mnda
motor neurone disease
association

Cambridgeshire branch

NEWSLETTER

EDITION 2 2025

CONTENTS

SOCIAL AFTERNOON GATHERINGS

Our monthly social afternoons for the latter part of 2024 were at The David Rayner Centre in September when we had an interesting presentation by Dr. John Blackwood, Vice-President of Biology at Samsara Therapeutics. October saw us meet in the Cambridge area again at Histon & Impington Royal British Legion Hall. November we returned to Hemingford Abbots when Liz Cooper our Community Support Co-Ordinator was able to join us. As usual in December we finished the year at the David Rayner Centre for our Christmas celebrations. We welcomed everyone with a glass of warm mulled punch (non-alcoholic), had festive goodies to eat and were entertained with music and songs by our own Association Visitor, Sue Hallifax and her partner, John.

The first 2025 afternoon was at our Histon venue and then February we were at the David Rayner Centre.

We welcome all our members, carers and family to these face-to-face afternoons where you can chat and make new friends, have a laugh, enjoy a cup of tea and light refreshments in relaxed and informal surroundings. You will also get to know most of the volunteers who help run the Cambridgeshire Branch. See the back page for the 2025 dates and venues.

Cambridgeshire Branch AGM

This year's Branch AGM will be held on Wednesday 2nd April at Hemingford Abbots Village Hall starting at 12.30pm.

There will be a presentation by Dr András Lakatos, Associate Professor of Neurology & Neurobiology at the University of Cambridge & Addenbrooke's Hospital Cambridge.

Our Branch Secretary, Margaret Poulter, has sent out the details for this with replies to be returned to her.

Online Chats/Meetings

The online chats/meetings continue and are hosted by members of the Association staff. The link on the MND Association's webpage with details and information on who each group is aimed at supporting is: www.mndassociation.org/online-support-groups.

CAMBRIDGESHIRE AT PRESENT IS INCLUDED WITHIN THE SOUTH EAST REGION FOR THE FOLLOWING:

Peer to Peer Support Group:

3rd Tuesday monthly, 11.00am-12.30pm.

An informal peer to peer support group offering an opportunity to share ideas and meet others living with and affected by MND.

For dates and more information contact Liz Cooper.

Recently Diagnosed Group:

3rd Friday monthly, 2.00-3.00pm.
(no meeting in April due to Bank Holiday)

Open discussion for people recently diagnosed with MND and their loved ones. For more information contact Lisa Burnard.

Online Group for Carers (daytime):

1st Tuesday monthly, 11am-12 noon.

A virtual cuppa and friendly chat with other carers of people living with MND. For more information contact Lisa Burnard or Kathryn Parkin.

liz.cooper@mndasociation.org
lisa.burnard@mndassociation.org
kathryn.parkin@mndassociation.org

OPEN ACROSS ENGLAND, WALES AND NORTHERN IRELAND

Black Indigenous and People of Colour MND Support Group:

3rd Tuesday monthly, 12 noon-1pm, starting 15th April.

A support group to ensure that those affected by MND have a dedicated space to connect, share experiences, and support one another. Open to people living with MND and carers welcome. For more information contact Abigail Igbokwe.

Evening Carers Group:

Last Wednesday monthly, from 6.30pm.

A virtual cuppa and friendly chat with other carers of people living with MND. For more information contact Abigail Igbokwe or Charlotte Stanford-Gibbs.

PMA-PLS Support Group:

2nd Monday monthly, 5.00pm-6.00pm.

For people living with Progressive Muscular Atrophy(PMA) and Primary Lateral Sclerosis (PLS) both of which are less common forms of MND.

For more information contact

MNDConnect

Toferson Treatment Support Group:

Monthly, times vary to suit as many people as possible.

For people living with MND who have the SOD1 gene and are on the Tofersen treatment. A peer-to-peer support group offering an opportunity to share ideas and experiences.

For more information and upcoming dates contact Alli Anthony.

Tracheostomy Support Group:

Timing alternates between evening and day time.

For carers of people living with MND who have had a tracheostomy. A peer-to-peer support group offering an opportunity to share ideas and experiences.

For more information and upcoming dates contact Lisa Burnard.

