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association

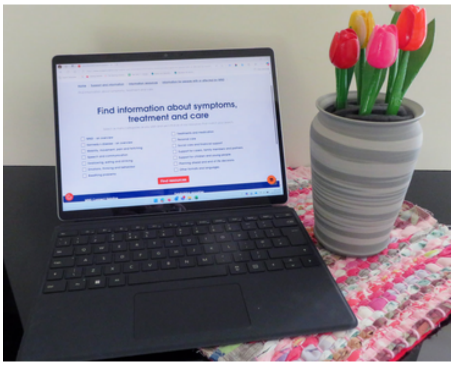
YORKSHIRE DALES BRANCH NEWSLETTER

CHATTER

MARCH 2025

New report calls for better wheelchair services - turn to page 5 to read the full story.

Living with MND online resources



There is a section on the MND Association website which looks at support for daily living and managing symptoms to maintain the best possible quality of life with motor neurone disease (MND). Some of this information may also be helpful if you have Kennedy's disease. If you don't have access to the internet but would like to see this information please let your MND Co-Ordinator know.

The link to view the support information online is:
https://www.mndassociation.org/support-and-information/living-with-mnd

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Message from your Chairman, John Pike

This spring edition marks a new look for Chatter, and some significant new developments for the Branch.

We have a new newsletter editor. We welcome Samantha George who has taken over from our secretary Ruth Pridmore. Ruth has valiantly combined the roles of Newsletter editor and secretary for several years, and we thank her for her dedicated work.
Ruth has also maintained the Branch website, and we are pleased we now have a new volunteer to take a role with social media, Sonam Mistry.
At a recent Branch meeting we met and welcomed Emma Chambers as a new voluntary MND Association Visitor (AV). Emma will play a key role in our work to support and stay in touch with the MND community in our area.
Finally, Alan Robinson agreed to join us as a committee member, and is our Fundraising Lead. Alan has hit the ground running from day one and you can read about him in the following pages.

I have written about quality of life grants before. In 2023 we awarded grants totalling approximately £11,000 to people living with MND and their families in our area. In 2024 the total was approximately £25,500. Each grant is not large but makes a significant difference to the recipient.

Already this year the signs are that the number of grant applications are on the increase again.

The economic situation and local authority cutbacks are a key factor, but the MND community is also becoming more aware of the additional financial help available if MND Association criteria are met.

We are committed to raising awareness of MND, to supporting and staying in touch with the MND community in our area so that they do not feel lonely and isolated, and to providing as much financial support as we can to improve their quality of life. All these new developments are going to help us in that mission.

John Pike.

Meet Alan, Fundraising Volunteer and Committee Member

How long have you volunteered for the MND Association?
I joined the MND Association Yorkshires Dales Branch as a Volunteer Committee Member, responsible for organising local fundraising in July 2024.

What made you want to volunteer?
I volunteered to help out at Headingley Stadium in 2023 for the inaugural Rob Burrow Leeds Marathon. It was here I met a lot of lovely people committed to helping those affected by MND, and finding a cure. My wife, Anne, and I then went to cheer on Kevin Sinfield during some of his remarkable exploits. Our youngest son Tom and I also used to go and watch the Rhinos on a Friday night when he was at Uni in Leeds, when Rob, Kevin and all the other lads were playing, so I was immensely affected by what happened to Rob.

What do you enjoy most about volunteering?
Now I have retired it gives me a great sense of purpose. I am able to use a lot of my transferrable skills. I get to spread the word about the fight to find a cure for MND, raise lots of money in the process and meet remarkable people within the MND Community.

Tell us about the different events you organise and attend?
I will be volunteering at the Leeds Marathon again this year. I have already organised a 'Bake It' event and a stall at Asda in Harrogate selling MND Association merchandise. The Yorkshire Dales Branch Committee and Fundraising team are active in raising awareness and funds, through Christmas trees at Otley Church, collection tins in pubs across the District and getting support from local businesses and organisations.

Do you ever need any helpers/additional support?
We are always looking for additional volunteers/helpers for events, either on an ad-hoc basis or in a more structured role. I would be delighted to hear from anyone who has ideas or time or just a passion for helping. You can contact me on either 07377 383926 or at alan.robinson@mndassociation.org

What else do you do in your spare time?
Well 3 Grandchildren of 10, 5 and 2 take up 3 half-days a week! I am also a Volunteer Schoolreader at a local school one morning a week. Apart from that, Anne and I love walking, cooking at home; and with two boys involved in sport, watching a lot of football!

Fundraising Round Up

A big thank you to everyone who completed events and fundraised over the last few months.

Here's a snap shot of some of the activities people were involved in to help raise funds for the Branch:

- A 'Bake It' sale , Christmas Card sale, along with MND Association merchandise sale at Pannal Village Hall raised £382.60.
- The Otley Christmas Tree Festival raised £194.43.
- A stall at Asda Harrogate selling Christmas goods and MND Association Merchandise raised £176.70.
- Adsa collection raise £175.
- Co-op Jennyfields collection raised £192.
- The male and female captains of Skipton Golf Club chose the MND Association as their charity of the year in 2024. They have raised just over £8500 for the Branch. A fantastic effort for which we are very grateful.

