



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

We are currently facing a steep rise in the cost of living which many people are finding challenging and worrying. If you have MND or provide support as a carer, you may qualify for a range of benefits or other types of financial support. In this issue, we'll include ways to help manage some of the cost of living challenges.

We have had some amazing fundraising and activities taking place over recent months including a charity golf day that raised over £11,000, a special charity rugby match, a fabulous inclusive boat trip, and a charity walk in Bristol. Read on to see and find out more.

Also in this issue, you can find out about our support groups we have across the region. We welcome new members and have lots of dates coming up. Alternatively, if you'd like to get involved with the Bristol and Bath group, we have plenty of exciting volunteer roles available. Even if you can only spare an hour or two once a month we'd be delighted to hear from you - please get in contact with Ellen Murdock ellen.murdock@mndassociation.org

We hope you enjoy our latest issue.

Jemma Martin

Bristol and Bath Group
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Support with the Cost of Living

If you have not claimed benefits before, you may find it daunting. However, it is your right to do so and it could make a significant difference to your financial position and peace of mind. If employed, you may also be thinking about options at work.

The MNDA are currently offering a one-off Cost of Living Support Fund up to the value of £350. This is to help people living with MND who may be struggling with household bills or food shopping costs. This fund is under continuous review. If you would like to apply, a simple form asks you to let us know what you would like the money for. You can download the application form [here](#). If you would like support to apply, please contact your Association Visitor or ellen.murdock@mndassociation.org.

In addition to this grant, the [Association's Benefits Advice Service](#) can offer guidance about benefits.

How can I spend less money?

- Citizens Advice provides guidance on debt and a useful checklist on ways to reduce living costs.
- [Money Saving Expert](#) offers suggestions on ways to save money, including current deals across a wide range of services and providers.
- Contact your bank or building society to discuss your finances, as they may be able to advise and offer support. They often give money-saving tips on their websites.
- If you are finding it difficult to afford food, contact your nearest food bank [here](#).
- Check your energy provider's website, as they may have recommendations or deals available. If you are unable to pay a bill, contact them for guidance.
- The Which organisation offers [10 ways to save on energy bills](#) with guidance.
- Warm hubs are heated spaces in community buildings, where local residents can visit. Find out more, including a map of the hubs, at: <https://warmspaces.org>



Summer Boat Trip

This lovely article is written by Lis Jeffrey

Our little Armada set off.

It was a grey afternoon but surprisingly warm despite the threatening clouds. The river was calm as our three small boats headed up river. Our boat had no cover so we prayed that the weather would be with us! We had the most informed 'driver' and as we purred up the river at the head of the others he was able to give us a potted history of the buildings along the banks. Logs floated past, looking for all the world like large crocodiles. There had been a report of a bus driver sighting a croc along the Cumberland road... I tried not to think of that!

We turned off to take a look at the Light Ship theatre and what used to be the old General Hospital. Re-joining the river we cruised past The Matthew and the SS Great Britain. We were dwarfed by them but it was interesting to see them from the river. St. Mary Redcliffe church looked spectacular from the river and prompted a conversation about the caves underneath..... maybe another trip?

Continuing up the river, it began to rain. That sort of misty rain that doesn't feel like much but after five minutes you realise you're soaked. However, we arranged the tarpaulin over our legs and hoped it would be over quickly. No sooner had it begun than it stopped as if the whole thing had been a mistake! Cruising under enormous weeping willows, we sailed up the Feeder road and shortly afterwards, turned for Baltic Wharf. We had planned to visit the tea rooms but with the weather and length of time to 'unload' us all there was a consensus that turning back was a good idea.



On the way down river someone spotted a cormorant and everyone turned to watch it at such a close distance. It ducked its head, fished around and came up with an enormous eel in its beak! It was obviously punching above its weight, as they say in boxing terminology.

The snake-like creature wriggled its way out of the cormorant's beak and escaped back into the river only to be pursued by a persistent bird. The cormorant ducked again, rummaged around and emerged with the eel in its beak again. All we needed was a commentary from Richard Attenborough. The scene was worthy of any BBC wildlife programme. Eventually the cormorant conceded defeat and the eel slithered away, sealing the fate on whether or not any of us would venture river swimming.

Easing into Baltic Wharf we were met by hoards of children learning to paddle-board. A couple of children had fallen into the water and were being admonished by an adult. After what we had just seen I wasn't at all surprised!

Safe on dry land we all disembarked amid lots of discussions as to another trip one day. The theatre was mentioned... I wonder if the panto is fully booked..." oh yes it is/oh no it isn't!" Only one way to find out I guess.



Carly's Walk

On 5th August 2023 Carly, who was diagnosed with MND in December 2022, courageously organised and participated in a walk around Page Park in Bristol. The day was very showery and cool, but many of Carly's relatives and friends came along to support and walk with her, and to keep her dry! Lily, one of Carly's 3 children did an amazing job in providing verbal encouragement together with manning the finish line. Logan kept everyone on their toes with his excitement, and Lolah was her normal, calm, quiet self.

Carly wanted to raise awareness and funds for the MND association who have helped her and others affected by the disease. She has reached £834 of her £1000 target, it's not too late to donate and help her achieve her goal. Here is the link to her Just Giving page [here](#)

In addition, Carly's Uncle, Michael Burrows ran the Bath Half Marathon for MND on behalf of his niece. His Just Giving page is still active for any donations, click [here](#) to view more info. Well done Michael!



