people across the UK for their fantastic support of his previous challenges.

Speaking at the finishing line, Kevin said: "The MND community is a beautiful community and it needs all of us to keep fighting. The awareness we've generated this week has been enormous again in Rob's name. Fundraising is so important because that's the thing that's going to shift the dial for us. That's the thing that's going to get us a cure.

"It's also the thing that's going to make sure families are looked after properly, if there's one thing you leave today with from our team, it's that."



Each day, Kev was joined by invited members of the MND community to run the Extra Mile



Caption

Rob and Kev's fundraising and awareness raising endeavours were recognised in King Charles III's New Year's Honours list. The pair joined the ranks of His Majesty's Commanders of the British Empire (CBE). MND Association Chief Executive Tanya Curry called them 'a truly deserving pair'.

The Extra Milers

Ryan Willmott with brother Ash in Brighton

Ryan Willmott and his brother Ash joined Kevin in Brighton for the Extra Mile. Ryan said: "When my mum was first diagnosed, none of us knew what MND was. The work that Kevin and Rob have done has put MND on the map. It has brought everyone together to find that cure."


Ash said: "We've raised over £20,000 for the MND Association and we wanted to show a little bit of support to Kevin in the Extra Mile of his challenge. When Mum died we felt like we needed to do something for her, so we did the Leeds marathon in May and we're planning to do some charity treks this year."

A photograph of two men, Ryan Willmott and his brother Ash, standing outdoors in Brighton. They are both wearing orange MND Association vests over dark clothing and winter hats. They are smiling at the camera. In the background, there is a body of water and a building.

Ryan Willmott with brother Ash

Janice Fenlon with her daughter Vicky

Another family supporting Kevin in Brighton was the Fenlons. Janice Fenlon, who was diagnosed with MND last August, joined the run with her two sons, daughter and Chip the dog. Janice's daughter Vicky King said: "I'm here to support my mum and I'm here to be part of what Kevin is doing, as it's absolutely magnificent. He's working so hard to bring lots of awareness and cash into this very worthwhile cause. I'm so excited to take part in the Extra Mile."


A photograph of an older woman, Janice Fenlon, sitting in a wheelchair. She is wearing a blue jacket and a colorful scarf. A younger woman, Vicky King, is sitting behind her, smiling and resting her hands on Janice's shoulders. They are outdoors at what appears to be a charity event.

Janice Fenlon with her daughter Vicky

Sam Perkins

Former triathlete Sam Perkins who is living with MND joined the Extra Mile in Birmingham. Sam said: "I feel very privileged to be part of it. Kevin is a huge inspiration to everyone in the MND community."


"People have told me they think I'm inspiring, and while that's not why I do it, I do it to show what you're capable of if you've got determination and the right team around you."

A photograph of three people. In the center is Sam Perkins, a man in a wheelchair wearing a red and black MND vest and a red beanie. To his right is Kevin, a man in a dark jacket. To his left is Sam Tooze, a woman in a pink beanie and orange top. They are all smiling.

Sam Perkins, Kevin and Sam Tooze

Tom Aleksandrowicz

Tom Aleksandrowicz ran 19 miles to get to the start of the Extra Mile. Tom said: "I've run from Wolverhampton to Birmingham along the canal to come and support Kevin and the MND Association. Kevin inspires people because of what he puts himself through for his friend, and to help other MND sufferers, so to get out there and do something myself is the least I can do."

A photograph of Tom Aleksandrowicz, a man wearing a black jacket, an orange MND vest, and a white beanie. He is smiling and looking towards the camera.

Tom Aleksandrowicz

Scott Newman

Watching Rob and Kevin win BBC awards at the *Sports Personality of the Year 2022* inspired Scott Newman to run 5K every day. Before he started the Extra Mile in London Scott said: "Today is day 340 of my 365 challenge. I'll be doing the Extra Mile and then the 5k afterwards. I'm really looking forward to running behind Kevin, who was the inspiration of my challenge this year."

A photograph of Scott Newman, a man wearing a blue t-shirt with the MND Association logo and the text "fighting motor neurone disease". He is also wearing a black beanie and is smiling.

Scott Newman

Chance encounter that led to a 20-year partnership

Fostering a culture of collaboration is a key component in the fight against MND. Our annual International Symposium on ALS/MND plays an important role in this, by enabling researchers to network, exchange information and, crucially, foster new partnerships.

One partnership formed at the 2003 Symposium in Milan between a PhD student and a neurologist led to the start of building a new team, and a centre of excellence at Oxford. Professor Martin Turner and Professor Kevin Talbot are now among the top MND researchers in the UK, and 20 years on from that first meeting in Milan, are still working together. At the recent Symposium we sat down with Kevin and Martin to chat about the lasting impact of meeting all those years ago.

How did you meet?

Martin: "It was 20 years ago at the Milan Symposium. I was a PhD student finishing off at King's College London. That evening, we had a nice night out with the team, talking a lot about science. It was my turn to go to the bar and that's where I met Kevin!"

Kevin: "We got chatting and it was clear he was interested in thinking where his career might lie. King's at the time was the big MND research centre in the UK. When I first started going to the Symposium I remember looking at the group of about 20 researchers from King's and saying that I want a table with 20 people around it from Oxford. Martin approaching me was the beginning of building the team in Oxford. Since then it's grown from strength to strength."



Martin and Kevin in 2013 at the Yankee Stadium in New York, wearing Lou Gehrig's number 4 baseball shirts. MND is sometimes known as Lou Gehrig's disease, the player was diagnosed with MND in 1939 aged just 36



Professor Kevin Talbot, left, with Professor Martin Turner, right, attending the 34th Symposium on ALS/MND in Basel

What has your relationship helped you achieve?

Kevin: "We built an environment where, although primarily the clinic is about caring for people and offering them support, it's also fundamentally about engaging with them as partners in our research. That is the thing we can say is the foundation of everything that we do."

Martin: "I think the thing that struck me more than anything is it all comes from the clinic. When I joined Oxford, I could see they had set up a clinic where care was happening in a joined up way but not much research was happening. But then when you started saying, well, could we start to collect samples? Could we work in partnership with you? That was a template that hadn't really been done. So, we integrated care and research and I do think that is a template that has been taken up over the last 20 years."

What would you like to achieve in the future?

Kevin: "I think the challenge is how do you turn this great science into something

that is going to make a difference for patients? You have to predict which of all these different things we hear about at the Symposium really relate to the disease. We have set up a pipeline that goes from trying to identify drugs and validating them in early models. Martin is leading the EXPERTS programme, which is about how we can get a signal in patients that tell us which drug to take forward to larger studies. I think this is in some ways the culmination of 20 years of organisation and thought processes."

Martin: "The partnership with Kevin is a great example as he is providing advice on the drugs which will be tested in the EXPERTS programme. The team are hoping to deliver this in a way that will definitely make a change to the efficiency of drug selection and confidence in the drugs we choose to take forward to big trials."

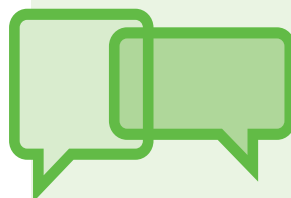
Kevin: "20 years ago I think we were in a fog of uncertainty and we didn't really have much idea what was going on with this disease. We are in a very different place now."

2023 **Our year in numbers**

At the start of a new year, *Thumb Print* takes a look back at the difference the MND Association have made in 2023 thanks to your incredible support.



Over 1,300 researchers representing 48 countries attended the Association's first in-person International Symposium on ALS/MND since the pandemic, held in Basel, Switzerland.

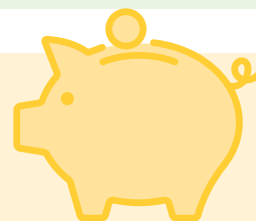


Our network of 88 branches and groups provided local support to people with MND in communities across England, Wales and Northern Ireland

22 MND Care Centres and Networks provided multidisciplinary care to 3,546 people with MND



£3.1 million of eligible state benefits were claimed through our Welfare Benefits Service



With your help, over £30 million was raised by the MND Association



326 Association visitors and co-ordinators offered one to one support to people living with MND, their families and carers

88,110 pieces of information were downloaded or sent to people with MND



9,250 people living with or affected by MND were supported by the MND Connect Helpline



6,123 people living with MND have signed up to the MND Register (as of July 2023)



Our research grant portfolio consisted of 111 grants, with a value of almost £21 million (as at 30 June 2023)



£2.2 million of support grants were awarded to 2,585 people living with, or affected by MND



Association membership rose to 12,304 in 2023

#TakeOverMND in 2024

Make a difference by joining #TeamMND

Last January, over 1,000 people were inspired to fundraise by our campaign to #TakeOverMND. The money raised from the many miles run, mountains climbed and cakes baked, has funded ground-breaking research studies to

bring us closer to finding a cure. This year, once again, we're asking you to help #TakeOverMND by fundraising to ensure we can continue to support everyone affected by MND who needs us. This is why your support matters.



James Shepherd Trott with husband Dan

James Shepherd-Trott shared how one of the MND Association's Area Support Co-ordinators, has supported him since he was diagnosed with primary lateral sclerosis (PLS), a form of MND.

He said: "Justine has been just amazing and has turned from a co-ordinator to a friend. She's opened my eyes to things like grants, which I knew nothing about until I met her, and put me in touch with someone else who is living with PLS. I wanted to link with someone who understands what I'm going through."

James, who is passionate about keeping fit, received a grant from the MND Association to pay for Pilates classes.

"I go weekly so the cost of the classes was a big financial burden. But Pilates is amazing. Not only does it test my



I climbed Snowdon because I wanted other people living with the disease to see that someone's climbing a mountain.

balance and my strength, it also helps stretch and relax those muscles, especially my legs," he explained. "It puts me in a good mental state as well as physical. I come home and I feel like I've achieved, and done better for my body to fight against the condition."

Eleanor Dalley was just 43 when she was told she had MND in July 2019. Sadly, the disease has had a devastating impact on her family. In the last five years, two of Eleanor's aunties and her dad have all died from MND.



Right from the beginning, we felt that fundraising was important. My dad was Jamaican, so we did a big Jamaican cook out event with all our friends and family.

She said: "I know this is going to sound crazy, but I just didn't contemplate my dad getting MND. Obviously now I look

back on it and know I got the gene from him, but I just didn't think about it at the time I was diagnosed. But in the summer of 2020, I noticed he was limping a little bit. I just thought, 'Oh God, this is happening to Dad!'"

Eleanor and her family have received a range of support from the MND Association, including grants for a wet room, a seat riser for her wheelchair and counselling for her niece. Eleanor was also pleased to be accepted onto a clinical trial to take the drug Tofersen.

