

Art Exhibition on 20 July, in Brighton

We are pleased to share details of a free exhibition taking place this summer, showcasing both the process and the work produced by people living with MND, and carers, during art therapy sessions.

The exhibition will take place on Saturday 20 July, from 2pm to 5pm, at Brighton and Sussex Medical School, in Falmer. We will soon be sharing further details of the event, but if you already know you would like to attend, please email julie.taghan@mndassociation.org, to secure a place.

Save the date

Saturday
20th July 2024

Exhibition

What does living
with motor neurone
disease look like?
Art therapy in practice

All are welcome to this relaxed
exhibition of work produced by
people affected by motor neurone
disease (MND) during art therapy.

Drop in 2-5pm
Talks at 2.30pm
Brighton and Sussex Medical School
University of Sussex
Falmer, BN1 9RY
Bookings will open
at the end of April.
More details to follow

Charity Play and Supper Evening: 'A Fete Worse Than Death'

There are still a few tickets available for our Murder Mystery Evening with the Goring Regional Occasional Players, on 27 April, at Horsham's Greenway Academy.

Doors open at 7pm for a 7.30pm start. Tickets are £15 per head and include a fish and chip supper (alternatives are also available).



There will also be a raffle during the evening, with some great prizes. Please contact Sue at sue.sheppard@mndassociation.org, or on mobile number 07815 148391.

Also in this issue:

- Dave Setters on NHS Continuing Healthcare Funding
- Fundraisers: Miles for MND
- Join the MND Association Regional Roadshows
- Events: new branch socials, Horsham collection, carers' meeting

Cycling 1,000 Miles for MND

On 12 May this year, Jonathan Holland, 54, from Sharpthorne in West Sussex, will begin the 1,000-mile cycle ride from Land's End to John O'Groats in aid of the MND Association. Jonathan wants to raise funds for frontline care in Sussex and for the charity's national research programme. He has set himself a fund-raising target of £7,777. Inspired by Kevin Sinfield's incredible "7 in" challenges, and of course the number 7 being Rob Burrow's shirt number, it seemed an obvious goal.

Jonathan is by no means a professional athlete, and only got a bike during lockdown in a bid to keep fit and to see if he would enjoy it. He now tries to get out every day and has entered a number of local cycling events, but nothing on this scale. Excited by the challenge ahead of him, he says he is trying to look at it like a holiday, albeit a bit more challenging than the usual family holiday!

You can find Jonathan's fundraising page at:
<https://www.justgiving.com/page/jonathan-holland-for-mnda>



"I have been inspired by the jaw-dropping fundraising achievements of Kevin Sinfield CBE and his friend Rob Burrow CBE, who has MND. I also hugely admired the late great Scottish rugby union star Doddie Weir OBE, who passed away after a long and dignified fight with MND."



Can you help at our annual Horsham Street Collection?

This year's collection is on Saturday 22 June, one day after Global MND Awareness Day 2024. This is always a very successful and important fundraising activity for us, so if you can, please help us continue that success by volunteering for an hour or so.

To help, please email Sandra Spriggs at:
sandracarolspriggs@gmail.com

Let's hope the sun is shining this year!

Join the MND Association Regional Roadshows

In 2024, Regional MNDA Roadshows are being held across England, Wales and Northern Ireland. These face-to-face events are a great opportunity to hear more about the future direction of the Association and our priorities for people living with, and affected by, MND. There will be a chance to hear more about our work from members of the Executive Leadership Team and our Board of Trustees. You will also be able to have your say and help shape our future plans. Our nearest Roadshow will be in London on 20 May 2024. For more information and to register, follow this [link](#).

Dave Setters on NHS Continuing Healthcare Funding

Dave answers questions on NHS Continuing Healthcare Funding (CHC), including:

- What is NHS CHC?
- How can you get it?
- What is the MNDA doing to improve access to it?

There is plenty of information on the Internet about NHS CHC and the application process. Please see

[NHS England](#)
[Beacon CHC](#)
[MND Association](#)

Essentially, it is a two-part process. First, you go through the "Checklist" with a health or social care professional. If you qualify, you go on to the second round, the full assessment via what is known as the Decision Support Tool (DST). This has 12 separate "domains", detailing your abilities and/or lack of them. Each domain is ranked and, generally speaking, the higher "grades" you get in each category, the more likely you are to be accepted for funding.

