

IT'S BEEN A BUSY YEAR



The Branch have had a busy old year with much work being done behind the scenes in care and fundraising by our remarkable volunteers. There is now a dedicated Campaigns Team established thanks to Mike, Sue and Cath. They're

already hard at work contacting local MP's and ensuring your local councils have signed the MND Charter. My colleague Alex and I will work alongside them bringing issues to the fore so if there is something you feel is becoming a systemic problem, please make us aware.

I would like to welcome new Association Visitors who have joined the team in the past year, they will introduce themselves by way of bios in coming issues. Although we don't have many, they are mighty in the provision of care and support. If you would like an Association Visitor, please let us know and we will endeavour to provide.

Just another quick thanks to Sue in her capacity as Treasurer and Secretary, a thankless and tireless back-room grafter. Branch Contact, Newsletter Editor and Facebook guru and all-round brilliant person Jackie Johnson (let's see if she prints that (Ha Ha., she did)) another one always grafting away in the background.

Our webpage is starting to look a little fresher thanks to Katy Carter so please start to look at it more often if possible. Venue and time changes are also shown there for the Get-Together and Cornflower Group (both now 1-3pm).

During 2025 we will see the Rob Burrow Centre open. The Leeds Care Team have been so dedicated in bringing this wonderful vision of Rob and his family to the fore, it will be terrific to see how people living and affected by MND can benefit from it.

That's all for now, and take care 😊

Michelle, Community Support Coordinator
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DATES FOR YOUR DIARY

Carers Groups 1st Wed in the month, Holiday Inn, Ossett WF59BE 10am - 12 noon

Get-Togethers 2nd Wed in the month, 1 - 3pm.

March 12th Normanton Golf Club, Hatfeild Hall, Aberford Road, Stanley, Wakefield, WF3 4JP

April 9th AMT Café St Michaels Lane, Headingley, Leeds LS6 3BR

Cornflower Past Carers Group Last Wed in the month, Skelton Lake Services, M1 Junction 45, 1.00-3.00pm

PMA PLS Support Group on Zoom 2nd Mon in the month 5pm

Tracheostomy Group on Zoom 3rd Tues, either 2pm or 6.30pm

Continuing Health Care on Zoom every 6 weeks April 14th 11am

Veterans Group on Zoom 4th Wed in the month 2.30pm

Black Indigenous People of Colour Support Group on Zoom 12-1pm 3rd Tues in the month (Starting in April)

<https://www.mndassociation.org/online-support-groups>

BRADFORD BULLS HELD A COLLECTION



On Dec 22nd, Bradford Bulls, at their match against Keighley Cougars, had a collection for MND and the Lord Mayor of Bradford's Appeal. The Bradford Bulls were the winners

of the Joe Philips Memorial Trophy. Thank you Ryan Whalley for alerting the Branch to the collection and to Richard Wood for paying in £101.35 to the West Yorkshire account. Much appreciated.

CHUBBY LAD RETURNS

Paul Stafford made a vow never to run the Leeds Marathon again after 2023, he says, "it was a killer and nearly broke me". However, 2025 is the return of the Chubby Lad that Runs. "I will be raising funds for the West Yorkshire Branch." Good luck Paul.

FLIXBY & BRIGHOUSE WI



On November 6th, Flixby & Brighouse WI invited Tracy Sanderson to their meeting. They have been fundraising for the West Yorkshire Branch, in memory of their last President, Marilyn Denney, who died from MND in January. Richard

Wood, Marilyn's partner, presented a cheque for £3,500, which was raised by holding an Elvis evening, a sponsored walk and a book sale. This fantastic amount will not be "Returned to Sender". Thank you.

KINSLEY RAIDERS

On October 19th, at a Reunion of the Kinsley Raiders Rugby Team from Pontefract, £375 was raised, Rob Burrow was their coach. This was donated to the West Yorkshire Branch. Thank you to Carl Brown and all the fundraisers.

KEVIN SINFIELD RAN HOME FOR CHRISTMAS

Kevin and his team started in Liverpool on the 1st of December, reaching Saddleworth on December 7th. They have raised a fantastic £1,372,522 for MND. 50% goes to the MND Association and the rest is split between 6 other MND charities.....and donations are still coming in. As part of each day, MND supporters were invited to join Kev, to run with him for one mile – the Extra Mile.