She said: "I'd heard about a drug which could slow progression for people with MND caused by the SOD1 gene mutation, which I have. That was part of the reason why I was able to tell my daughter about my diagnosis. Her words to me were, 'Mum that's amazing. That gives us hope that there might be

a cure in the future'. She'd worked out that this was genetic in our family, that it might affect her in the future too."

The family have held a series of fundraising events.



Eleanor Dalley with her sister and friend at the Rob Burrow Leeds Marathon

Make a difference join #TeamMND



Great Birmingham Run
Sunday 5 May, Birmingham
13.1 miles (also 10km route)

Rob Burrow Leeds Marathon
Sunday 12 May, Leeds.
26.2 miles



Jurassic Coast Challenge
Saturday 18 and Sunday 19
May, Dorset. Varying routes
from 10km to 100km

Lake District Challenge
Saturday 8 and Sunday 9 June,
Cumbria. Varying routes from
10km to 100km



RideLondon 60
Sunday 26 May
London - 60 miles
(also 100 miles)



Fundraise Your Way
Organise your own fundraising, anytime, anywhere



Kirti Thakrar's husband, Harish, sadly died from MND. She said: "We were not just husband and wife; we were very good friends. We did everything together. He has left such a big void in my life, and that emptiness will never go away."

Like Eleanor and James, Kirti and her family received support from the MND Association funded by our generous fundraisers.

"Without the Association I think our journey would have been a lot more difficult," said Kirti.

Kirti reflected on the support she received from our helpline, MND Connect, when Harish was first diagnosed with MND.

She remembers: "Harish left me the

task of finding a neurologist. For about half an hour, I was in shock, I couldn't do anything. But then I remembered the Association. I didn't feel like I could speak on the phone, so I emailed them and said that I needed to find a good neurologist.



Without the Association I think our journey would have been a lot more difficult.

"Within an hour I got a reply back with a neurologist in Oxford and Birmingham, which I thought was amazing."

Eleanor, James and Kirti are just three of thousands of people who receive support thanks to people fundraising on behalf of the MND Association.



Kirti Thakrar attending Chai and Chaat (afternoon tea) for family and friends

Join us this year and help us make sure we can be there for everyone who needs us. Visit www.mndassociation.org/takeovermnd to find out more.

Regional Roadshows for 2024



PROMISE 5
WE WON'T REST UNTIL
NO ONE FACES MND ALONE

We are delighted to invite you to attend one of our new in-person Regional Roadshows in 2024, to be held at various locations across the three nations.

If you're a person living with MND, a carer, member or volunteer, these events are a great opportunity to hear more about the services and support available from the Association, both at national

and local level and, most importantly, meet other people living with or affected by MND.

There will be an opportunity to ask questions and hear more about our work from the Executive Leadership Team and our Board of Trustees, supported by regional staff and local volunteers. The input from these events will help shape our future local and national plans.

Attendees will hear about the latest developments in MND research, care and campaigning as well as practical tips and advice from people living with or affected by MND. You'll also have the opportunity to meet local service and support providers.

The first of our Roadshows will be held at Dunsilly Hotel in Antrim, Northern Ireland on Friday 12 April followed by the Wales Regional Roadshow which will be held on Thursday 9 May at the Mercure Cardiff North Hotel. Future dates will be advertised in *Thumb Print* and on our website. Members will be personally invited to attend either by post or email where we have these contact details.



If you would like to register your interest to attend one of our events please contact conference@mndassociation.org or telephone 01604 611844

Open water swimming is not for the faint-hearted. It requires courage, adaptability, strength and, most of all, grit. Two brave fundraisers recently took the plunge to raise money for the MND Association, but they each also had a deeper reason pushing them to take on the weather, cold water and, in the case of one, miles of jellyfish!

Taking the plunge to raise funds

Mark O'Brien was diagnosed with MND aged 53 on 17 March 2022 with his diagnosis re-confirmed in December 2022. In the days immediately afterwards, he travelled to Egypt to consider how he'd break the news to his family. While swimming in the Red Sea, Mark made a promise to himself that he'd turn his situation into something positive. By the time he returned home, Mark had formed a plan to break the Guinness World Record for the longest, non-stop, unaided, open water swim by a person living with MND.

Mark said: "Life felt like it had come crashing down on me when I was diagnosed with MND. But I thought I could curl up into a little ball, or try to find some positivity. Attempting this challenge was a way for me to show my family that whatever time I have left, I want to live life to the fullest.

"Seeing everyone at Denham Lake, including all the TV crews and journalists, the enormity of what I'd taken on started to weigh heavy on me. I knew I could do the distance, but I was worried about the temperature of the lake. It was cold, very cold.

"Four kilometres into my swim my breathing became laboured. Everything quickly deteriorated. It was horrendous. My right hand and leg had frozen up. My swimming slowed down and I became less aware of my surroundings. It was at



Mark O'Brien raised over £23,000 with his record breaking swim

this point my swim coach dived into the lake. He thought I'd blacked out.

"I swam the last seven kilometres using just my left leg. I'd kick with it and work hard through the shoulder. Everything was against me, a huge wind started blowing across the lake. I remember thinking 'I'm not giving up. Throw at me whatever you like. I'll either complete this challenge or I'll need to be pulled from the lake'.

"My three children, Lauren, David and Georgia dived in to join me for the last 1.5 kilometres. The cheers and music were getting louder, but I had to focus my full attention on not blacking out. Once

my feet hit dry land the sense of relief was enormous. But it soon gave way to violent shivers. I was quickly wrapped up in foils. I'd pushed too hard. I'd gone over what my body was now capable of. The hyperthermia had set in.



I wanted to show people that you can still do something positive, even if you're living with MND. I also wanted to help support my local branches and contribute towards MND research.

"It took six weeks before I started to feel better. When I look back, it was risky, but I was very clear in my reasons for doing this. I wanted to show people that you can still do something positive, even if you're living with MND. I also wanted to help support my local branches and contribute towards MND research.

"On a more personal level I wanted to show my children that they will be faced with adversity. And that even if they think something is lost, they must find a way to power through. I'm proud of what I've done, and I hope I've created a moment that my family and friends will always remember."



Mark's children supporting their dad's swim



Lauren, David and Georgia joined David for the last 1.5 km

Pub landlady swims the English Channel



Dani Cameron raised £6,000 swimming the English Channel

In September, pub landlady Dani Cameron swam the English Channel, completing it in 12 hours. Dani wanted to do something 'big' in memory of her dear friend 'Uncle Al', who died of MND. This is her story in her own words.

I met Uncle Al over 20 years ago when we worked on the oil rigs in Scotland, in the Health and Safety Executive. Seeing Uncle Al's progression of MND crushed me. Each visit I saw how he could do less and less, from having his food cut up, to consuming his beloved Irn Bru ice cream through a feeding tube, to using a communication aid.

I'd cared for my mum during the last 18 months of her life when she had lung cancer, but at least she could communicate, Uncle Al had this taken away from him. This really struck me. I'd never seen MND before and it hit me hard to see what it did to someone I loved.

Over the last few years, I'd taken on more and more physical challenges.



I'd cared for my mum during the last 18 months of her life when she had lung cancer, but at least she could communicate, I'd never seen MND before and it hit me hard to see what it did to someone I loved.

I knew I had to do something in Al's memory, and I wanted to raise money to fund a communication aid. I love to talk and I can't imagine not being able to communicate.

I trained for the challenge in all weathers. At times it felt like I was swimming inside a washing machine, wind, rain – it was relentless. On the day of the challenge, I was lucky. I had perfect weather. But while the Channel gives

with one hand it will take away with the other. The warm weather resulted in hundreds of jellyfish halfway across (and even more at the end). I felt like I was swimming in jellyfish soup, they were impossible to avoid.

I wasn't allowed to touch the boat during the swim. So I had to swim and eat at the same time. I was also taught not to look forward because it will destroy you to not see land for so long. So I kept my gaze to the side. The hours passed, until my friend told me to look forward. I couldn't believe it – I saw the Cap Gris Nez cliffs.

Next, I saw sand underneath my feet. I made it. It was the most incredible feeling ever. Uncle Al would have found this all really funny. He still serves as a huge motivator for me. On a cold evening when I feel like I can't be bothered to get off the sofa and train, I think of Uncle Al. He didn't have a choice about what happened to his body. I do have a choice over what mine does and I owe it to Uncle Al not to waste that.



Radio 4 shares Dimbleby family's MND story



It was the first time I had ever done an intimate conversation of that kind. Nicholas said he wanted to say something about what the experience [of being diagnosed with MND] is like, thinking maybe it will be useful to other people to have a sense of it

An intimate conversation between renowned brothers Nicholas and Jonathan Dimbleby was curated into a moving two-part Radio 4 programme *The Bright Side of Life*, broadcast in November.

Sculptor Nicholas was diagnosed with MND in spring 2023, after suffering a series of unexplained falls. Keen to use his experience to help others, Nicholas engaged the support of his older brother, broadcaster and journalist Jonathan Dimbleby.



The pair chose the kitchen of Nicholas's family home in the south west to record six conversations over a period of months as MND affected Nicholas's movement, speech and ability to eat.

The result is a programme described by Charlotte Runcie in the *Daily Telegraph* as 'real, gritty and sad but never desolate. It's golden with love'.

Jonathan described the experience

as 'profoundly affecting'. He said: "It was the first time I had ever done an intimate conversation of that kind. Nicholas said he wanted to say something about what the experience [of being diagnosed with MND] is like, thinking maybe it will be useful to other people to have a sense of it.

"We have talked endlessly over the years, but I was entranced by his

extraordinary gift for words. He found the exact words to express the feelings he had. I think that partly came from the strain of using his voice when it was failing, and it was tiring for him to speak.

"I have admired him as a sculptor and loved him as a brother but I came away from our conversations thinking 'what a very lovely and remarkable man.'"



World record broken 'for Mum and uncle Graham'

Kenny Skelton's family has been hit hard by MND. His wife's uncle Graham died from MND in 2018 and in May this year, Kenny's mum Lynne was diagnosed with the disease.

To raise money and awareness for MND, Kenny broke a world record by rowing 31 marathons in 31 days, raising £7,500 for the MND Association. The world record had previously stood at 30 marathons rowed in 30 days.

Kenny said: "I did this to raise money in



I'm always humbled by how much courage those who have been diagnosed with MND have, the bravery to push on so they might cherish every moment with their loved ones.



memory of Graham and also in tribute to my wonderful, beautiful mum Lynne. Graham's motto was 'don't worry about me' even as he suffered greatly, as he was slowly losing his ability to perform everyday tasks and relied on others for help – and yet throughout he never once complained about having this predicament thrust upon him.