Join our team of volunteers!

General Volunteer

We are looking for volunteers in the Harrogate and Ripon areas to assist our Yorkshire Dales Branch at events, including support and fundraising events.

Become part of a friendly and dedicated team and help to make a positive impact to the lives of people affected by MND.

For more details contact:
Michelle Malouf, Community Support Coordinator
michelle.malouf@mndassociation.org
01604 800619

MNDYorkshireDales @MNDA_Dales

www.mndassociation.org
Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
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We're always on the look out for volunteers. If you would like to join #TeamMND please contact Michelle Malouf, Community Support Co-ordinator: michelle.malouf@mndassociation.org.

The Local Lotto

On average we receive at least £30 every month from the Local Lotto.
If you would like to find out more or join in and boost our monies then please have a look at the website and buy some tickets! The website is: https://www.thelocallotto.co.uk/support/motor-neurone-disease-association

Snippets of MND Association National News

New report calls for better wheelchair services

The MND Association has backed a report by the Wheelchair Alliance which calls for a 'more integrated approach' and 'greater prioritisation of wheelchair services in the NHS'.

The report, funded by Motability Foundation, was launched at the House of Lords in November and completes a trilogy of annual reports first released in 2022.

This third and final report outlines three recommendations that could greatly improve wheelchair provision and help to ensure the voices of wheelchair users are heard.

The recommendations include:
- Creation of an NHS England senior responsible officer and dedicated wheelchair service commissioners
- Addressing the postcode lottery
- Better procurement and supply chain management.

The MND Association is urging the Government and the NHS to take note of the findings of the Wheelchair Alliance and act upon its recommendations.

People living with MND and others facing mobility challenges cannot wait. It is a basic human right that everyone who needs a wheelchair should get the right chair at the right time. Wheelchair users should be listened to and have confidence that every NHS wheelchair service across England provides appropriate choice.
Anne Buchanan, MND Association Care Improvement Co-ordinator

The MND Association has a team of experts to support people with MND in accessing wheelchair services.

You can read more by visiting the wheelchair support service webpage, or email: wheelchairs@mndassociation.org.

Snippets of MND Association National News

MND-SMART Update

In December the MND Association welcomed the announcement from the MND-SMART team confirming the drug amantadine will continue to be evaluated as part of the MND-SMART platform trial. Studies suggest amantadine could reduce abnormal clumping of proteins in cells, which is thought to play a role in the onset and progression of MND.
You can read more about the update on the MND Association website.

EXPERTS-ALS programme for rapid drug screening open for recruitment

An innovative, experimental medicine programme, designed to identify potential treatments for MND more quickly has launched at six centres, with a further five due to open during this year.
The EXPERTS-ALS platform will enable researchers to more rapidly screen potential drugs in people with motor neurone disease (MND). Read more on the MND Association website.

BBC Lifeline Appeal success

Presenter and journalist Charlotte Hawkins has shared her thanks to everyone who donated to the Motor Neurone Disease Association's BBC Lifeline Appeal, which raised £31,356.

New remote monitoring platform TiM-R widens access to research

A Telehealth in MND-Research (TiM-R) is a new digital platform that will make it easier and quicker for large numbers of people with MND across the UK to take part in scientific studies. It is hoped this will have a significant impact on accelerating the search for a cure, by speeding up the process of research studies, and widening access to research for all people with MND. Read more on the MND Association website.

Coffee and a Catch up

The first Tuesday of every month we host an informal meet up for all those affect by MND.

It's a place where you can share your stories, ideas and meet others affected by MND.

Michelle Malouf, Community Support Co-ordinator, said: "People living with MND and their carers who regularly attend these events enjoy the chat and the support they get from others."

Chris from Ferensby attends the coffee catch ups, he is a carer for his wife, Joy. He said: "Over time I have found that attending the MND support group once a month has been incredibly beneficial. Initially I didn't want to go into the meeting because I didn't wish to see other patients in a more advanced condition than my wife. Once I was persuaded to join the gathering with my wife I soon realised how much the group could support me emotionally. Talking to others who are in the same position has been a huge comfort. It is helpful to share experiences with people who truly understand the challenges I face as a carer. I no longer feel that I'm struggling on my own; the group has provided a sense of community, solidarity and friendship and reminding me that I'm not alone on this journey."

The catch ups run 2pm until 4pm in the café at Weetons (was Crimple) just outside Pannal on the road into Harrogate. All are welcome, just show up, or if you want more information then do please get in touch. We hope you can join us.

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Coffee & Catch Up

Yorkshire Dales Branch Support Group

First Tuesday of the month 2-4pm

Crimple Hall Garden Centre Cafe
The Carr Leeds Rd, Pannal, Harrogate HG3 1EW

Libby Wade 07803 208139
Margaret Thompson 07704 421513
Michelle Malouf 07876 575032

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www.mndassociation.org
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Registered with FUNDRAISING REGULATOR

Did you know?