EXTRA MILE

ANDREW GOUGH GOING THE EXTRA MILE



I was diagnosed with MND (PLS) in April 2024 having had the misdiagnosis of cerebellar ataxia in 2016. My wife Hazel and I joined the MNDA and started attending the West Yorkshire Support Group meeting straight away. We have met

some wonderful and inspiring people, including the people who run the group. One day, out of the blue, I received an invitation to do the extra mile with Kevin Sinfield in Hull. Michelle had very kindly put my name forward. I felt very honoured. Having been a lifelong supporter of Leeds Rhinos, (my grandad used to take me to watch Leeds when I



was a young boy) I naturally accepted the invitation.

We were loaned a racing wheelchair, and, on the 5th December, we went to the Costello Stadium in Hull. The weather was kind to us – chilly but dry. It was a very well supported event, including children from a local school and there were lots of runners, so Kevin arrived to lots of noise and clapping. He chatted with people in wheelchairs who were taking part. The mile consisted of four laps of the track. My son Matthew and nephew Arran took it in turns to push me round. It was an experience I will never forget. It was a real family affair as most of my family came to support us and cheered us on every time we completed a lap. It was up there as one of the best days of my life, emotional but fabulous and wonderful memories were made.

ROB SMITTEN, AXLE FOLEY & RICHARD BENNY SHAW



Rob Smitten tells us, "That on Thursday Dec 5th, it was a privilege to be in Hull and join Kevin Sinfield for his Extra Mile". Rob was accompanied by Andrew Gough, Richard Benny Shaw and Axle Foley . Axle says ". What an amazing experience to have been invited for the extra mile in honour of the MND Association. To be a part of such a diverse set of people, all with a story to tell and still dare to dream, thank you and thank you to Kevin Sinfield and his amazing team for their ongoing fundraising and belief in finding a cure".



BEN & PHIL'S CRAZY 7 IN 7



Ben Wildman and Phil began their challenge on the 14th October and ran a half marathon each day for 6 consecutive days; on the 7th day, (20th October), they ran the Yorkshire

Marathon in York. That's a total of 105 miles! They were running with a mate for a mate. Sally Brown was diagnosed with MND back in 2023. £10,535 was raised. Ben says, "We only went and did it!" <https://www.justgiving.com/page/phil-ben7in7...>

COFFEE MORNING SUTTON IN CRAVEN



On Sunday November 3rd, Rachel Peacock-Adams organised a **BAKE IT** at Greenroyd Mills in Sutton in Craven. A lively event with a generous amount of donated homecooked cakes. The raffle had many prizes and then we took part in a quiz all about cakes. The

morning was inspired by Rob Burrow and Phil Stevenson, a local rugby player from Keighley Cougars who passed away from MND in 2019. 50% of the money raised was given to the Kevin Sinfield Running Home for Christmas challenge, part of this fund will be awarded to the MND Association.



Huddersfield Parish Church



Saturday November 30th Katie Carter & Colin Hey at Huddersfield Parish Church Christmas Fair. £136.54 raised.

ROB BURROW SCOOTER RIDEOUT RAFFLE



Tracy writes, "What a great day with Axle Foley and Mandy Foley in Bridlington on Saturday October 26th where the raffle for a scooter was drawn. Thank you for all you've been doing in 2024 to raise funds for the Branch."



BRADLEY PARK GOLF CLUB



At Bradley Park Golf Club in Huddersfield, funds are raised throughout the year at a number of events. Each year the Captain nominates a charity to which the funds will be donated. This year Paul Walton, Captain, has nominated the MND Association as his chosen charity. So far £1,300 has been raised and donated to the Branch, a little more will be added in the first quarter of 2025, when the contents of the collection boxes have been counted. Paul's captaincy ends in March 2025. Thank you to all the golfers.

HORSE & JOCKEY QUIZ, RAFFLE & AUCTION



The Horse and Jockey pub, Horbury Bridge held a charity night for the West Yorkshire branch of the MND

Association on 30th November 2024. We had a quiz with photo board music round, raffle and an auction. It was such a brilliant night, the whole community came together to support us including local businesses donating raffle prizes, Just Heating who sponsored our raffle tickets and The Horse and Jockey pub who sponsored the pie and peas. The pub was packed to the rafters and we managed to raise over £2,835. Thank you to everyone who helped organise the quiz and who attended. Everyone said how much they enjoyed it so, watch this space, we are hoping to make it an annual event!