"In May, my mum Lynne was also diagnosed with MND. She is easily one of the strongest, most positive people I have ever known. I'm so proud of her for the amazing outlook she has, seeing every day for the wonderful precious thing it is.

"I'm always humbled by how much courage those who have been diagnosed with MND have, the bravery to push on so they might cherish every moment with their loved ones. Also the unbounded love of families and specialists as they fight alongside, trying to make people as comfortable as possible in the face of this devastating illness."

Celebrating 35 years of MND volunteer support in North Wiltshire



The North Wiltshire Group celebrated 35 years of supporting the local MND community at a special afternoon tea party. Past and present group volunteers, families affected by MND, healthcare professionals and local VIPs came together to mark the special anniversary.

The afternoon began with a welcome speech from North Wiltshire Group Chair Heather Smith, who was followed by guest speakers Tanya Curry, Chief Executive of the MND Association, Jeremy Lune, Chief Executive of Prospect Hospice and Angus Macpherson, Deputy Lieutenant of

Wiltshire. Dr Graham Lennox, Consultant Neurologist in Swindon gave a toast to the Group, while MND Association patrons Jeremy Vine and Charlotte Hawkins sent video messages.

In recent years, the volunteers of the North Wiltshire Group have been instrumental in campaigning for a new MND co-ordinator in Swindon. This effort will ensure those living with MND receive enhanced care thanks to a partnership between the MND Association and Prospect Hospice

Heather Smith, Group Chair said: "The party was an amazing success, a tribute to



our great organising team and the whole committee working together to celebrate our 35 years. We were delighted to have so many people living with MND and their families with us on the day, they are who we are here for and we will continue to be here for them for many years to come, providing the help and support they need."

Trustee elections 2024

Can you add your skills and experience?

In our 2024 trustee elections there will be four positions open for nominations. Elections are held over the spring with the new trustees announced at the Association's AGM in early summer.

What does a trustee do?

Trustees bring their wide range of skills and experience to the Board. As part of the Board, they have a responsibility to ensure the mission and long-term aims of the Association are met, and that it meets the needs of people affected by MND.

Together, with the other volunteer trustees, they have overall responsibility for the charity and act collectively to govern it. This includes legal responsibility for overseeing the affairs of the Association and making sure it is financially secure and well-run.

Trustees attend board meetings and committee meetings throughout the year, with the average time commitment around two days of work a month. They are either elected to the Board by our members, or are appointed to the Board because their particular skills are required.

Could you become a trustee?

You can find out more about becoming a trustee and find out who our current trustees are here: www.mndassociation.org/get-involved/volunteering/becoming-a-trustee

We will be opening the Call for Nominations on 7 March 2024. If you are interested in becoming a trustee, then please check our website to understand how you can submit a nomination form.



I start this message by acknowledging the sad news of the death from MND of our fellow trustee, Susan Fletcher Watts. Following a diagnosis of MND in 2021, Susan threw herself into fundraising for the Association, raising over £80,000. She was subsequently elected to our Board in June 2022. Susan made a fantastic contribution as a trustee, bringing her experience, knowledge and insight to all that she did. My thoughts are with Susan's husband Brian, and her children Aidan and Jessica.

Last year, MND research continued at pace. While the road from 'bench to bedside' can be a long and arduous one, I can promise our community that we will do all we can to reach that common goal.

Time has gone so quickly that I note with surprise that it's been a year since Tanya Curry joined the Association as our Chief Executive. Bringing energy, enthusiasm and an open minded approach, Tanya has worked closely with the Board to assess how the Association can work in as efficient and effective manner as possible. She has also spent a good deal of the last months on the road listening to the community and our key partners, and I look forward to seeing the rewards in the near future.

The Association ended 2023 by hosting in Basel, Switzerland another highly successful International Symposium on ALS/ MND. This year's event saw record numbers of medical and scientific experts come together to discuss the many exciting developments which are making colleagues ever more hopeful of meaningful breakthroughs, in the treatment and care of this most devastating of diseases.

I'm certain that 2024 will be another productive and impactful year for the Association, but before I sign off I want to thank all of our members, volunteers and staff for their continued support. The Association would not be able to do what it does to support those living with and affected by MND, advocating in support of their needs and providing leadership in the global research programme.

Wishing you all the best for 2024.

Susan Fletcher Watts

Obituary

We were sad to announce the death of Susan Fletcher Watts in November, a member of our Board of trustees, a hugely passionate fundraiser and supporter of the Association.

Susan was diagnosed with MND in 2021, just before her 60th birthday. Living by her mantra 'Walking the Positive Path', Susan channelled her positivity into fundraising for the MND Association, and later as a valued trustee.

Almost a year after being diagnosed with the disease, keen hiker Susan set out to complete the 260-mile Pennine Way. Four weeks later, with the support of 184 people, Susan crossed the finishing line. Her efforts, along with extra fundraising at a thank you party afterwards, saw the total raised for the MND Association top £80,000. Susan was able to share her fundraising success and positive outlook with numerous local and national media

outlets, further increasing awareness of MND.

After taking early retirement from her role as a Chartered UK and European Patent Attorney, Susan was elected to be a trustee of the Association in June 2022.

Tanya Curry, Chief Executive of the MND Association, said: "Susan's contribution to the Association was significant. Her professional background proved invaluable to the Board in terms of insight and assisting with decision-making.

"Her zest for life and unwavering determination to raise awareness and funds for the Association was admired and respected by all of us.

"Despite challenges she increasingly faced, she continued to encourage all those around her. Susan will be very missed by so many in the MND community."



Platform trials in MND

There has been a lot of discussion about clinical trials and how to design them to give a potential treatment the best possible chance. One of the new innovative trial designs is platform trials, which test multiple treatments at the same time. These trials provide lasting infrastructure for a number of years, giving more people with MND the chance to take part.

MND-SMART, the UK's first platform trial in MND and part funded by the Association, tests existing medicines that



are used to treat other diseases to see whether they might be beneficial for people with MND. Trial participants taking different treatments are compared with a single group receiving a placebo (a dummy drug). This means that people in MND-SMART are more likely to be randomised to receive an active treatment when compared to other clinical trials, where typically half of the participants receive the placebo and half the active treatment.

MND-SMART was testing three different drugs in over 500 people with MND. The trial is designed with regular monitoring in place for each drug to assess whether to continue testing that drug.

This means that drugs which aren't showing positive signs can be stopped at time points in the trial and that people with MND aren't continuing to take a drug which is showing no benefit. The monitoring point has been reached for the first two drugs in this trial and a committee reviewed the data. Unfortunately, it was decided that testing of the two drugs should not continue as it is highly unlikely that either drug will benefit people with MND.

Platform trials also allow for the easy addition of potential new drugs into the trial. One drug is still being tested and there are plans to add an additional three drugs to the trial over the next couple of years. Participants who were on the drugs which have been stopped will be given the opportunity to re-join MND-SMART and be randomised again to receive either the placebo or one of the other drugs being tested through the trial.



MND Association launches TV advert

Louise and Rob share a tender moment



This campaign represents a substantial and important investment for the Association and one which we are confident will help drive forward our ambitious plans to ultimately enable us to provide more support to people affected by MND, and fund more research towards finding treatments and a cure.

The MND Association is set to launch its first television advert for more than a decade as part of a wider awareness campaign.

The campaign has been prompted by ITV's ongoing *Coronation Street* storyline following the journey of character Paul Foreman, played by Peter Ash, who was diagnosed with MND last summer. The *Coronation Street* team has been working closely with experts from the MND Association to ensure an accurate depiction of the disease, from Paul's physical deterioration to the conversations he has with healthcare professionals.

But as realistic as actor Peter Ash's portrayal is, the six million *Coronation Street* viewers are still watching a fictionalised version of MND. The new campaign shows in moving detail the stories of people for whom MND is a reality.

Featured in the campaign are three people with MND, Louise Jordan with her husband Rob, Mike Sumner with his wife Zoe and Mike Small with his MND Association Area Support Co-ordinator Alli Anthony. Sadly, just a few weeks after filming Louise, who was diagnosed with MND in 2021, died. Her wish, and that of the family, was that the campaign, including the advert featuring her, go ahead to raise awareness of the devastating effect of MND.

A film crew spent time with each, capturing some of their most intimate moments. While the devastating impact of the disease is clear to see, so is the powerful connection between the pairs. And that's what is reflected in the overarching campaign message *The Love Inside*.

The adverts, set to Roberta Flack's



PROMISE 4
WE WON'T REST UNTIL
YOU ARE HEARD



longer do, but raising awareness is something I can still do. I've always been interested in film and TV, so it was really fascinating to see all the work that goes into filming. I hope the campaign makes more people Google MND and if only one more person understands, or volunteers for the MND Association, then it's been worth it."

Mike's wife Zoe added: "I wanted to support Mike, but I also wanted the world to see what life is like with this condition. It was a bit overwhelming to have a film crew in a small space, with all their equipment, but they were really professional and accommodating, so it was a good experience. Like Mike, I hope it raises awareness and prompts people to have conversations around MND in their day-to-day lives."



I hope the campaign makes more people Google MND and if only one more person understands, or volunteers for the MND Association, then it's been worth it.

stunning song *The First Time Ever I Saw Your Face*, finish with the on-screen message 'Motor neurone disease takes everything, but it can't take the love inside'.

Launching at the end of January in the commercial breaks of *Coronation Street*, the series of 60 and 30 second adverts will give viewers already familiar with MND a vivid reminder that Paul's on-screen experiences are what people with MND face every day.

For Mike Sumner, taking part in the ad campaign gave him the opportunity to take action against the disease. Mike said: "There's so much about MND that's negative, and I don't like to admit defeat, so I thought it was important to do something positive in whatever way I could.

"Since I was diagnosed in November 2020, there are many things I can no

Alongside the television adverts will be media coverage, and new website and social media content encouraging those inspired by the adverts to find out more about MND and the Association's work, with the hope of us engaging them more with the MND community in the future.

The MND Association's Director of External Affairs Chris James said: "The storyline on *Coronation Street* has really touched people and given us an incredible opportunity to raise further awareness of MND and the MND Association with a new audience.

"This campaign represents a substantial and important investment for the Association and one which we are confident will help drive forward our ambitious plans to ultimately enable us to provide more support to people affected by MND, and fund more research towards finding treatments and a cure."