Veterans Support Group:

4th Wednesday monthly, 2.30pm-3.30pm.

For military veterans who are living with MND. An opportunity to share your experiences and common interests. For more information contact Grace Kay.

abigail.igbokwe@mndassociation.org
charlotte.Stanford-gibbs@mndassociation.org
mndconnect@mndassociation.org
alli.anthony@mndassociation.org
lisa.burnard@mndassociation.org
grace.kay@mndassociation.org

OPEN ACROSS ENGLAND

Let’s Talk Continuing Healthcare (CHC):

Mondays every six weeks, from 11.00am.

A peer support group for people living with and affected by MND, Association volunteers and Health and Social Care Professionals wanting to understand more about CHC funding processes or are facing problems with an existing care package.

For upcoming dates and further information contact Anne Anderson.

anne.anderson@mndassociation.org

FUNDRAISING

Dear All,

As always, it's been an exceptionally busy period for us in terms of fundraising.

Presentation by PO Martin Kaleem

I had the privilege of attending Littlehey Prison near Huntingdon, where both staff and inmates were inspired by Rob Burrows' story. They organized a sponsored touch rugby game, and I was honoured to receive a cheque for £156 on behalf of the branch, presented by Po Martin Kaleem.

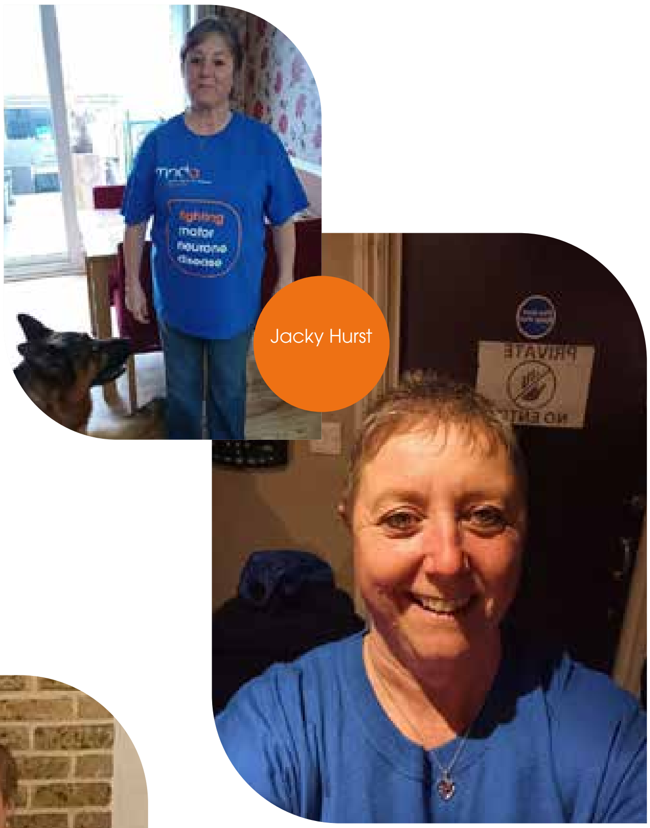
We also hosted a Christmas stall at Serpentine Green, which successfully raised both awareness and funds for our cause.

On New Year's Day, I had the opportunity to deliver a speech at St Ives Golf Club to mark the beginning of Lol and Edwin's captaincy year. As part of the event, Edwin took part in a drive-off, and we contributed a bottle of Jack Daniel's. The event raised £400 to kickstart their year of fundraising. We wish them both a successful year ahead.

St Ives Golf Club

On Saturday, 8th February, we held a cake stall at St John's Church in Peterborough, raising a total of £153.67. I would like to extend a special thanks to Maire Patel, her friend Christine, Sherry Redhead, Hayley Randell, Barbara Davis, and Natalie Smith for their baking contributions, as well as Hayley Crooke for assisting on the day.

Later that evening, I attended the Mill Pub in Huntingdon, where Jacky Hurst took part in a "Brave the Shave" event in memory of her father. The pub was filled with supporters, and a nervous Jacky did a fantastic job, looking great both before and after the shave. To date, Jacky has raised an incredible £1,030.63.



