



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

This month one of our association visitors, Alex Millard, had the pleasure of interviewing Kery Vickey - MND Care Centre Co-ordinator from The Bristol Care Centre. She tells us all about her role, how she supports those across the region living with MND and what superpower she'd like to have!

We have useful information inside this issue on ReMap, a national charity run by retired engineers that makes aids and equipment to help disabled people have more independence. We also talk about where to go and find information on financial support grants from Cost of Living to Quality of Life Grant.

If you and or friends/family have a few hours to spend on 31st August and or 1st September, we have a stand at [Truckfest Southwest](#) and need help to set up and run the stand. It will be a great couple of days and we'd love to hear if you can help in any way or have some ideas for the stand.

We hope you enjoy our latest issue. Please do get in touch if there is anything you'd find useful or would like featured in the newsletter.

Jemma Martin

Bristol and Bath Group

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Interview with Keri Vickery

We were delighted to spend 30 minutes interviewing Keri Vickery this month. She is the MND Care Centre Co-ordinator at The Bristol Care Centre, providing support and information across the region.

What do you love about your role? I love getting to know the people and families I am supporting. In previous roles, I have only been involved in people's care for a short window of time but this role enables me to help people throughout their journey, from diagnosis to the end of their life. Ironically, I think this is also the hardest part of my role.

Tell me about your role and what it entails. The role is busy and varied. I work across the acute and community settings to support people living with MND (plwMND) and also the professionals who are working with them. I aim to be as accessible as possible and can be contacted for advice or support. I attend our twice-monthly MND clinic, which is a good chance for me to catch up with those I am supporting. I also undertake teaching/education and service development within the service.

What is a typical day for you? I will arrive at the office to a significant number of messages and emails and I start off by prioritising and responding to those that are urgent. I will often have pre-booked community visits or clinics to attend. I aim to keep some space in the diary to respond to urgent reviews or needs.

What is the hardest part of your role? Supporting those living with progressive conditions is very challenging, especially as you get to know people and their families. I have worked in palliative care for 10 years now and although I have developed ways to cope, sometimes it is tough, especially when juggling many conflicting demands from multiple families who may need input at any one time.

Who do you work with on a day-to-day basis? Although we are a very small team at the Bristol Care Centre (2 consultants, psychological and myself), I actually connect with dozens of professionals each day who are supporting our patients. I work most closely with the community neurology teams (OT/PT/SLT), hospice teams, and also the lovely MND Association Visitors (AVs) but I might be contacted by GPs, paramedics, community nurses, and more! We also have good links with the wheelchair services, AAC West, and Assistive Electronic Services teams.

What area do you cover? The Bristol Care Centre covers the north half of the South West but the majority of our core patients are located in Bristol, North Somerset, and South Gloucestershire.

What services do you offer to people living with MND and their families and carers? We invite patients to come to the MND clinic around every 3 months. Here they will be reviewed by the neurologist and have an opportunity to connect with myself and also our specialist dietician and counselling psychologist. From here, various referrals are made to connect people with the correct services. Where people are unable to attend clinic then I will visit them at home for support.

How many families are you currently supporting across the region? This number varies but will be between 75 and 100 at any one time.

If you had a secret superpower what would it be? To be able to clone myself so that I could spend more time with more patients as it never feels like enough!

Thank you Keri for taking the time out of your busy role to speak to us.

To contact Keri please email Keri.Vickery@nbt.nhs.uk



ReMap

Back in January, we were very lucky to have the amazing charity ReMap join us to speak to our support groups.

Remap is a national charity that makes aids and equipment to help disabled people have more independence. There are Remap panels of volunteers (mainly retired engineers) in most major cities in the UK, and all equipment that they make is given free of charge. In general, they do not make items that can be obtained commercially. The Bristol Panel works on an individual basis with clients and Occupational Therapists in the Bristol and Bath area.

Anyone can apply to ReMap, and the easiest way to do so is for you, or your health professional, to make a referral on their website – www.remap.org.uk

The Bristol Panel covers Bristol and Bath, South Gloucestershire and North Somerset.





Truckfest South West - we need your help!

Europe's largest trucking festival since 1983 is coming to the Bath and West Showground near Shepton Mallet from 31st August to 1st September this year. [Truckfest](#) is a family-friendly event with monster trucks, arena shows, celebrities, rides and more.

The MND Association is delighted to have been offered a stand at this end-of-summer event to raise awareness of the disease, fundraise and recruit volunteers. We would love some extra pairs of hands to help on the stand over the 2 days whether it be setting it up, running the raffle/tombola, giving out merch, or chatting to people.

If you're available to help no matter how big or small please get in touch with Jemma Martin via mndbristolandbath@gmail.com



Financial Support Grants

Do you need help with financial support? The MND Association can help with:

- cost of living support to help with household bills and food shopping
- 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

How do I apply?

Each of the grants below has a link to the application form. These are all in word format and can be saved and emailed to us, or printed and posted to the MND Association. Each form will explain what to do.

[Cost of living support fund](#)

[MND support grant](#)

[Quality of life grant](#)

[Carers and young carer's grant](#)

[Children and young person's grant](#)



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 Coordinator](#)

[General Volunteer](#)

[Group Leader](#)

[Support Group Meeting Facilitator](#)

[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



MND Matters

Sometimes emotional, sometimes humorous, always honest – [MND Matters](#) gives people affected by MND the chance to share their stories. The podcast, brought to you by the MND Association, tackles a host of subjects with the aim of sharing experiences, offering informal advice and support, and raising awareness.

In the latest episode, Sports journalist and West Yorkshire branch patron Tanya Arnold sits down with Chief Executive Tanya Curry, who recently marked one year in post at the MND Association. In this episode, Tanya discusses her tenure so far, her passion for supporting people affected by MND and her ambitions for the Association in 2024 and beyond.

Listen to episodes of MND Matters using the links below, or search MND Matters in your chosen podcast provider

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



Bristol and Bath Group

Upcoming Support Groups

Wednesday 1st May at 2pm

Venue: Tickenham Village Hall, 205 Clevedon Road, Tickenham, BS21 6RX

Thursday 16th May at 2pm

Venue: Saltford Hall, Wedmore Road, Saltford, BS31 3BY.

A Support Group for people living with MND, their Carers and Family members.

Tuesday 21st May at 7pm

Carers Support Group on Zoom. For carers and relatives of people living with MND.

This will be a 'Cuppa and Chat' session which gives an opportunity for people to share experiences, ask questions and support one another. This Zoom is open to anyone living in Bristol, Bath, North and North East Somerset, South Gloucestershire, Gloucestershire and Wiltshire.

Please contact Alex Millard 07957 440291 for further information.

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

Contact us

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

Email us: mndbristolandbath@gmail.com

Social

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

Follow us on Twitter: twitter.com/mndaBristolBath