Area Support Co-ordinator Alli Anthony ensured Mike Small was well cared for throughout the filming process



Mike's daily care routine captured the love and compassion of his wife Zoe and their shared bond



Through keen observation the final edit of filming reflects the special connection between each pair

New UK MND Research Institute

to accelerate search for a cure



An Institute brought together by collaboration to accelerate the arrival of treatments is just what patients want to see. I am optimistic this will be the springboard to a better future, offering hope to patients and those affected by MND.

One of the flagship studies within the broad portfolio of the UK MND RI is the **EXPERimental medicine Route To Success in ALS (EXPERTS-ALS)**. This platform has been designed to accelerate progress towards effective drug therapies for MND. The study will screen potential medicines in people living with MND, quickly identifying those which are demonstrating a likely benefit. These will then be prioritised for testing in larger placebo-controlled trials.

The new UK MND Research Institute (UK MND RI), launched in November, aims to discover new treatments that could ultimately mean MND becomes a curable condition. The virtual Institute brings together a network of MND labs, clinical centres and researchers conducting MND research across the UK.

Under the co-directorship of MND clinician researchers Professor Ammar Al Chalabi and Professor Christopher McDermott, the vision for the UK MND RI is to be a world-leading, independent, virtual entity focused on accelerating drug discovery from laboratory science to phase 3 clinical trials.

David Setters, who is living with MND, has been a driving force behind the creation of the Institute. At the launch event held at King's College London, David said: "An Institute brought together by collaboration to accelerate the arrival of treatments is just what patients want to see. I am optimistic this will be the springboard to a better future, offering hope to patients and those affected by MND."

The Institute began work in 2022, prior to the official launch with clinicians, scientists and people with MND, charities and other funders, working together in a more co-ordinated way than ever before.

A portion of the £50 million pledged by the Government for targeted MND research is already supporting programmes and initiatives which fall

under the Institute. The MND Association is also funding peer-reviewed research programmes within the Institute made possible by the significant sums raised through Kevin Sinfield's challenges over the last few years..



Much of the planned pieces of work under the UK MND RI umbrella have their roots in Association-funded research studies, and we are delighted to be contributing to this next significant step forward in the fight against MND.

Additional funding is coming from MND Scotland, My Name's Doddie Foundation, medical research charity LifeArc, the National Institute of Health and Care Research (NIHR) and Medical Research Council (MRC).

Dr Brian Dickie MBE, Director of Research Development at the MND Association said: "Much of the planned pieces of work under the UK MND RI umbrella have their roots in Association-funded research studies, and we are delighted to be contributing to this next significant step forward in the fight against MND."



Sarah Ezekiel who is living with MND



L-R: Paulo Ferraz, Director, BRICS/Emerging Markets, Newstar Ventures Ltd and Raquel Martins PhD, Postdoctoral Research Associate, Sheffield Institute for Translational Neuroscience (SITraN)



L-R: Tanya Curry, CEO of the MND Association, Jill Douglas, CEO of the My Name's Doddie Foundation and Rachel Maitland, CEO of MND Scotland



Professor Ammar Al Chalabi, Professor of Neurology and Complex Disease Genetics at King's College London and one of the co-directors of the UK MND RI giving the keynote address



Professor Chris McDermott, Professor of Translational Neurology at the University of Sheffield speaking at the launch event



Yasmin Ali, Research Associate Department of Neuroscience Sheffield Institute for Translational Neuroscience (SITraN)



David Setters who is living with MND and a speaker at the launch of the UK MND IR

Funding for MND nurse reinstated

after campaign by Jersey Branch

The Jersey Branch of the MND Association successfully secured a reinstatement of government funding for the island's only MND specialist nurse. The Government announced in October that it would

once again pay for the specialist nurse's post, described as 'vital' by people living with MND on the island.

The role was funded by the Government until 2022. The local branch

stepped in to subsidise funding to ensure the service stayed in place to support the 13 people living with MND on the island and their carers. But this wasn't a sustainable solution.

Don Connolly, Chair of the Jersey Branch said: "Now we can focus as a charity on getting back to supporting people on the island with the disease. Time has been wasted. It's a relief to be able to put this behind us."

Minister of Health and Social Services Karen Wilson said: "I can assure patients that funding for the MND nurse specialist will be permanently awarded. The MND nurse is a hugely important clinical role and highly valued by patients, families and carers. I'm committed to ensuring patients with MND are supported and I hope my statement provides additional reassurance for patients in that regard."



"As soon as the money comes in, it goes out"

Herefordshire and Worcestershire Group

The Herefordshire and Worcestershire Group had a bumper year, raising over £12,200. Group Leader Phil Clayton tells *Thumb Print* how this local support enabled the group to provide warmth, comfort and joy to families living with MND.

"As soon as the money comes in, it goes out. We've funded family weekend breaks, decorated children's bedrooms and recently bought an off road scooter to enable a man to continue to enjoy the countryside.

We can't take away MND, but we will certainly do whatever we can to enable those affected by it to live as full a life as possible. In the autumn, we funded a shed for a couple who loved their allotment, but the husband needed somewhere to shelter. Now he has a comfortable shed to relax in when he gets tired, and they're able to continue to do something together they enjoy (see John's letter on page 38).

We also fund a lot of equipment like Bio Bidet toilets, stairlifts and hoists, and we like to provide grants to carers, things like pamper days, to give them a break from caring for a loved one 24/7. We couldn't do any of this without the huge support we've received from local communities and families whose lives have been touched by MND.

“Volunteering gave me something to focus on and I'm honoured to be part of such a wonderful group helping others affected by MND.**”**

One of our members Ruth, died earlier this year. Since her death, Ruth's daughter-in-law Stacey and granddaughter Sophie have organised fundraising events raising over £1,200. Another member Margaret, is a talented baker, and is selling her baking book for



£10 (including postage). She's already sold 500 copies, raising a huge amount for the group. If anyone would like to buy one please contact philip.clayton@mndassociation.org.

It's priceless to see the difference our small group can make. Volunteering for the MND Association has added so much value to my life. I went from caring for my wife Ann, to an empty home. Volunteering gave me something to focus on and I'm honoured to be part of such a wonderful group helping others affected by MND."

Research round-up for 2023

Three exciting studies our community made happen

MND research is taking place in labs, universities and hospitals across the country thanks to the support of our incredible community. Here is a snapshot of three exciting studies that started in 2023 thanks to the generosity of the MND community.

1. Joint fund to progress new therapies

In January, the MND Association, LifeArc and the My Name's Doddie Foundation jointly awarded £1 million to researchers at University College London to progress two promising new therapies. This is part of a £1.5 million joint fund for translational research aiming to develop new gene and cell therapies for MND.

2. MND Association launches new pre-fellowship scheme

In September, the MND Association announced that two UK researchers are the first to receive funding through its new pre-fellowship scheme, a collaborative arrangement with MND Scotland. The pre-fellowships are designed to bridge the gap between a PhD and a longer-term fellowship for early career researchers wanting to establish a career in MND translational



research. The pre-fellowships were awarded to Dr Alannah Mole, University of Sheffield who will examine the sequence and timing of events that lead to neurone failure in MND and Dr Emily Carroll, University of Oxford who will investigate the repurposing of existing drugs to treat MND.

3. Introducing 'care research fellowships'

In October, the MND Association announced a partnership with the National Institute for Health and Care Research (NIHR) to introduce research fellowships which investigate ways to improve the lives of people living with MND. This is the first time the MND Association has offered specific health

and social care research fellowships and awards will be given to care improvement projects. This is in addition to our established Lady Edith Wolfson Fellowship programme that funds both clinical and non-clinical researchers.

The MND Association is committed to funding the most promising MND research. Our portfolio is supporting the highest number of grants ever, topping 113 grants in 2023. With MND research accelerating at pace, it's reassuring to know that funding is becoming available to support both cutting-edge research and vital care projects to help improve the lives of people living with MND.

Rob's BBC podcast

showcasing inspirational stories

MND Association patron and rugby league legend Rob Burrow CBE has launched a BBC podcast showcasing inspirational stories from sporting greats.

In each episode Rob, using his communication aid, talks to a different sports legend about their careers, challenges and successful moments.

The podcast, called *Seven: Rob Burrow* after the number on his rugby shirt, is a seven part-series available on *The Total Sport Podcast* on BBC Sounds. Among those who stand up to the host's cheeky interviewing style is England football star and former Birmingham City manager, Wayne Rooney.

Other sporting legends interviewed on the podcast include former England rugby union player and world cup winner, Jonny Wilkinson; British double-Olympic gold medallist, Dame Kelly Holmes; former Scottish rugby union player, Kenny Logan and his wife, BBC sports presenter Gabby Logan and British wheelchair racer Hannah Cockcroft.

Rob said: "I've loved making this podcast and talking to many inspirational sporting heroes and friends. Having this disease doesn't mean I don't have a voice. I live life to the full every day and refuse to give in. I've really enjoyed being able to showcase my personality in my podcast and have a laugh."



Local authorities 'must do better' to support MND carers

We published our *State of Carers' Assessments in the UK report on Carers' Rights Day*, detailing how carers of people with MND across England, Wales and Northern Ireland are not getting the support they need from local authorities.

The report reveals many local authorities are unaware of

the number of carers in their area, with almost one-third (31%) not holding a register of carers. The findings suggest that local authorities are only identifying between 6 and 13% of carers in their local area, leaving the majority unrecognised and unsupported. Without understanding how many carers there are, local authorities can't put in place effective support for those who need it.

In addition to problems with identifying carers, the report also shines a light on the long waiting lists for a carers' assessment. Over the last five years the average time between requesting an assessment and receiving one has been over six weeks – too long in the context of a rapidly progressing condition like MND where needs can change dramatically over a short period. There is also a postcode lottery for how quickly people receive an assessment, ranging from weeks to, shockingly, over a year depending on where people live.

Our report highlights other areas where local authorities are not delivering for people with MND:

- 82% of local authorities do not have fast-track routes to assessments in place to account for the progressive nature of MND.
- 71% of local authorities do not provide routine reassessments for people with severe, progressive diseases like MND to ensure that the level of support changes as their needs do.
- 85% of local authorities do not have ring-fenced budgets for carers' assessments which would guarantee funding.

Alex Massey, Head of Campaigning, Policy, and Public Affairs at the MND Association said: "Unpaid carers make an enormous contribution to the care of people living with MND. Yet as our report makes clear, too many carers are left unidentified and unsupported by local services.

"Carers' assessments are the ticket to further support, so local authorities need to do better to identify carers and facilitate timely access to an assessment. Without improvements to the system, carers will continue to be forgotten and left to cope alone. We are clear that local authorities must do better and ensure the needs of carers are met. We will continue to shine a light on this important issue on a national level through our *Support MND Carers* campaign and raise issues locally where improvements are required."