Charity Music Evening

Join us for a fun-filled event on Sunday 22nd October in Kingswood



!LOOK!
IN KINGSWOOD
Mike presents
An Exclusive Charity Event
in aid of Motor Neurone Disease
and for Carly, my granddaughter
Sunday 22nd October 2023
at Rumors Pub/Club, High Street, Kingswood BS15 8LJ
(opposite the Clock Tower)

1960/70/80's Music


OUTATIME (top duo)
Singing all 1980's songs, well known.

BAZ (from Hampshire)
Singing UB40 songs, Bob Marley etc.

DALE
*Top local DJ with vinyl/Decks doing
60/70/80's Reggae/Motown etc.*

Doors Open / Music 4pm Music till 9.00pm
No Admission after 5.30pm Bar till 11pm

TICKET £10 Contact Mike - 07879 228451

A person wearing a blue button-down shirt is holding a rectangular piece of brown cardboard. The words "VOLUNTEERS NEEDED" are written on the cardboard in red, hand-drawn capital letters. The person's hands are visible at the edges of the sign.

VOLUNTEERS NEEDED

Interested in Joining Us?

Our group is run entirely by volunteers, we would love to welcome new members to our Team!

We are looking for:

[Association Visitor](#) - Association visitors play a vital role in helping us to ensure people with Motor Neurone Disease (MND) and their families receive the support and services they require. This is a challenging but rewarding role and you don't need personal experience of MND, just the desire to make a difference.

[Campaigns Volunteer](#)

[Events Organiser](#)

[Support Group Meeting Facilitator](#)

[Support Group Meeting Facilitator \(Volunteer\) Weston-super-Mare](#)

[Support Volunteer](#)

[Carers Champion](#)

If you would like to have a chat about volunteering with us please contact Ellen Murdock – ellen.murdock@mndassociation.org or alternatively contact the volunteering team by email volunteering@mndassociation.org



A Tee-riffic Day at Chipping Sodbury Golf Club

Helen Mackie, our Regional Fundraiser in the South West attended the Chipping Sodbury Golf Club Captain's Charity Day back in July. Kevin Ell, the men's captain for 2023 generously chose to support the MND Association as his charity of the year in honour of his father-in-law. He has been busy all year raising awareness and funds to help make a difference. His official captain's charity day on the 7th of July saw teams from the club, local golfers, and businesses come together to raise as much money as possible for the Association.

A bountiful raffle and some amazing raffle prizes organised by Kevin meant that over £11,000 was raised on the day. Local businesses also helped to reach this incredible total by sponsoring each golf hole and donating generously to the day.

Everyone was rewarded with plenty of sunshine on the day and a well-deserved BBQ after the 18 holes.

Helen said "I had the privilege of helping throughout the day on the halfway house providing much needed cold drinks and ice to all the players. It was wonderful to meet everyone and be there to answer any questions people had about MND and say thank you in person for everyone's generosity. I want to say a huge thank you to Kevin for how hard he worked to make the day such a success. He put his heart into the event making sure it raised as much as possible and that people enjoyed themselves throughout. It was a fabulous day from start to finish and a wonderful way to honour Kevin's father-in-law, Michael Eldridge"



Rugby 4 MND

Lockleaze Sports Centre in Bristol hosted a very special rugby match organised by Graeme Bloom who is living with MND. Graeme who lives in London chose Bristol as the place to host his Rugby 4 MND having built up links with Lockleaze Sports Centre.

The local team Ashley Down OBs played against a specially formed MND Wanderers team kicking off at 3pm on 12th August.

Graeme said "I thought, what could I do while living with MND? No two days are the same. Some good days and bad days. So, I used the good days to organise this event. I have always been interested in rugby and especially the match officiating. The rugby community has massively come together to support people like Rob Burrow and Doddie Weir. So I thought I could organise an event where I could raise money for the MND Association which also involves one of my personal goals to be a rugby referee".

He said, "I am living with MND, I am in a wheelchair, and I am disabled but I wanted this event to show that I am living my life to the fullest. It shows how people with disabilities can be involved in sport".





Support Groups

Would you like to meet other people with, and affected by MND?

Quite a frightening idea for some, but you may be surprised. We are a friendly and supportive bunch, you will gain new friends and be able to share experiences and information with others. Most of all we hope you will enjoy yourselves. There is always lots of chatter and laughter.

Often, we meet just for a cup of tea and chat, but recently, have been visited by a massage therapist, had a mindfulness session, a talk from Bristol Carers, a visit from a Health professional, and a demonstration from the Assistive Technology team in Bristol. This Summer some of us went out on a boat trip around Bristol Harbourside! See the article in this newsletter.

Come and join us!

On the next page, you'll find details on the upcoming dates of our support groups, or for more information, call **Alex Millard** on **07957 440291**.



Bristol and Bath Group

Support meetings

- **Next Group Support Meeting TICKENHAM** - Tickenham Village Hall - Wednesday 1st November at 14:00
- **Next Group Support Meeting SALTFOURD** - Saltford Hall - Thursday 19th October at 14:00 and Thursday 16th November at 14:00
- **Next Carers' Support Group Meeting - ONLINE** - Tuesday 17th October and Tuesday 21st November at 19:00
- **Next Bereavement Walk WILLSBRIDGE** - 9th November at 10:00. Meet at Longbeach Road car park, BS30 9UA, the walk is around Willsbridge Mill Nature Reserve.

To join any of the above, please email Alex Millard at 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

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