The MND Association offer a grant for young people aged 18 or under who are residing with a person with MND, to help support purchases of anything that may help them in their day to day life. This may be a contribution to buying a laptop, going on a school trip or any type of financial support and can be applied for up to 12 months post bereavement. The direct email for Children & Young Persons Services is cyp@mndassociation.org

Hello and Welcome to...

We are delighted to welcome to our Yorkshire Dales Branch volunteer team:

- Emma Chambers Association Visitor
- Sam George, Newsletter Editor
- Sonam Mistry, Social Media Volunteer

We hope to catch up with some of our volunteers for the next edition so you can hear about some of the things they have been getting involved in.

Emma

Sam

Sonam

Quality of Life Grant

The quality of life grant is offered to to anyone living with MND. It can contribute towards services or facilities that helps a person with MND to maintain independence, dignity, comfort, and social connections. It can also be used towards the cost of things which promote the well-being of the person with MND and immediate family.

Any family member, Association Visitor, Health & Social Care Professional or Community Support Coordinator can apply for the grant.

To find out more about the grant please contact the Yorkshire Dales Branch. Contact details are on page 10.

RAFFLE & TOMBOLA PRIZES NEEDED

For Yorkshire Dales Branch events

Please contact Alan if you can help with prizes for fundraising events
alan.robinson@mndassociation.org or 07377383926

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Did you know?

The Yorkshire Dales Branch was founded in 1988 and is now one of over 80 Branches in the country.

Our sole aim is to serve all those in our area who are affected by MND, including people with MND, their carers, family and friends.

Dates for your diary

Yorkshire Dales Branch Quiz Night

Fri 21st March 2025
6.30 pm for 7pm

Bilton Cricket Club, Bilton Ln,
Harrogate HG1 3DQ

Booking essential please email
clubsecretary@biltoncc.com or
call 01423 561199

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Quiz Night
Friday 21st March,
6.30pm
Bilton Cricket Club, Biton Lane,
Harrogate, HG1 3DQ

Teen Day
Saturday 26th April
9.30am-4pm
Doncaster Leisure Park
The South Yorkshire Branch is inviting teenagers (ages 13-16) to a day out at Doncaster Leisure Park. They can bring one friend each and choose to do 3 of the following: bowling, adventure room, karaoke and ice skating. You do not have to be from South Yorkshire to attend - this event is open to all young people affected by MND. For further information and to register contact Brian Jackson brian.jackson@mndassociation.org or 07794480110
Please register by 28th March 2025.

Coffee and Catch up
Tuesday 1st April, 2pm-4pm,
Café at Weetons
Leeds Road Pannal, HG3 1EW

Tuesday 6th May, 2pm-4pm,
Café at Weetons
Leeds Road Pannal, HG3 1EW

Flower Arranging Event
Saturday 17 May 2.30pm - 4.30/5pm
Pannal Village Hall, Station Road
Pannal, HG3 1JG

100 Club Draw Winners

Congratulations to:
September – Amelia McGill
October – Amelia McGill
November – Jasmine Davey
December – Alfred White
January – Libby Wade

Tell us your views

YORKSHIRE DALES BRANCH NEWSLETTER
CHATTER
FEBUARY 2024

We hope you have enjoyed reading our newsletter. We would love hear your views; what you enjoyed, didn't enjoy or would like to see more of. Please email your views to samantha.george@mndassociation.org. The next edition is due to be published in Summer. We would really like to share stories from across our Yorkshire Dales MND Community. We want to share fundraising events and support activities your doing for the branch, any stories, poems, pictures of artwork. Email your ideas to samantha.george@mndassociation.org Can you help us save money by sending you paperwork by email instead of the Royal Mail? If you have an email address just let us know.

Find us online

Yorkshire Dales Social Media Channels are:

Instagram
mnd_yorkshire dales

X: @MNDA_Dales
https://x.com/MNDA_Dales

Facebook:
https://www.facebook.com/MNDYorkshireDales

Yorkshire Dales Branch

Location
Yorkshire Dales
Phone
01423 569754
Contact
Veronica Ace
Email
veronica.ace@mndassociation.org

Make a donation to the branch

Welcome to the Yorkshire Dales Branch

The Yorkshire Dales Branch was founded in1988 and is now one of over 80 Branches in the country. Our sole aim is to serve all those in our area who are affected by MND, including people with MND, their carers, family and friends.

We have our own trained Association Visitors who are well supported by the

Website
www.mndyorkshiredales.co.uk

Your Yorkshire Dales Branch Contacts

- Branch Contact, Veronica Ace – 01423 569754 versace412@gmail.com
- Chairman, John Pike – 07775 586357
- Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk
- Treasurer, Geoff Catley - 01423 870143
- MNDA local contact, Michelle Malouf - 01604 800619, michelle.malouf@mndassociation.org
- Local Relationship Fundraiser for North and East Yorkshire, Jenn Scribbins - 01134 830706, jenn.scribbins@mndassociation.org

National Contact Information:
www.mndassociation.org
MND Connect – 0808 8026262