The Care Act 2014 in England gives anyone aged 18 years and over – who is looking after another adult who is disabled, ill or elderly – the right to a carers' assessment.



25% of carers of people with MND had either received a carers' assessment or were in the process of having one



75% of local authorities have a Single Point of Access for information and guidance on carers' assessments



36% of unpaid carers of people with MND are also working



An average wait of 42 – 47 days between 2018 and 2023



82% of local authorities have no formal fast-track process for the delivery of carers' assessments for carers of people with severe, progressive conditions



Top five Government asks

Ahead of an expected 2024 general election, we share our five asks of government along with our manifesto, detailing the MND Association's policy recommendations to support people affected by MND.

1. Act to adapt

We are asking local authorities to remove the red tape and fast-track people with MND for appropriate housing adaptations.

2. Access to medicines

We are asking for sustained investment and support to bring new disease modifying and life extending drugs for MND to those who need them.

3. Cost of living

We are pushing for targeted energy support to help people affected by MND through the winter, as well as long-term solutions such as an energy social tariff.

4. Social care

We need the government to provide a sustainable social care funding settlement with a clear plan to address workforce shortages to fully support people with MND.

5. Support MND carers

We are calling on the government for a full review of the support available to unpaid carers.

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Fundraising ball raises £17,000 for Manchester and District Branch

A group of six people, all touched by MND and all strangers before joining the Manchester and District Branch of the MND Association, organised an epic night of entertainment, raising £17,000 for the branch.

Held in November at Bolton Stadium Hotel, this was the second Winter Ball the branch's fundraising committee had organised. *Coronation Street* stars came out in force to support the event, with Daniel Brocklebank, Peter Ash, Harriet Bibby and Jane Hazlegrove joining 300 members of the local MND community for an evening of food, music, entertainment and dancing.

Liz Groundland, Chair of the branch's fundraising committee, shares her motivations for devoting so much of her time to the event. Liz said: "All six of us on the fundraising committee work full-time. We all have families and other commitments, so I can't say organising a big Ball is easy, but it's a way to come together and do something positive.

"I'll never forget the feeling of utter helplessness when my brother, Philip Wall was diagnosed with MND in 2014. He was just 37. Watching him progressively deteriorate I knew I had to do something, so in 2017, I organised my first charity event and joined the branch.

"To raise more funds to help people locally we set up a fundraising committee in 2019. Our first Winter Ball in 2021 raised £19,000. I think people were keen



to get together again after lockdown as the tickets sold quickly. It was tougher to sell tickets this time, but we still had 300 people in the room and raised an amazing amount of money.

"I think the biggest factor in our success is that it's a team effort. We pull in favours, and contact local businesses and others connected to MND to ask for support, from donating auction prizes to providing entertainment.

"Everyone on the fundraising committee has experience of MND. We have Steph Mills and her husband Nigel, Paul Golds, my brother Alec Wall and his wife Rachel, and Sylvia Hinde who also runs the support groups and is an Association visitor. They're an incredible bunch of people and I'm so happy to volunteer alongside them, even though we were brought together under such sad circumstances.

"I'm proud of everyone who works so hard to pull off the event. As a member of the branch, I see where the money gets spent and that's what motivates all of us to continue. We use some of it to provide grants to people living with and affected by MND. We also use it to fund our support groups, like the one at Bolton Hospice.

"The Winter Ball is a legacy to our loved ones who have died of MND, but we also do it for those who are living with the disease today. We want to be there to make their lives as comfortable as possible."



The Winter Ball is a legacy to our loved ones who have died of MND, but we also do it for those who are living with the disease today.

Liz Groundland, Branch Chair

“We wanted to do all we could to help the MND community”

Carol Deytrikh-White’s husband, Alex, died in March 2009 of MND and, in 2022 her brother, Brian, also died of the disease. Carol chose to create Tribute Funds for Alex and Brian to celebrate their lives, and took on walking challenges in their memory. Carol said: “We need to raise funds, funds, funds. Not just to help researchers find a cure, but also to get support to families who need help now.”

When Carol’s brother, Brian, was diagnosed with MND, she felt like she’d been ‘thumped in the stomach’. Brian’s diagnosis came just a few years after Carol’s husband, Alex, died of MND. Carol was reminded of how she felt when she learned of her husband’s diagnosis and wanted to help and support her brother as much as she could. Carol said: “I understood the journey he could be facing, and I didn’t want anyone else to experience it.”

Carol describes Alex as honest, honourable, conscientious, and someone who was always checking in on friends and colleagues. She said: “From the moment he received his MND diagnosis, Alex wanted to raise as much money as possible, and tell as many people as he could about MND.”

He worked for the RAF, which arranged psychological, physiological, and medical support immediately after his diagnosis. Carol and Alex even held a fundraising



Carol’s husband Alex Deytrikh-White

dinner that raised over £14,000 for the Association, where so many people came together to support him and the cause. Carol said: “We recognised we were luckier than most people affected by MND to have so much support, and we wanted to do all we could to help the MND community.”

A few years later, Brian was living in Thailand when he noticed he was losing his voice at the end of each day. He received his formal MND diagnosis during a trip to the UK. Carol describes her brother as ‘quite the character’, and her children lovingly referred to him as the ‘fun uncle’. As a nurse herself, Carol went to Thailand to help her brother, having only previously come across one patient with MND.

Carol’s support became long-distance during the pandemic, as Brian chose to stay in Thailand. He died in early 2022.

Carol set up Tribute Funds for Alex and Brian to fundraise in their memories. The funds have raised a combined total of over £43,500 for the Association. “After Alex died in 2009, I felt lucky to be alive and able to continue his fundraising work as a way of celebrating his life,” Carol added: “Brian’s daughter is doing a lot

of fundraising, and his Tribute Fund is a lovely way for his children to celebrate his life.”

Carol has taken on walking challenges over the years, inspired by Alex’s love of walking. With her husband, John, Carol is completing a walk along the entire coast of the UK – that’s 11,000 miles – to raise money for the Association. She said: “I’ll never forget how the generous fundraising by other supporters meant the Association could fund Alex’s last holiday, and how grateful I am that we were able to create a wonderful experience for Alex and make lasting memories. I want to make sure others affected by this cruel disease get the support they need too.”



We need to raise funds, funds, funds. Not just to help researchers find a cure, but also to get support to families who need help now.

Carol Deytrikh-White



Carol’s brother, Brian

A Tribute Fund is a special way to remember someone you love and create hope for a future free from MND. If you’d like more information on Tribute Funds, please visit www.mndassociation.org/tribute-funds or contact the Tribute Funds team 01604 611849 or via tributefunds@mndassociation.org

A lasting legacy of ground-breaking research

Over 30 supporters joined our 'Meet the Researchers' legacy event at the John Radcliffe Hospital, Oxford in November, to hear from leading MND researchers working hard to find a cure.

The supporters heard how vital gifts in Wills are to the work of the MND Association. Accounting for around one third of our income, they have a huge impact on the research and care we can commit to funding in the future.

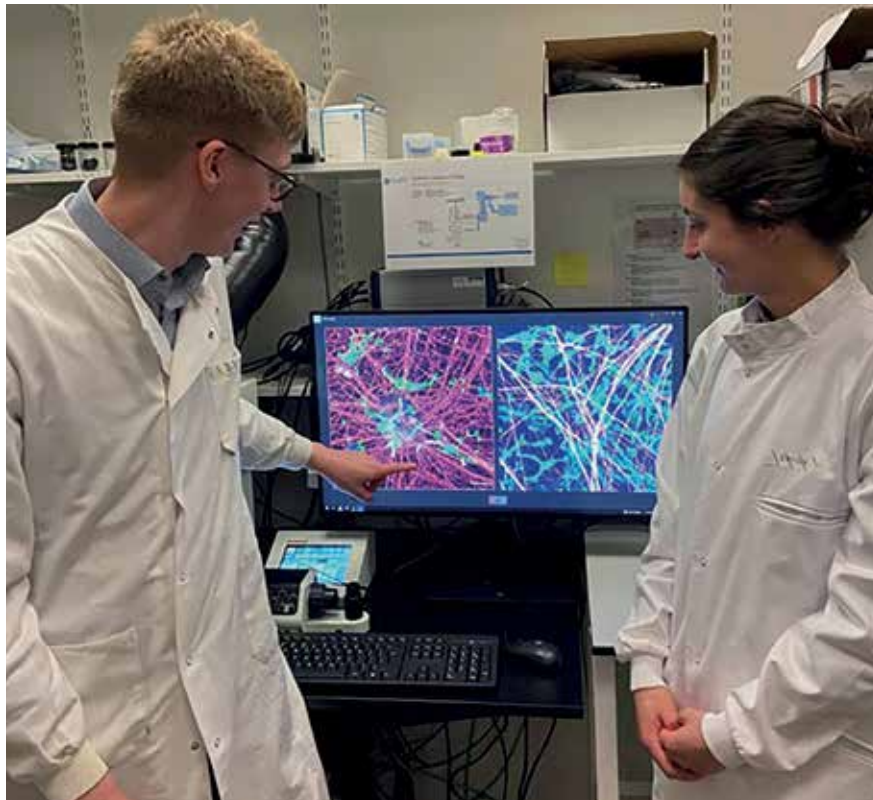
Thanks to the generosity of our supporters, including those who have left the Association a gift in their Will, we are currently funding 113 research grants like those at Oxford. From gene sequencing to growing stem cells, scientists are discovering new things every day. Their aim is to turn the remarkable progress in understanding motor neurone degeneration into treatments.



We're really making good progress. We won't rest until we find a treatment. We may be on the cusp of being able to do something positive about MND.



Liz Haworth with Dr Alexander Thompson who measures proteins and chemicals in blood and spinal fluid to develop ways of assessing changes in the nervous system of people with MND and those at risk aiming to accelerate effective treatments



Dr Bjorn Vahsen and Dr Emily Carroll have been studying motor neurones and other cells for five years

During the event, supporter Liz Haworth heard how her brother's gift of his body to research has already made a difference to others living with MND and will continue to do so into the future. Richard Haworth died in 2017, aged 50, from MND, just a year after he met Dr Alexander Thompson, a scientist and consultant neurologist at the Oxford MND Care and Research Centre. The father of three daughters had been very fit, running marathons and cycling until the devastating diagnosis of MND.

Liz, who volunteers for the Reading and West Berkshire Branch, believes Richard decided to help after meeting Dr Thompson and the team, and being impressed by their progress in the laboratories. Now she has been able to see how people affected by MND are coming together to help scientists find effective treatments and an eventual cure.