There will be many patients who do not qualify, but please don't be put off by someone saying "you're not bad enough" without looking into it yourself first. It's important to emphasise that the process can be daunting but it can also be very worthwhile for your family's financial affairs. In other words, be prepared for a struggle but if you are successful the results can be "game changing", given the cost of care today.

Note that NHS CHC is not means tested. You might see it as a benefit, but it comes from the NHS, not the DWP.

In my opinion, difficulties and misunderstandings arise due to the lack of a definition of a "primary health" need. Whether you qualify or not is left to the interpretation of guidelines and the opinions of health and social care professionals, that will often be subjective. And, decisions can, it is feared, be influenced by pressures on local budgets.

So, the key message is to PREPARE for the process. Involve key members of your health and social care team; if you feel comfortable working with them and that they are "on your side", this can be particularly effective. The process is undertaken largely in "NHS Speak" - having professionals at your side can help to "interpret" the jargon. Professionals might include (but are not restricted to) your specialist nurse/practitioner, your occupational therapist, your GP or your neurologist.

While much of the evidence to support your application can be in writing, I believe the most important thing that helped us was to have my specialist nurse/practitioner at the DST assessment.

MNDA is also beefing up its services and information to assist patients with CHC applications. Please see:

[MNDA Youtube channel](#)
[Beacon CHC](#)

A CHC Improvement Coordinator was recently employed on a 1-year contract. Part of her role is to scope out local services which may already be available to help.

For example, I understand that hospices often have people who will help in this regard. It is well worth asking them.

In the meantime, the MNDA has run "CHC Peer Support Group" online calls every six weeks. We not only share our experiences of the application process, but also of appeals and trying to get an appropriate care package in place. For details, please contact anne.anderson@mnda.org.

The availability and knowledge of NHS CHC funding will differ from area to area, but good starting points should be your MNDA Area Support Coordinator or Specialist Nurse/Practitioner. Failing that, any of your health and social care professionals may be able to point you in the right direction.

While I have to be clear that I am not a professional adviser, I am happy to share my experience, which will differ from others', with fellow patients and their carers. Just drop me an email on davidsetters@hotmail.com.



Dave and Helen Setters



New Branch Socials, Starting Sunday 12 May

Following on from our recent survey into what members would like from our branch socials, this year we will be trying some new venues, to enable us to reach all parts of the large area covered by our branch.

We do hope that you will be able to join us throughout the year, as we try out some new venues across West Sussex. Our first event of the year will be on Sunday 12 May, in Pease Pottage. We will be serving our usual homemade cakes along with tea and coffee. Full details below:

Venue: MacNaughton Hall, Old Brighton Road South, Pease Pottage RH11 9AH ([Venue](#))

Date and time: Sunday 12 May, 3pm - 5pm

Are you caring for a person living with MND? Why not join our online carers meeting?

We hold regular online meetings, to enable carers to connect with each other, to discuss various subjects and issues; we are here to answer your questions, lend support and facilitate discussion. Many members tell us that they find these meetings a great help.

If you are interested, we would be delighted to welcome you to the next West Sussex North Carers Meeting, on **Thursday 16 May, at 7.30pm**

Zoom link [here](#).

Meeting ID: 820 0932 9844

Passcode: 440073D30



More miles for MND

Support Charlie Sheppard in his fundraising efforts for the MNDA. He will be joining the Ford Ride London-Essex 100 on Sunday 26 May 2024.

Follow his preparation for the 100-mile ride, and donate, [here](#).



National News



In the latest [MND Matters](#) podcast, sports journalist and West Yorkshire branch patron Tanya Arnold sits down with Chief Executive Tanya Curry. To listen, follow the link [here](#).

Branch Fundraising update

- Easyfundraising: £380.44
- Recycle for Good Causes: £40
- Giving Lottery: £612.40
- Just Giving: £680
- Text2Donate: £25

Thank you to everyone who has supported us!

