

MESSAGE FROM YOUR CHAIRMAN

You may recall that I was 'not best pleased' when writing my piece for the last edition of Chatter with the lockdown having just made our lives and the care and contacts we were able to provide for those of you living with MND much more difficult with all activities having been summarily cut off. As luck would have it, as I write this piece the shielding has been lifted and so we can consider where we go from here to restore them and if anyone is in need of a call or visit please do let Libby or Margaret know.

And talking of where we go from here, this will be my last Chairman's message as I will be stepping down from this position in the near future. To all I have met and known during my two spells as your Chairman I would just like to say what a privilege it has been and I have met some wonderful – not to mention courageous – people in that time, the memories of whom will be with me for ever.

All will be revealed in the next Chatter but in this edition I must take the opportunity to pass on our good wishes to Michelle Malouf who recently joined us as our Area Support Coordinator. As stated elsewhere, the next issue will feature a contribution detailing our friends from Francis Crick House (the Association name replacing that of the original David Niven House) of which Michelle has a key role. We have yet to meet her in person as we've only been able to 'zoom' her so far, but that will be corrected shortly.

So it's goodbye from me (although I am not intending to leave the BMC) and a big welcome and lots of luck to my successor!

Peter Thompson

WINNERS OF RECENT 100 CLUB DRAWS

At our Branch Meeting held (online by Zoom) in early July we drew the first three winners for 2020 and they are.

April – Janet Green / May – Molly Gilmartin / June – Helen Clarkson



Well done all three, we will be drawing winners for July, August and September at our Branch Meeting on 10th September.

If you have not yet joined in but would like to do so please contact Secretary Ruth with your contact details and the "names" that you would like to be included, and you can pay the subs online (£20 per year per name – sorry no discount for part year) to Lloyds Bank, with sort code 30-96-09 Acct 02973838 and please add the reference YDales100. You can of course apply by post by sending your information and cheque to Ruth. If you would like a form sending again (it is some time since we sent them out) then just let Ruth know.

FUNDRAISING UPDATE

Just a quick update – thanks to the persistence of one of our BMC members we were delighted to receive £333 from the Waitrose Green Token Scheme in Otley. We are also grateful for various donations in memoriam and are expecting some monies raised by some grass cutting by the same BMC member!

MEET THE TEAM / OPPORTUNITIES

You will have read in Chatter on many occasions the phrase BMC and you may have even heard mention of people from the Association who work with us. We have recently been advertising online for more volunteers to join our team as with so few of us we sometimes struggle to do a lot of fundraising or hold other events – and we are so looking forward to both once we are allowed to do so!

BMC stands for Branch Management Committee - we are all volunteers whose aim is to provide support for people living with MND in our area, also their families; and to raise funds to help the Association continue its valuable research and support work.

We are currently looking for more volunteers to join our merry gang – to help with anything you fancy, but if you are interested in training to be an Association Visitor training is available. For more information please follow this link <https://volunteering.mndassociation.org/vacancy/association-visitor-421107.html> .

Anyway without further ado here are the current team - photos were taken during our most recent Zoom meeting so sorry if the quality isn't that great! We haven't included info about the people from the Association that we work with as we thought we would save that for a future edition!

Chairman - Peter



Peter has had two spells as our Chairman (1999 to 2009 and 2015 to present) in which position he was pressganged into accepting from the outset! He himself was diagnosed with MND in 1997 but this proved to be incorrect and he is therefore a long-standing member of the BMC. Of his role, he says "I see myself as the cricket captain of a fine team made up of the necessary 'batters and bowlers' to achieve our objectives. These are of course primarily to oversee the raising of funds and the provision of support and care for all those in our area who suffer from MND and at the same time making as much a contribution to research as possible.