CHRISTMAS BUCKET COLLECTION



Micaela Frank says thank you to everyone who donated to Team Foggy's Christmas MND Association Bucket Collection, both in cash and online. We raised a fabulous £636. Eric has been having a hard time recently and is so grateful for all your efforts. He

would be out there collecting himself if he could! So far you have helped him to raise £24,708.64. Every single penny goes to the MND Association who are the most amazing, supportive charity, in many ways. In July 2015 Dad was diagnosed with MND. This was completely devastating. Now, over 9 years on, Dad is still fighting as fiercely as ever, despite losing the ability to talk, walk, eat and do anything for himself. We cannot do anything to change this. We cannot make Dad better. What we can do is to commit to raising as much money as possible on behalf of our hero to try and make a difference to other people living with this disease, together with support and care for their families. Funding vital research for this disease is also massively important to Dad, in the hope that one day, no one will have to suffer this debilitating, life limiting disease. Thank you. <https://eric-frank.muchloved.com/>

IMAGINATION

Polly (Lesley) Day, who recently passed away from MND, lived in Hebden Bridge where she attended a local writing group. The theme for the session was 'Imagination' and this is her poem.

Imagination let me see,
What the word means to me

Twenty-four hours every day
February March April May

August perhaps until next July
As oft when on my couch I lie

Not in pensive or vacant mood
Enforced and rigid solitude.

Unusable hand right and left
Without my pens, I feel bereft

Never more to write or draw
Or walk barefoot across a floor

Nowhere to go or ever work
Excuse me not, to sit and shirk.

With time enough to cogitate
I dine off china eat 'til late

Danced a waltz danced a jive
Listen to bees dance in their hive

Picked Italian lemons in the sun
A life of never-ending fun

Enticed a kitten out to play
Smelt the scent of new mown hay

Traced patterns of winter frost
Until fingers feeling almost lost

Seen magical flowers bright
Hold on through darkest night

When parachuting in the rain
I wish I'd never left the plane

Feel the breeze against my skin
And such happiness within

More time please to cogitate
Especially with a new date

For more oft when on the couch we lie
My wicked imagination and I

Mugs for MND for the West Yorkshire Branch



£7.50 plus postage


'In a world full of adversity, we must dare to dream'. Inspired by Rob Burrow and Kevin Sinfield. Different designs available including personalised or bespoke designs - please just ask.

£2.50 from each sale of each mug will be donated to the West Yorkshire Branch. Buyer pays postage. Mugs will be posted via Royal Mail. Small parcel £4.79 1st class or £3.75 second class.

Order by emailing inkpantheyorkshire@gmail.com or whatsapp 07508210892

West Yorkshire Branch @MND_A_WestYorks

www.mndassociation.org
Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
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mnda
motor neurone disease
association

PARK PLAZA
LEEDS

Tanya Arnold presents: THE GLITTER BALL on behalf of the West Yorkshire Branch


Saturday 12th April 2025 7pm until late
Park Plaza Hotel, Leeds

- Tickets £60 each including 3 course dinner and welcome drink
- Featuring live entertainment with Janet Jaye
- Grand raffle and auction
- All in aid of the West Yorkshire branch to support local people, their families and carers
- Dress to impress!

Please contact Karen to book tickets on karen.jeffery@mndassociation.org or 07801588735

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NEW COMMITTEE MEMBERS

KAREN MERREY (back for a second round)



I first went onto the committee to represent our Carers Group in 2018 and then went on to become Chair. In 2022 I had to step down as life had become more demanding, but last year was asked if I would like to rejoin. It

was a yes as the branch has supported Steve and I for so many years in so many ways. I want the branch to continue to be there for others and make a difference, plus I enjoy time spent with the other committee members.

Don't miss out, get your tickets soon, for a fun evening while raising money for MND.

KATY CARTER - Webmaster

Katy Carter with daughter Betsy.



I joined the WY branch as a volunteer last year sending 'thank you' cards to people who fundraise for the branch. Since then, I've started to get more involved in other activities like monitoring the Facebook page, updating the branch website and supporting fundraising events where I can, so joining the committee seemed like a natural step to get more involved. Due to family and work

commitments, I can't always attend meetings but everyone has been so helpful and flexible, and I'm looking forward to getting more involved during 2025!

CATHERINE WALTON Campaign Lead



Hi, I'm Cath and I am a campaigner for the MND Association. The reason I campaign is that I cared for my dad, who had ALS, and felt the frustration at the care and services he sometimes received. People didn't have awareness about the disease and didn't

understand how quickly it could progress.