Jacky Hurst

Carol & John

Presentation by Lorna McIndoe

I'm also pleased to report that Carol Deytrikh White and John White continue their impressive walk around the UK coast. They've reached the west coast of Scotland and are receiving well-deserved local media attention, further raising both awareness and funds for the cause. Well done to both of you!

Lastly, on Tuesday, 18th February, I had the pleasure of attending the Fleet Community Centre in Peterborough, where Lorna McIndoe and her team presented a cheque for £500. They raised these funds through an incredible Burns Night Supper, and I would like to extend my deepest thanks to Lorna and her team for their hard work and generosity. Thanks also to the Real Pie company and Lyn Huber for their contribution.

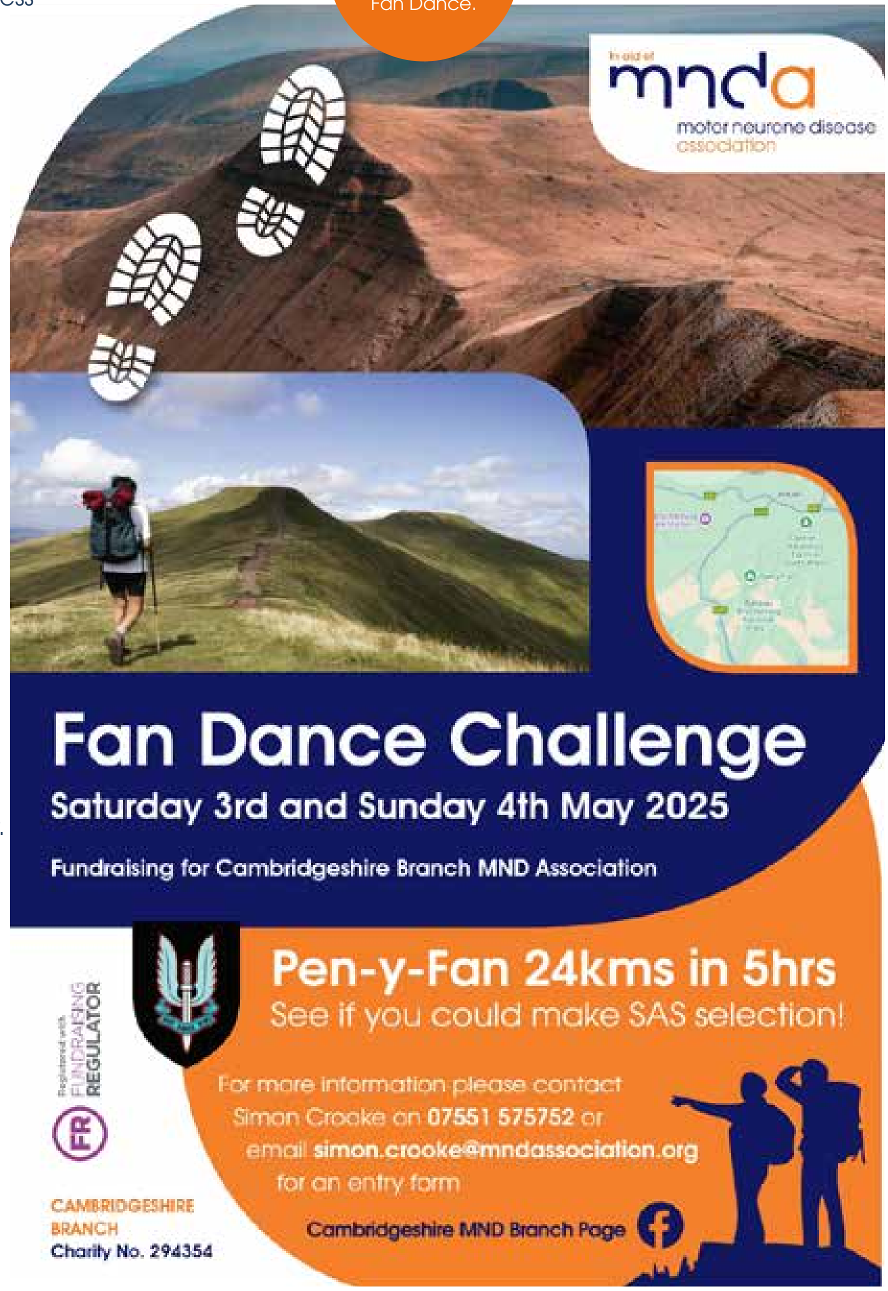
If you are interested in fundraising for the branch, please feel free to reach out to me directly at simon.crooke@mndassociation.org or call 07551575752.