The message from the researchers throughout the event was clear – with research comes hope. Dr Nick Cole, the MND Association's Head of Research said: "We're really making good progress. We won't rest until we find a treatment. We may be on the cusp of being able to do something positive about MND."

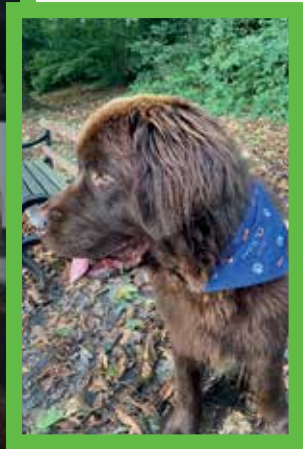
Did you know you can make or update your Will for free at any time?

Making or updating your Will couldn't be simpler. As a member of the Association you can make use of our free Will partnership, with the Free Wills Network. Please see the enclosed leaflet for further information or visit www.mndassociation.org/free-wills

To see the difference a gift in your Will can make, why not join one of our future legacy events visit www.mndassociation.org/wills or contact the legacy team on 01604 611860 or legacies@mndassociation.org to register your interest.

Pawsome pooches

raise over £170,000



We asked our Facebook community to find dog owners to join our brand new challenge to walk 75 miles in October with their pets. More than 2,000 people signed up to the challenge alongside their furry friends. Across the country almost every breed of dog was represented from Newfoundlands to Dachshunds. We loved seeing photos of dog walks – here are some of our favourites.



The challenge was such a huge success, we will be going for 'walkies' once again next October. To register your interest join our #TeamMND Facebook group.



Celebration of life concert in tribute to musician Nick Care

Not a single seat in the 1,200 capacity theatre was left unoccupied for the special tribute concert dedicated to the memory of much-loved trumpet player, band director and teacher, Nick Care. Nick was diagnosed with MND and frontotemporal dementia in 2016. He died in 2020, aged 62.

Nick's students from across the world, including the Grammy award-winning composer, conductor and arranger Jules Buckley, played at the concert. Jules had played in Nick's bands from the age of nine to 18 and has since established himself as a leading figure in music, collaborating with musical legends such as Paul Weller, Stormzy, Quincy Jones, Tori Amos and the BBC Symphony Orchestra.



Organised by Nick's widow, Kathy Gifford, the concert featured 160 performers and raised £15,000 for the



Kathy Gifford presents Rita Beaumont, volunteer for the Bedfordshire Branch of the MND Association with a cheque for £15,008.45

MND Association. The majority of the funds raised will be invested in MND research, with a percentage going to the Bedfordshire Branch, which supported Nick.

Throughout his career, Nick won national and international awards for his work and was an educator at Aylesbury Music Centre for 30 years, where he was instrumental in Aylesbury becoming known as a centre for musical excellence. Nick's bands performed live on BBC's *Blue Peter* seven times, and also played at Buckingham Palace, the Royal Albert Hall, London Palladium and BBC *Proms in the Park*.

Kathy said: "All the things he enjoyed doing; teaching, playing the trumpet, going for walks, being funny and witty, eating out and making conversation with friends, were one by one whittled away

by the disease. Despite all this, Nick being Nick, he carried on, stayed positive and kept everyone around him smiling and laughing.

"The music profession, particularly in the Jazz genre, is peppered with alumni of Nick's bands and lessons. Many others are working as teachers, concert managers, record producers, and in numerous sectors of the music world. Although Nick had a small funeral in lockdown, the main event was always going to be this concert. A positive celebration. Many of his students talk about learning from his attitude to life and overcoming setbacks. Nick was always 'Mr Positive'. An amazing legacy."

The concert is available on YouTube: search 'Nick Care Paean' and the JustGiving Nick Care Concert page is still open for donations.

Community of Practice Annual Networking event: Inspiring and supporting good care for people with MND

Research shows that enabling healthcare professionals to form networks, exchange information and share good practice contributes towards better care. The MND Professionals' Community of Practice is a 1,300-strong network of health and social care professionals united behind a shared mission to improve the lives of people affected by MND.

In October, over 130 Community of Practice members came together to explore the role of the multidisciplinary team in advance care planning for people

with MND. Keynote speaker Trish Sealy, Consultant in Palliative Medicine, gave a brilliant overview presentation that was followed by lively and informative interactive group sessions.

The day saw important new connections made between colleagues, and attendees were able to take valuable ideas back to their services. Sally Hughes, Director of Services and Partnerships for the MND Association said: "This was a fantastic, informative event. It was a great opportunity for healthcare professionals to get together with people who are



passionate about MND and share knowledge to benefit the people they care for."

Toyota (GB) extend charity partnership for another year

Toyota (GB) and Toyota Financial Services have extended their charity partnership for another year, taking their fundraising commitment to the MND Association up to 31 March 2025.

The partnership, originally intended to last three years, has seen the two companies raise more than £176,000 between them. Colleagues have undertaken various fundraising challenges, including a 24-hour static cycle, the Lake District Ultra Challenge and RideLondon.



Toyota staff take on a 5K Santa Run raising over £5,000

The businesses chose the MND Association as their charity partner via a staff vote. Fundraising since then has felt even more crucial following the death of much-loved colleague Rachel Rollason in 2022.

Toyota (GB) President and Managing Director, Agustin Martin said: "We are very pleased to be supporting the great work the MND Association does, especially since we lost our colleague Rachel to MND. This staff-selected relationship has prompted great efforts in fundraising and



In high temperatures, students completed the 50K Lake District Challenge even finishing with a smile!

also in trying to understand what MND is and how it affects sufferers. We hope that it continues to be a hugely inspiring partnership."

Fran Kenny, Toyota Financial Services UK CEO and Managing Director shared how this partnership is like no other. "Never has a Toyota charity partnership created such a positive reaction among staff and a willingness of so many to become involved in fundraising events. We look forward to further success in helping develop treatments and ultimately a cure."



A new event for Toyota, colleagues smashed the challenge of Ride London

Norton Way Group launches first charity partnership

The Norton Way Group, a dealership group based in Hertfordshire and London has chosen the Association as its first official Charity of the Year.

Ben Athrow, Head of Marketing and Digital Transformation, suggested the MND Association following the diagnosis of his father-in-law, Mike. With his wife Jenny already fundraising for the Association, he said: "Charity partnership felt like a natural next step, which Norton Way Managing Director, Jason Cranswick, agreed to support."

"It's now very visible the effects this disease is having on Mike's body. The



The Norton Way Group charity fundraiser, clay pigeon shoot at E.J. Churchill, Buckinghamshire ground



Participants on the day included a range of companies from the automotive sector

MND Association has been nothing short of amazing since his diagnosis, fitting the house with numerous aids for mobility, arranging several consultations and helping with his voice banking. He has even recorded a few stories that can be played by the machine for my daughter, so he doesn't lose the opportunity to read his granddaughter her bedtime story.

"Ever since Mike's diagnosis my wife has fundraised for the Association. She is a true inspiration and has completed two marathons just four weeks apart.

Now I'm keen to play my part. That's why I proposed the idea of having a charity of the year for Norton Way Group.

"As a family we take comfort from the work and fundraising efforts of people across the country that one day a cure will be found, and we won't stop helping this amazing charity until that day!"

The group has already held its first event, a charity clay pigeon shoot which raised an incredible £14,000 and colleagues have signed up for the London Tough Mudder in 2024.

2023 Annual Stephen Hawking MND Lecture



PROMISE 2
WE WON'T REST UNTIL
EVERYONE GETS THE CARE
THEY NEED WHEN THEY NEED IT

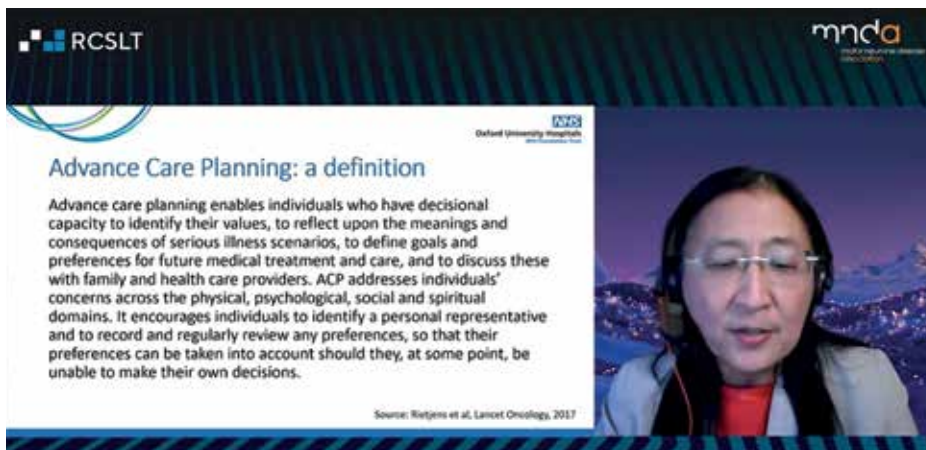
Every year the Association holds the Annual Stephen Hawking MND Lecture. This year, it was delivered as part of our partnership with the Royal College of Speech and Language Therapists (RCSLT). Each lecture, delivered by an expert in their field, is designed to highlight current research and demonstrate how this might feed into their practice.

More than 1,200 professionals from a wide range of disciplines registered for the event, which took place virtually in November. The lecture was led by Professor Bee Wee CBE, Consultant in Palliative Medicine at Sobell House and Katharine House Hospice, Oxford University Hospitals NHS Foundation Trust and Associate Professor at the University of Oxford.

Professor Wee explored the topic of advanced care planning for people living with MND, and its positive impact on the patient. The lecture included practical examples of how professionals can support advance care planning in their own environment to ensure patient centred care.

The MND Association is grateful for the financial support received from the Stephen Hawking MND Foundation to make this lecture possible, and to the RCSLT for their partnership. Jennifer Bedford, Head of Partnerships, Education and Information at the MND Association said: "We are so pleased this lecture reaches so many people. From the feedback we receive, we know it's valued and supports our health and social care professional colleagues to provide great care for people living with and affected by MND."

All of the past lectures are available on our website at www.mndassociation.org/hawkinglecture



Marathon mate

Gary Curtis led a full and active life, regularly clocking up the miles on his daily walks – and he thought nothing of walking the equivalent of over a marathon a week. But life for Gary changed beyond recognition when he was diagnosed with MND in 2022.