After emailing my local MP, he invited me to talk to him about MND and the issues and problems we encountered. After this I was asked to join the campaign team which involves updating myself on the MND national and local campaigns, sending emails to local MPs and counsellors and sharing news and campaigns on social media.

Attending the West Yorkshire Branch monthly 'get togethers', helps me gain a better understanding of the issues people living with MND and their families are having now. For example, some people were having problems booking wheelchair taxis so we invited Leeds city council taxi enforcement officers to attend our get togethers so we could explain to them about some of our concerns.

MND is such a cruel disease, I hope that, in some small way I can help and support people by helping to raise awareness. I hope that other people might read this and feel like they could join us.



Get-Togethers 2nd Wed in the month 1.00-3.00
March 12th Normanton Golf Club, Hatfield Hall,
Aberford Road, Stanley, Wakefield, WF3 4JP
April 9th Headingley AMT Café St Michaels Lane,
Headingley, Leeds LS6 3BR

MND Carers Group



Current carer for a person with MND?

If so, you're welcome to join us on the 1st Wednesday of the month. Meet others in the same situation in a friendly, supportive and gentle environment.

Where: The Holiday Inn, Queens Drive, Ossett WF5 9BE
Time: 10-12noon

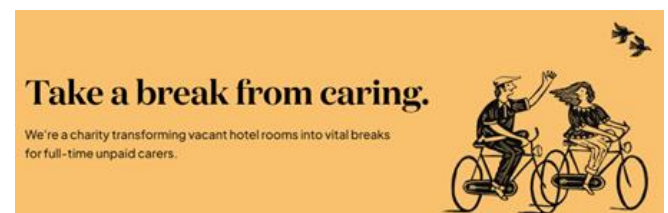
For more information contact:
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mndassociation @mndassoc or MNDA_WestYorks

www.mndassociation.org
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ARE YOU AN UNPAID CARER THINKING ABOUT TAKING A BREAK?



Carefree is an organisation offering low-cost hotel stays across the UK for unpaid carers. These breaks help carers recharge and manage their caring responsibilities more effectively. To apply, simply sign up on the Carefree website and provide details about yourself and the person you care for. You will need to submit proof of your caring status, either by uploading a document or nominating a professional referee. Once approved, you'll gain access to Carefree's booking portal, where you can browse and request a hotel stay. Each break costs £33 and includes up to two nights' accommodation (often with breakfast included!). To sign up, visit their 'take a break' page. *Article from Leeds Carers.*

<https://carefreespace.org/>

THE CAVENDISH SPENCER TRUST



CS Disabled Holidays gives grants to people who are severely physically disabled with neurological or neuromuscular illness, enabling them to enjoy life-changing holidays of their choosing. CSDH believes that disabled people, and carers, need a holiday or a respite break more than any other group in the UK. Without our help, many disabled people cannot afford to go away, to get the change of scene they so desperately need.

We offer grants of up to £2000 per year to individuals over 18 who are severely physically disabled by a neurological illness or condition towards the cost of a holiday of their choice.

<https://www.csdisabledholidays.co.uk/>

FULLY ADAPTED SELF-CATERING COTTAGE

The Beamsley Project is an independent charity with over 25 years experience in providing wheelchair friendly, self-catering holiday



accommodation in the Yorkshire Dales. We would like to ensure everyone can experience the delights of the Yorkshire Dales. The Beamsley Project is close to the historic market towns of Skipton, Ilkley and Harrogate, home to the famous Betty's Tearooms. Experience the spectacular view of the Beamsley Beacon, enjoy the wheelchair friendly walks at Bolton Abbey. Absorb the history of the Royal Armouries in Leeds or take a canal boat trip in Skipton.

<https://www.beamsleyproject.org/the-cottage>

UPDATE ON THE ROB BURROW SCOOTER RIDEOUT WITH CHEQUE PRESENTATION



Axle and Mandy Foley handing over the cheque to Michelle Malouf and Tracy Sanderson. The total raised from the sales of merchandise and the raffle is a whopping £8,392. Thanks for all the support from the Yorkshire Scooter Alliance. We're looking forward to the next ride out.

BRANCH CONTACTS

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Cornflower Group: Michelle Malouf

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West Yorkshire Branch Motor Neurone Disease Association



@mnd_west_yorkshire



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