Libby and Margaret open for us as the first contacts in their Association

Visitor roles and we have a solid middle order in Geoff, Veronica and Ruth who ensure necessary actions are taken as requested by the Association and other professionals. I am our wicket keeper in attempting to prevent nothing is missed and then we have our bowlers in Paul and Ruth who are always looking out for ways of improving our fund and donation raising. At the moment we lack a couple of all-rounders to complete the team.....so do you know of anybody?!"

Treasurer / Deputy Chair - Geoff



Geoff was first involved with the Association when his wife, now sadly deceased, was diagnosed with MND. Not quite sure what the future held he rang the Association for any available information which led to them receiving great support and help both physically and emotionally. Geoff then decided to become a BMC member as this gave the opportunity to say 'thank you' and to help increase awareness of this terrible disease by whatever means possible, so that others may also benefit.

Secretary – Ruth Pridmore



Ruth joined the BMC five years ago as the then Secretary was about to move away from the area. She knew Peter from their work together on the Committee of Harrogate Choral Society where she is still Secretary and when Peter asked if she knew of anyone from HCS who might be able to help the BMC out she volunteered. In a previous life in paid employment Ruth was an administrator for Harrogate Council and also worked in HR admin. Her final role with HBC involved work on a project to implement a new HR system for the local council. Thus with admin and IT skills she is appropriately qualified for secretarial duties which include managing the Yorkshire Dales Website and Facebook pages, as well as

compiling Chatter! However if anyone with IT skills would be interested in joining our team Ruth is more than willing to share the load!

Branch Contact and Association Visitor – Margaret



Margaret Thompson was first involved with MNDA in 1999 - originally as a committee member and latterly as an Association Visitor. "It was through my husband Peter that I first became interested in MND as he was and as it happens misdiagnosed with it in 1997. My background is mental health so, having retired, I felt I would like to do some volunteering and becoming a Visitor seemed the obvious way to go. I completed my A V training in 2010 and have since met some amazingly courageous people who are all so inspirational and make me feel privileged to be part of their lives. I also attend the MND clinic

at our local hospital where my colleague Libby and I have very much been made to feel part of the team. I help to facilitate our monthly get togethers for clients and their carers at a local garden centre (when Covid allows) and also occasional lunches. This has been a very fulfilling role in which I have made some good friends. I would highly recommend anyone with an interest in volunteering and can spare a few hours a month to consider joining us. You will meet some lovely people and be made to feel very welcome."

Association Visitor – Libby



Libby trained as an Association Visitor in 2005 just after moving to Ripon. "At that time I was looking for some voluntary work as I had more time and I thought that would make use of my skills having been a district nurse and worked in a hospice. My father in law had died of MND in the 1980s and I knew of the work of the Association. It is very satisfying helping to support people affected by MND during a very stressful time providing information, emotional support and sometimes access to financial support. I really enjoy our monthly coffee meetings and quarterly lunches (although not at the moment), getting to know people and visiting them at home when they can no longer manage to

come to the meetings. Sometimes it is only for a short time and sometimes it is for years when you build up a strong relationship. I also help on the committee which is fun. Over the years I have made many new friends both in the Association or people with MND.

Minutes Secretary – Veronica



"My family and I have lived in Harrogate for over 20 years, before that in different parts of the world. I am a general member of the committee and, because of my office background/shorthand, I take the minutes at our regular meetings and try to support as much fundraising as possible. My brother died of MND four years ago and I originally joined the committee in 2014 to find out how to help him with such things as endless paperwork, attempts to get a comfortable wheelchair, expensive changes to his house and an appropriate car. The MNDA were a great support. We are a lovely committee and very happy to do anything we can to help those with MND.

BMC Member - Ruth



Ruth joined the BMC following our AGM in 2018. She is what is known as a "general volunteer". "I took early retirement a few years ago and as my sister died a number of years ago from MND I wanted to give something to the Association both to help people living with MND and also to support research into the disease. I've been involved with looking out for opportunities to raise money and also in running some small events, such as local coffee mornings, to raise funds.

