



AUTUMN 2022

Welcome to our autumn newsletter brought to you by the MND Association Bristol and Bath Group.

We've had a busy autumn so far with our support groups going from strength to strength as well as a fabulous day at the Bath Half Marathon where 11 runners took on this famous course to raise funds for the MND Association. And next month sees a Christmas Cracker Chill Swim at the beautiful Vobster Quay near Radstock.

In this issue, Alex Millard, one of our long serving AVs (Association Visitors) will be sharing her advice on how to cope with MND at Christmas plus we will be giving some useful guidance on what support grants are available and how to access them.

We are delighted to have 6 new volunteers join the MND Association Bristol and Bath Group who, amongst other things, will be helping us to enhance what we can offer the local community. Their roles will include events, fundraising, social media, campaigns and website so watch this space for some exciting updates very soon. We are always on the lookout for more volunteers, so if you are interested in lending a hand do look on our website page for the latest vacancies -we'd love to hear from you.

We hope you enjoy our latest issue.

Jemma Martin

Bristol and Bath Group

07921 396 493

mndbristolandbath@gmail.com



Over £7,000 raised at the Bath Half Marathon

Last month, 11 runners bravely took on the 13.1mile challenge around the beautiful city of Bath to raise funds for the MND Association.

Collectively they raised a staggering £7,000 which will be used to support families affected by MND in the Bristol and Bath area.

A big thank you; to our fabulous runners, to everyone who sponsored them, to everyone who supported them along the route and to everyone who stopped by our stand.

If you or someone you know would like to run in next year's [Bath Half marathon](#) on Sunday 15th October, we have a few places available - please contact our group admin, [Jemma Martin](#) . The course route is relatively flat with a wonderful atmosphere and when else do you get to run through Bath with no traffic?!





Christmas Swim at Vobster Quay

If you're looking to kick off the festive season in style, Vobster Quay in Radstock is hosting a [Christmas Cracker Chill Swim](#) on 11th December in aid of the MND Association. It is all about festive fun and participants are encouraged to dress up and hit the water in their finest festive fancy dress.

After an invigorating winter swim, warm up, tuck into some festive food and enjoy some amazing live music by the firepit from the Midnight Tides.

[Click here](#) to find out more and sign up.

Gates open at 15:00 and our team will be there selling raffle tickets for £1 a ticket with all proceeds going towards the MND Association. There's some amazing prizes on offer kindly donated by some of the biggest names in swimming.



Coping with a terminal illness at Christmas

The festive period may not be a happy time for everyone. One of our AVs shares some advice for coping with a terminal illness at this time of year.

If you are a carer or a friend, listen to the person with MND and find out how they would like to celebrate. Accept offers of help and take any stress out of the day. Have emergency numbers to hand, and if you're using carers from an agency, ask them to confirm the rota well in advance so any changes can be made.

Christmas can be a time to spend quality time together and for presents to take a back seat. However, some favourite gifts to give may be a digital photo frame, a memory blanket, a subscription to audio books, a day out or something homemade.

If you are living with MND, think about how you would like to spend the holiday. Keep it simple, there is no right or wrong way to cope. Ask family and friends to help with preparations and present buying. Factor in some relaxation time and if you would like a nap in the afternoon, include that into your plans. No one will be offended if you say you would like an evening to yourself.

Everyone, please enjoy spending the Christmas period together, and we look forward to meeting with you again in 2023.

Kevin Sinfield's

Ultra 7 in 7

mndassociation.org/7in7



Behind the Scenes of Kevin's Ultra 7in7

Earlier this month, MND Association patron Kevin Sinfield took on his third challenge, inspired by his friendship with team mate Rob Burrow, who is living with MND. The challenge itself saw Kev run 7 ultra marathons in 7 days, from Edinburgh to Manchester finishing the 280 mile route to be greeted by a standing ovation from the 70,000-strong crowd at the men's Rugby League World Cup final.

Kevin and his team ran 40 miles every day for a week all to honour his friends Rob Burrow MBE, Stephen Darby and Doddie Weir – Kevin mapped the route to stop in places of significance for the trio of former sportsmen.

Crowds lined the streets from before sunrise each day to cheer Kevin on, with many donating generously to his fundraising challenge, raising money for the MND Association and four other MND charities.