Interview: Tufnells' Charity Card Sales

In recent years, Tufnells in Lindfield, run by Lisa and Jeremy Goodger, has been a strong supporter of our branch, raising funds for us by selling MND Association Christmas cards in their shops. For our latest newsletter, we took the opportunity to learn about their backgrounds and their reasons for supporting us.

What is the history of Tufnells' shops in Lindfield?

We discovered Lindfield 18 years ago, and soon afterwards Tufnells was created. We had both previously worked for a national charity, but we were now looking for a new challenge and wanted to work for ourselves. Neither of us had any retail experience, but we were confident that we could create a shop that would attract both local custom and visitors to the village.

Lindfield is a very traditional Sussex village, with a pretty High Street, and businesses are generally well supported. We're open seven days a week; we mostly see local customers during the week, and visitors at the weekend.

Over the years, we've created a Lifestyle Shop, mixing homeware with gifts and fashion. From April to September we also open our pretty garden at the rear, to sell garden furniture, planters, pots and gardening gifts. We stock some of our popular brands permanently, but also ring the changes with other stock, by forever sourcing new and interesting products which keep bringing customers back!

When did you first start supporting charities in your shops?

We've supported various charities since the beginning, by selling items such as Christmas Cards, Easter gifts and pet treats, as well as by donating raffle prizes, or organising in-shop raffles ourselves. We feel it's a way we can give back a little.

How do you decide which charities to support?

We usually support local charities, which have been brought to our attention by customers. For example, we've sold Christmas cards for charities such as our local hospice, and local branches of Riding for the Disabled, the British Heart Foundation and New Hope Animal Rescue. We've also supported one National Charity which is close to our hearts - 'Breaking the Chains', whose tireless work in Ukraine helps both people and animals affected by the war.

So when did you start supporting the West Sussex North branch of the MNDA?

Five years ago, one of our customers - Liz Carter, who was for a long time the secretary of your branch - asked us to sell MNDA Christmas Cards. Sadly, this coincided with us having lost a good friend to the disease, which heightened our interest in the work of the local branch and we were very keen to support the cause. We've sold MNDA cards every year since, and will continue to do so.

When choosing cards, are your customers most interested in the charity they're supporting, the cards' designs, or a bit of both?

It's definitely a bit of both! Some customers want to support specific charities, no matter what - MNDA cards certainly fit into this category, especially as we've all been made more aware of the disease via the media in recent years.

Others choose the design they like most, and as long as it's a charity card, they're happy. Our charity cards are always far more popular than any commercial cards. They're also such good value, with customers asking for them from October onwards.



Lisa (right) and colleague Sue welcome customers to Tufnells, on Lindfield High Street, West Sussex

Treasurer's list of monies received and spent

Thank you to everyone for their contributions.
The below are the cleared funds received for the period October-December 2023.
(All information was the best available at time of going to press.)

Money received

Fundraising

Giving Lottery	£26
Gift Aid	£208
Easyfundraising	£34
Nick Butcher - Great South Run	£838
FBC Run 60 Miles (A. Fry)	£55
Christmas Cards	£273
Calendar Sales – Sandra Blaskett	£250

Donations

Haywards Heath Arts Festival	£1,500
Cleethorpes & Grimsby	£847
Martin Wilson	£40
PAGS Golf Society	£50
S Spriggs Giving Lottery prize donation	£25

Donations in Memoriam

Bequest K. Knowles	£33,933
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Other Monies Received

Riser Recliner Chair Reimbursement	£430
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Money spent

Grants

Riser Recliner Chairs	£630
Quality of Life Grants	£693
Adaptations	£1,500

Other Costs

Christmas Card Costs	£128
Contribution towards Network Day costs	£373
Carers' Vouchers	£500
AV and Branch Expenses	£122

MNDA CEO Appeal; Annual transfer to National Office

To Care	£3,000
To Research	£3,000

Your West Sussex North Branch Committee

Chair: Julie Taghan

Treasurer: Keith Walder

Association Visitors:

Chris Sheridan
Mike Agius

Vice Chair: Chris Sheridan

Committee Members: Joan Moon
& Sue Sheppard

Secretary: Christian Goldsmith

Keep in touch...



www.mndwestsussexnorth.com



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If you do not wish to receive further information, please contact a member of the Branch Committee.

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