We have **one more BMC Member - Paul** but no photo (sad face) as he couldn't make the most recent meeting. Paul became involved with Yorkshire Dales at the beginning of 2011, taking part in the Swinsty Reservoir "Walk to Defeat" and formally joined the Branch later that year having sadly lost his first wife Carol to MND. He has arranged fundraising lunches at Mirabelle, Harrogate and a small music festival in Pannal – we hope he has more schemes up his sleeve!!

MISSION 5000

We expect to lose over £2 million this year due to the cancellation of community and sporting events as a result of the COVID-19 pandemic. But our fight against MND cannot be delayed. People affected by the disease need our support now, they need their voices heard today. People facing MND in the future need our vital research to continue. That's why we're on a mission, and we need you to join us. Together we want to cover 5,000 miles, that's a mile for every person living with MND in the UK today. Take part and run, walk, swim, cycle or even scoot however far you can. Every penny you raise will bring us closer to achieving our ultimate mission, a world free from MND. So we are looking for people to join in with this virtual fundraiser to support The Yorkshire Dales Branch. Along with MND Association national office and Branches and Groups across the country, we want to unite the whole MND community and cover 5000 miles. That represents a mile for every person living with MND in the UK.



Participants can join the challenge and run, walk, swim, cycle or scoot (or anything way they choose!) their miles, between 13 September and 18 October. Every penny raised will help us achieve our ultimate mission; a world free from MND. Anyone can take part and raise funds for us. Sign up by visiting www.mndassociation.org/mission5000 and don't forget to mention you are supporting the Yorkshire Dales Branch on the sign up and on your fundraising page (for example justgiving.com)

A QUICK UPDATE FROM THE NATIONAL WEBSITE

Scrap6Months - A year since the announcement of a review into the benefits system, more than 2,000 have died from MND, many struggling to access the benefits they desperately need. The review, announced in response to the Association's campaign has not yet been published. And, indeed, little progress has been made. The current system unfairly excludes many of those living with unpredictable terminal illnesses like MND. The Scrap6Months campaign calls on the Government to change the law to scrap the 6 months rule and replace it with the judgement of a clinician so that all terminally ill people can access benefits quickly and sensitively. Supporters are urged to send a tweet to DWP MP Justin Tomlinson [@JustinTomlinson](https://twitter.com/JustinTomlinson) asking for action.

Mission 5000 Response – The MND Association has received a response to its open letter to the UK and Welsh Governments concerning unpaid carers. While the Welsh Government has provided some tangible proposals to better support unpaid carers in their jurisdiction, the Association is disappointed by the response from Helen Whatley, the Minister of State for Social Care which fails to address the vast majority of our asks. Thank you so much to all supporters who signed and championed the open letter. The huge swell of support that the letter received is truly appreciated and it was amazing to see over 3000 signatures in such a short space of time. The Association will continue to deliver on its [commitment to carers](#) and we will follow up with a wide range of carers organisations and coalitions of which we are a member, to ensure the voices of MND carers are heard by decision makers.

BRANCH WEBSITE AND OTHER INFORMATION

Please let us know if you would like to publish something on either our facebook page <https://www.facebook.com/MNDYorkshiredales> or our website www.mndyorkshiredales.co.uk . Or perhaps you might like to contribute to Chatter? It would be lovely to publish something from one of our members - just send your article to Ruth Pridmore

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 Ruth know and she will add it to the database.

Branch Contacts

Chairman, Peter Thompson – 01423 870130 chair@mndyorkshiredales.co.uk
Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk
Treasurer, Geoff Catley - 01423 870143 treasurer@mndyorkshiredales.co.uk
Branch Contact, Margaret Thompson – 01423 870130 margaret.thompson730@ntlworld.com
Association Visitor, Libby Wade - 07803 208139 libbywade22@outlook.com

National Contact Information

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MND Connect – 0808 8026262