This challenge gave the MND Matters team the perfect excuse to leave the studio behind and get out on the road. They followed Kevin's extraordinary exploits during that incredible week to bring you exclusive coverage of the challenge. In episode 21 of MND Matters you will get to hear from people they met along the way and enjoy an exclusive MND Matters message from the man himself by listening here

<https://www.mndassociation.org/media/mnd-matters/>

You can also listen to all previous episodes of MND Matters which cover a wide range of interesting stories from the MND community, care and support topics and projects from the MND Association. Visit

<https://www.mndassociation.org/media/mnd-matters/previous-episodes/> or search MND Matters with your chosen podcast provider.

At the time of writing Kevin has raised an incredible £2 million. Kevin said " he just wanted to be a great friend" by fundraising to find a cure. "If we can all try and be a bit of a better friend from time to time, I think we'll have a bit of a better place to live in. Kevin, we salute you.

May we take this opportunity to pass on our sincere condolences to Doddie Weir's family following his passing last week. Doddie became an inspiration to so many, raising awareness, fundraising and campaigning tirelessly on behalf of people with MND. Doddie set up the My Name's Doddie Foundation which has funded MND research projects across the UK and generously donated to the MND Association's support grant programme. Rest in peace Doddie.



Access to Support Grants

Trying to work out what sort of grants and government support you are eligible for can be a bit of a minefield especially when you're newly diagnosed.

Did you know the MND Association is able to offer some financial support to help with:

- Emergency funding to support with additional living costs such as food shopping or bills
- Funding equipment and services that people with MND have been assessed as needing
- Funding for children and young people living with someone with MND
- Non-paid carers supporting someone living with MND
- Improving quality of life for someone living with MND

Apart from the MND Support (Care) Grant, which must be applied for by a health and social care professional, most other grants can be applied for by the person living with MND, a family member, volunteer or health and social care professional.

Grants available include: Emergency grant, MND support care grant, quality of life grant, carers' and young carers' grant and young persons' grant, and they are not means tested. Our website has links to each of these forms - [see here](#)

The MND Association has also provided a useful [support grant summaries document](#) to provide guidance on what grants are available and whether you can apply.

Understanding How Carer's of People with MND Experience Palliative Care in the UK

Did you care for your partner with Motor-Neuron Disease (MND) and receive support from Palliative Care services?

Do you want to help psychological research?



Understanding How Carers of People with MND Experience Palliative Care

Georgia Steed of the University of Southampton is looking for volunteers to take part in an hour long interview to help understand how carers of people with MND experience palliative care here in the UK with the aim of helping psychological research.

Participants must have at least 6 months experience in caring for a partner/spouse with MND (from when symptoms started), before sadly losing their partner, and must have experienced some palliative care input or support.

For more information, please contact Georgia g.steed@soton.ac.uk



Music Event Raises Over £5k

On Saturday 12th November, around 300 people enjoyed an evening of music at Christ Church, Downend. It was organised by Peter, who has been living with MND for many years, to raise funds on behalf of the MND Association in memory of his good friend Martin Brown. Some people nearly missed the event when their sat nav tried directing them to New Zealand (!) but all was well in the end.

The evening started with a mix of current and classic pop and rock songs by the Riff Raff Choir, an excellent a cappella, Bristol based choir that sings for fun. There was then a short screen based presentation about MND, another opportunity to raise awareness of what it is and how it affects people that live with the condition.

The rest of the evening belonged to The Music Train, set up in Bristol by Milestones Trust to provide regular live and inclusive music events for everyone, with an opportunity to listen to, and join in with, their very talented musicians. Guests were entertained by various individual and group performances of pop & rock songs from recent decades, including many classics from the 60s and 70s, which got the audience foot tapping and clapping along.

A great evening was had by all and a big thank you to Peter for organising it and raising over £5,000 to help others in the MND community.



Bristol and Bath Group

Support meetings

Next Group Support Meeting - Saltford Hall - Thursday 15th December at 14:00

Next Carers' Support Group Meeting - online - Tuesday 20th December at 19:00

Next Bereavement Walk - Will take place on 7th December at Willsbridge Mill

To join any of the above, please email Alex Millard on:

millardalex@hotmail.com or call her on **07957 440291**.

Donate to the group

JustGiving page: <https://www.justgiving.com/fundraising/mnd-bbww> AND NOW by

text: TEXT 'MNDBBNS' to the number **70085** to donate £5

Our webpage: www.mndassociation.org/bristol-and-bath-group/

Email us: mndbristolandbath@gmail.com

Like us on Facebook: facebook.com/mndassociation.bristol.bath

Follow us on Twitter: twitter.com/mndaBristolBath