Gary found it difficult to tell people of his diagnosis. As he battled to come to terms with it, he delayed breaking the news until visual signs of his symptoms became apparent to others. When he did eventually tell his friends and family, they quickly rallied round.

Gary's long-time drinking buddy, Keith Hosking had already secured a ballot place in the London Marathon, and asked Gary if he could run on his behalf and raise funds for the MND Association. While Keith is an avid runner and sportsman, regularly marshalling and participating in Poole Park fun runs, he had never competitively raced over 10km before, so the marathon was a huge new goal.

Despite the challenge ahead of him,

Keith was spurred on by the idea of raising funds for the MND Association and showing support for his mate. And while Keith did all the running, the fundraising was a joint effort. The two friends set an initial target of £2,000, but thanks to the generosity of friends, family and colleagues, the final total was an incredible £5,130.



It's with eternal thanks to people like Keith for raising funds and awareness of the MND Association, so that they're able to help sufferers like me through unpleasant and frightening times.

Gary said: "It is because of fundraising that the MND Association is able to



Gary pictured left, with his marathon mate Keith Hosking

provide support to help people with their day-to-day hardships. I've been able to benefit from the charity's support grants to assist with the installation of handrails to ease access to my property, as well as the provision of a lightweight wheelchair to aid my mobility."

Meet the professionals: Orthotists

People with MND can be in touch with up to 20 different health and social care professionals. Our regular 'Meet the professionals' feature, spotlights the different professionals and how they support people living with MND.

Orthotists help people with problems in their muscles, bones and nerves. They make, adapt and fit special devices called orthoses which help support, protect or improve movement in parts of the body that are weak or difficult to move. Orthoses can be customised to suit different needs, such as helping someone walk better, keeping joints in the right position, or aiding in the healing of injuries. Orthotists generally work in a hospital or outpatients' department, supporting people with a wide range of needs and conditions, including MND, to find the best solutions for their needs.

Orthotics used in MND include:

Ankle-foot orthoses: These are devices that provide support and stability to the

foot and ankle. They can help prevent and manage foot drop (a common symptom in MND), improve walking ability and reduce the risk of falls.

Hand and wrist orthoses: These devices include functional wrist, hand or finger splints to support the individual to participate in daily activities, or resting splints to help maintain muscle length and reduce risk of contractures.

Knee orthoses: Knee braces or orthoses may be recommended if there is weakness or instability in the knee joint. These braces can provide additional support, improve stability and assist with walking.

Neck collars: In some cases, people with MND may experience weakness in the neck muscles, leading to difficulties in holding the head upright. Neck collars or cervical collars provide support to the neck and help maintain proper alignment.

How to access support

The NICE guideline on MND recommends that the multidisciplinary team should have established relationships with, and prompt access to orthotists. Ask your MND team or GP for a referral if you think orthotics might be helpful for you. Many occupational therapists also have expertise in orthotics, so they may also be a useful person to contact.

More information is detailed in the MND Association's information sheet 11C – *Equipment and wheelchairs* and the *Personal care booklet*. Professionals can access further information in our Occupational therapy for MND guide and Information sheet P1 – *Head supports*.

You can download these from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Volunteer experience survey

Volunteers are the lifeblood of the MND Association – we couldn't deliver our national and local services without them.

Whether they're cheering our marathon runners across the line or providing friendship to a family reeling from a recent MND diagnosis, we are immensely grateful to every one of our 7,000 volunteers.

This incredible group of people have a huge range of skills, knowledge and experience. But most of all, they always keep the needs of people affected by MND close to their hearts.

Volunteering works both ways – it's important all our volunteers feel recognised and supported. In December we launched the 2023 *Volunteer*

experience survey. This survey represents an important step in our ongoing efforts to enrich and enhance our volunteer journey, and we're digging deep into the experiences, challenges, and diverse perspectives of our volunteers. We've been curious about the highs, lows, and everything in between experienced by Association volunteers.

By gathering these insights, our aim is to refine and enhance our volunteer programme, ensuring it reflects the needs and aspirations of our volunteers and people living with MND. Once the responses are in, we'll keep you informed about the survey results and any subsequent developments in future editions of *Thumb Print*.

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Using information when making decisions about your care



PROMISE 3
WE WON'T REST UNTIL
EVERY DAY COUNTS

For people facing the challenges of MND or Kennedy's disease, a wide range of support is available. Yet, with many options for therapy and social care, the choices can feel bewildering. How do you begin to make sense of it all?

Conversations with your health and social care team can help you find the right support. Yet, knowing where to start or who to contact can be confusing. Our information resources are here to help.

Planning is key. From introductory booklets to detailed guidance about living with the disease, our content is designed to help you feel better prepared.

It can help you feel informed so you can have more effective conversations about your needs. As one person with MND told us: "I found the comprehensive information from the MND Association to be the greatest help in talking about the issues and steps to be taken with the professionals. Information is liberating."

And, of course, knowing what's available means you can make informed decisions that feel right for you. It also

helps you understand how each choice could affect you and those close to you.

Our booklet *Types of care* is a good place to begin thinking about the different ways you can find support. When you meet with health or social care professionals, our pocket guide *What you should expect from your care*, provides easy prompts to open discussions. This small guide is based on the NICE guideline for the management of MND, which gives recommendations to professionals about care and treatment.

Our new web page *What do the words and initials mean?* at: www.mndassociation.org/words is the perfect place to help you understand the abbreviations and acronyms you may come across. There is more detail in our information sheets, which can also help with a range of decisions from therapies and treatments to making benefit claims.

Our larger guides explore sensitive subjects with empathy and honesty, such as our *End of life guide*, to help you plan when you feel ready.

Find a summary of publications



I found the comprehensive information from the MND Association to be the greatest help in talking about the issues and steps to be taken with the professionals. Information is liberating.

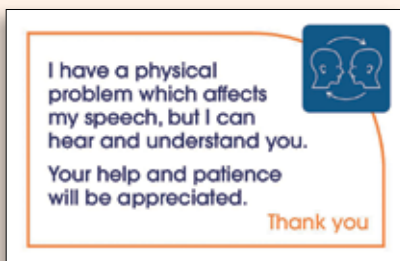
and tools to help with choices in the drop-down option for *Decision making resources* at: www.mndassociation.org/careinfo

Search for our resources by need, using our *Care information finder* at: www.mndassociation.org/careinfofinder

If you would like to know more about our publications or order printed copies, contact our MND Connect helpline: 0808 802 6262 or email: mndconnect@mndassociation.org



CARE INFORMATION UPDATE



Speech card

Our pocket-sized *Speech card* carries a short message to explain that you have difficulty speaking. It now includes the Communication Access Symbol used by organisations and venues with staff members trained to support people with communication difficulties.

Updates to booklets

We have updated and refreshed three of our small booklets:

- *Telling people about MND*
- *Emotional and psychological support*
- *Changes to thinking and behaviour with MND*

Revised information for professionals

We also offer resources to health and social care professionals, to help them provide tailored support. The following items have been updated:

- *Managing respiratory symptoms in motor neurone disease*
- *Occupational therapy for motor neurone disease*
- *Motor neurone disease: A guide for social care services*

Would you like to help with our information development?

We work alongside people with MND or Kennedy's disease, and their carers, to develop and improve our information. If you would like to get involved, you'll have opportunities to feed into a range of different content and formats. You can pick and choose which tasks you want to work on and make a difference from the comfort of your own home. To find out more contact: infofeedback@mndassociation.org

Visit www.mndassociation.org/publications or order printed copies from our MND Connect helpline: 0808 802 6262 or email mndconnect@mndassociation.org

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Thank you

Everything we're able to do is because of our amazing supporters and their generosity in helping us to fight MND.

In 2023, we sent out three fundraising appeals, along with two *Your Impact* newsletters. Your generosity has so far raised an incredible £615,000, with donations for our Christmas appeal still coming in. The funds raised will go directly towards vital research to fund the search for a cure and help improve the lives of people living with and affected by MND.

Our Christmas appeal saw messages of support pouring in for families affected by MND. Thank you to everyone who sent a message - your words were beautiful and showed people they're not alone. It really demonstrated the true spirit of the festive season and the strength of the MND community.

Thank you to everyone who has donated over the last year, we are so grateful for every gift. We couldn't do what we do without you.

Festive fundraising raffle raises £119,000



Thank you to everyone who bought and sold tickets for the Christmas raffle – your efforts helped to raise a fantastic £119,000 for families affected by MND.

Congratulations to all those who won prizes including Mr and Mrs Ditte from Bradford-on-Avon who won first prize of £5,000, Mrs Wisby from Shefford who won £1,000 and Mrs Bostock from

Edinburgh who won £500.

A full list of all the lucky winners is available at www.mndassociation.org/raffle

If you didn't win this time, don't worry! There will be another chance to win some great prizes and support people living with MND at the same time in our Summer Raffle. Look out for more details in the spring.

Thank you

to all our fundraisers

Share your pictures at
[www.facebook.com/
mndassociation](https://www.facebook.com/mndassociation)

If you are sending in photographs to feature on these pages please ensure you have full permission to use the images.



Mullet chop: Ten-year-old Davis Farnworth shaved off his beloved 'mullet', raising over £2,000 for people affected by MND. The young rugby player was inspired by our patron, Rob Burrow CBE. His mum Becki said: "When he heard about Rob Burrow, and he saw his documentary, to say Davis was gutted for him was an understatement. Since Davis started playing rugby he's always been the smallest, so we told him about Rob."

£2,000



£30,000

Power pounds: Olympic weightlifter Emily Muskett and Winners 2000 Fitness Ltd hosted the third Lift Me Up weightlifting competition. Since it started, the competition has raised an amazing £30,000 for the Association and inspired a new generation of weightlifters.

Batting for Mick: Mick Coote's family organised a charity cricket match following his diagnosis of MND. Two teams battled it out and raised money for the MND Association and the Nottinghamshire Branch. A rematch is in the planning for 2024.



£11,300



£10,000

Captain's club: When Bruce Macfarlane was appointed Captain at Belton Park Golf Club he set to work raising over £10,000 for the Association. Even though his year as Captain is over, Bruce's fundraising continues and he's considering running the Rob Burrow Leeds Marathon in May 2024.



£11,000

Having a ball: The West Sussex South Branch's fundraising ball raised an impressive £11,000. The ball was organised by Olivia Albon-Carey who lost her granddad John to MND. Supporting the Association is a family affair, with Olivia's mum Cathy helping families affected by MND as an Association visitor, while her nan Barbara is the Branch Chair.



£3,000

Wheels & Walkies: Over 80 people and 20 dogs joined the East and West Surrey MND branches' Wheels & Walkies event at Denbies Wine Estate in Dorking. First held in September 2020, the event is the brainchild of 50-year-old Carlos Lopez Lansdowne, who is living with MND and regularly takes his dog, Cooper, for a walk around the wine estate in his powered wheelchair.

If you've been inspired to take part in a fundraising event for the Association, there are loads of ideas to make a difference at www.mndassociation.org/fundraising



£8,000

Running for Mum

Despite windy conditions, Evie Hardman, her boyfriend Max Laing and their friend, Sarah Corney made good time running the 10K in Brighton, in November. Evie's mum Samantha who has MND is currently being supported by the East Sussex Branch. Together they raised £8,000.



£5,000

2,023 miles in 2023: Jacqui and Tony McAleese raised £5,000 by walking 2,023 miles across Lancashire, including walking around the pitch of Blackburn Rovers FC!



£825

Inspired by Rob: Eight-year-old Harry Higginson, eight was inspired to fundraise for the Association by Rob Burrow CBE and then persuaded his family to hike Snowdon with him, raising £825. Well done Harry!



£3,500

Perfect note: International concert pianist Nurry Lee performed to a sold-out audience in Bath, and donated all the proceeds to the MND Association.



£1,600

Spurred on for Dad:

Alison and Daniel Lethbridge did their first ever marathon in honour of Alison's dad who died from MND. The couple carried a Tottenham Hotspur flag over the finish line in tribute to Alison's dad, who was a keen fan of the football club.



£3,700

For Serena: The Jenner family took on the 17 peaks of the Malvern Hills in support of Serena, who was diagnosed with MND last January. Lucy, her niece said: "Serena struggles every day, so for us to have to struggle for one day is minor. At the halfway mark people were getting tired and seeing Serena there cheering us on gave us the motivation to continue. And to see her at the end just made us all feel so proud and happy."

30 years of volunteering: Margaret Weaver (pictured standing) became a volunteer after her husband Bob was diagnosed with MND in 1991. He died in 1995, but Margaret has carried on his legacy by continuing to raise money and awareness for her local Southampton and Winchester Group where she is also an Association visitor. Thank you for your long years of service to people living with MND.



Members' letters

If you have something you would like to share with other members of the MND community, we would love to hear from you. Letters, which must include your full address, can be sent via email to editor@mndassociation.org or posted to Your letters, *Thumb Print*, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ

Please note that letters may be edited. If you are including photographs please ensure you have full permission before sending.

Dear Editor,

I would like to outline a few ways in which the MND Association has supported my wife and myself in maintaining a quality of life whilst living with MND. Since my diagnosis seven years ago, the MND Association has always been there for us. Whether that be for information and advice, signposting to other agencies, or by issuing grants to support our quality of life.

Alongside the support available at the end of the phone or email, we have also benefited by being allocated an Association visitor who has worked tirelessly over the years to ensure that we have the support we most need.

Our latest grant application was for a holiday, a garden shed and a carer's weekend away for my wife Sharon. The impact that these have had and continue to have is many fold.

On holiday we had a week at a slower pace and re-connected with each other without the usual stresses and strains

of living with MND. We took our time to walk short distances, visited Bicton Gardens and Otterton Mill, and attended a literature event in Budliegh Salterton.

Having a shed for our allotment gave us a positive opportunity to share with family and a few friends - well, someone needed to build it! It was a lovely two days spent focusing on something for the future. Now the shed is complete Sharon and I are able to enjoy being at the allotment even more. It's important to have a focus and work towards some attainable future goal. The grant for our allotment shed gave us that in the short term and continues to have an impact on our wellbeing every day.

Sharon's carer's grant for a weekend away has been booked. This will be a chance for Sharon to step away, relax and reset. Being a carer is a difficult and demanding role and without the MND Association's support grant this wouldn't happen and our quality of life would undoubtedly suffer in the longer term.



John and Sharon outside their new allotment shed funded by the Association

The work that the MND Association do is invaluable, a game changer and a life support for those living with or affected by MND, which enables us to live our best life despite the challenges we face.

A massive thank you to you all.

John

Dear Editor,

I have just reached my fifth anniversary of receiving the dreaded diagnosis but am happy to say I believe I am doing well.

Back in October 2019, when I completed a four-day challenge cycling from Birmingham to London to raise funds for the MND Association, I didn't envisage ever being on the receiving end of the sum raised. However, after relieving my mother-in-law of her redundant car I had it converted to hand controls and the MND Association

significantly contributed to the cost. The conversion has restored my independence, and I am truly grateful. After a shaky and nervous start at giving up any control with my feet I was delighted that I performed a necessary and successful emergency stop last week. Despite 45 years of driving conventionally I now feel fully competent with hands only and can't express how grateful I am to the MND Association.

I was also generously awarded a Quality of Life grant last week. We moved

house last year to a property that will accommodate my future needs, but we have also taken on a high maintenance garden. The grant will be very useful to pay for much needed work to reduce the size of borders and long-term maintenance and ensure the garden is manageable.

All in all, the MND Association have been very supportive both socially and financially and I wish to sincerely thank them for that.

Jane Bryant

The MND Association is committed to minimising impact on the environment. As such we have taken the decision to replace the magazine's potato starch outer wrapper, replacing it with a fully recycled paper wrap, 100% sustainable and the most environmentally friendly solution available.

ThumbPrint is printed on paper sourced and certified by the Forest Stewardship Council (FSC) and is carbon balanced – offset by The World Land Trust – an international conservation Charity committed to buying and protecting environmentally-threatened land throughout the world

The person I admire most

Some people look up to celebrities. Some admire their favourite athletes. Political figures. Singers. The most important people in the world. However, I admire someone entirely different. His love, care and joy can light up anybody's day and his happiness is a warm welcoming fire. Well, my hero might not actually be famous, but in my heart, he is still massively important and significant. He has a huge place inside of me. The person I admire most is my grandpa.

My grandpa's smile is a beam of joy radiating from his face. He always has enough love to share between anyone who is in need of it. He might be testing my maths or playing a game with me. However, no matter what he is doing or where he is, he will never fail to remind me to be positive, caring and original. To just be myself.

His advice has got me through many hard decisions and his wisdom has answered my questions and problems. These qualities have taught me the valuable life skills that I know now and I could not forget them. On top of this, he is fighting MND for his life and is bravely pulling through. His familiar half-Ugandan, half-Indian accent brightens up my face as I remember his warm voice always telling me to be kind and spread my natural joy.



Left to right: Laksh (Milli's younger brother), grandma Sumi, Milli and grandpa Ramesh

My favourite thing about my grandpa is his care. He is the first to ask about my day, listen to my questions, play a game. He will never leave me by myself. He cares for me as much as I love him and he is the one that can really show me the significance of love, care and family.

In conclusion, my grandpa is who I admire most for his love, care and joy. In the real world, he might not be famous or important, but in mine, he is. He keeps me cheerful. Reminds me to stay positive and shows me that I should be respectful towards others. He is a role model to me and I hope I grow up to be even half as inspirational as him. He will always be my leader, my grandpa and my hero.

Milli Radia (age 10)



MND Matters

MND Matters is the Association's podcast series, sharing stories, advice and information from and with members of the MND community and beyond.

Listen to episodes on our website at www.mndassociation.org/mndmatters or search MND Matters in your chosen podcast provider.

Episode 29: Cultural challenges with MND

In this thought-provoking episode, Yvonne Johnson, living with MND, and author Liv Little, whose dad died from MND in 2022, talk about some of the cultural challenges around navigating the disease.

Episode 28: When Eddie met Lesley

Academy Award-winning actor Eddie Redmayne takes the reins as he sits down with the incredible Lesley Connor, an MND Association volunteer whose unwavering dedication has spanned two decades.

Episode 27 – Rob Burrow Leeds Marathon

This special episode takes you behind the scenes at the inaugural Rob Burrow Leeds Marathon. Hear from members of the MND community and why they were inspired to take part.

About us

The Motor Neurone Disease (MND) Association


We improve care and support for people with MND, their families and carers, and fund and promote research that leads to new understanding and treatments.


We also campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.


As a charity we rely on voluntary donations. Our vision is a world free from MND.

Social media

Online forum A place for people affected by MND to share experiences and support each other. <https://forum.mndassociation.org>

 [mndassociation](https://www.facebook.com/mndassociation)

 [mndassoc](https://twitter.com/mndassoc)

 [mndassoc](https://www.instagram.com/mndassoc)

MND Connect

Our MND Connect helpline offers advice, practical and emotional support and signposting to other organisations.

Open Monday to Friday 9am to 5pm and 7pm to 10.30pm.


0808 802 6262
mndconnect@mndassociation.org

Membership

To receive a regular copy of *Thumb Print*, call 01604 611860 or email membership@mndassociation.org

If you would prefer to receive your copy of *Thumb Print* under plain cover please let our membership team know.



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The latest Luggie Lexington shows off its all-weatherproof canopy... perfect for any winter outing!



ON THE COBBLES... Farokh's Luggie makes light work of the cobbles near the Trevi Fountain

Howzat for Mobility! Farokh's Luggie Hits A Six in Rome Visit

FAROKH Engineer, the Indian test cricket legend, took his Luggie Scooter on a scenic adventure to Rome recently. At 85, he's proving that age is just a number when it comes to exploring the world. "My Luggie became my new legs, confidently carrying me over the cobbles to Rome's Trevi Fountain. It's given me a

fresh zest for life," says Farokh.

So good, even on Rome's bouncy cobbled streets...

His story shows how the Luggie's lightweight and foldable design opens up a world of possibilities, effortlessly airplane friendly, ensuring no destination is out of reach. Whether you're off for a bit of winter sun or navigating the UK's variable weather, the Luggie is your perfect travel partner. Its range of optional canopies are designed to keep you warm and dry during the colder, wetter months ahead.

Local Mobility, the family-run business behind this innovative scooter range, is committed to enhancing lives through mobility. To experience their 5-star service and premium scooters for yourself, book your free no-obligation home demonstration today. Call free on 0800 012 4258.

WHEN IN ROME...

Indian cricketing icon Farokh Engineer finds a winning partnership with his Luggie scooter. Here he is enjoying Rome's splendour (left) – and he's always ready to catch some winter sun. He's out there proving life's innings can always bring joy. Explore your boundaries and book a free test drive today. Call 0800 012 4258 now.



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Introducing the Luggie Plus Scooter: robust and agile with a wider front wheelbase and suspension for stability. It supports up to 25.7 stone, features a spacious seat, enhanced motor, and an LED display. You're guaranteed a comfortable ride with a travelling range of up to 18 miles.

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