Thank you for your continued support.

Best regards,

Simon Crooke

There are still spaces available for this year's challenge, the Fan Dance.



Fan Dance Challenge

Saturday 3rd and Sunday 4th May 2025

Fundraising for Cambridgeshire Branch MND Association

Pen-y-Fan 24kms in 5hrs

See if you could make SAS selection!

For more information please contact Simon Crooke on **07551 575752** or email **simon.crooke@mndassociation.org** for an entry form

Cambridgeshire MND Branch Page

Registered with FUNDRAISING REGULATOR

CAMBRIDGESHIRE BRANCH
Charity No. 294354

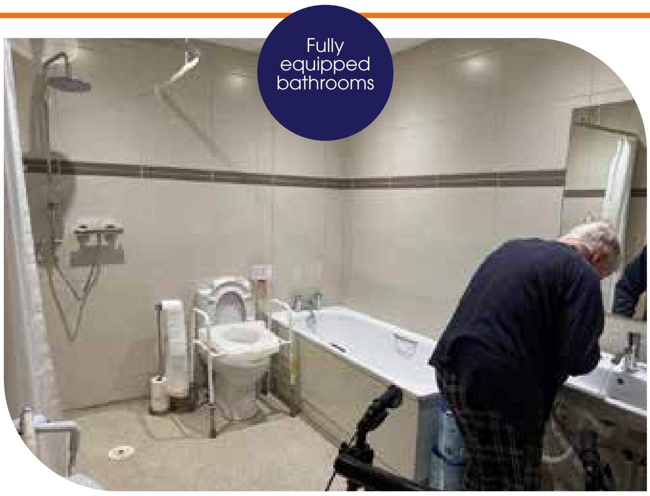
HOLIDAY ACCOMMODATION

Gil Boyd

Some holiday accommodation and information about adapted properties which may be of interest and helpful when and if thinking of getting away for a break. The details have been collated from information passed on to us.

Disclaimer: Please note the MND Association and Cambridgeshire Branch do not endorse or accept responsibility for the accuracy of any of the details provided in this article. Please do your own further research if you wish to holiday at any of these locations.

Wallops Wood Cottages



Fully equipped bathrooms

Wallops Wood Holiday Cottages, Hampshire

Pam Wilkie, a branch committee member and former Association Visitor, had a family holiday in 2024 at Wallops Wood Holiday Cottages, Hampshire: wallopswoodcottages.co.uk. This is her report and thoughts.

"I would like to recommend this accommodation in Droxford, Hampshire. My husband has serious mobility issues so we needed everywhere to be fully accessible.

Wallops Wood Cottages offer high quality accommodation, all on one level and wheelchair accessible. All have underfloor heating, a riser/recliner chair, television in all bedrooms, ensuite bathrooms, some cottages having fully equipped bathrooms for the disabled. There is even a hot tub on the patio!

The owners have ensured all cottages are wheelchair-friendly and with advance notice will supply most equipment needed to suit individual requirements. Hoists can be requested and all equipment will be in the cottage on arrival.

There are fully fitted kitchens with high quality units. Home cooked meals can be ordered in advance and are placed in the fridge prior to arrival. We made use of this facility and can report the food was delicious.

Swimming pool with hoist

Wallops Wood Cottages

Brickhouse Holiday Cottages
Brickhouse Holiday Cottages are a collection of cottages around a fishing lake, all with facilities for the disabled and their carers. Each has a hot tub with a hoist, there is a café and shop on site, and a sensory room and hydrotherapy pool. The owners are lovely, and it is a thoughtfully laid out environment, in the countryside but near to Blackpool, where the promenade is wheelchair friendly and goes on for miles by the sea.
Brickhouse Lane, Hambleton, Near Blackpool, FY6 9BG www.brickhousecottages.co.uk 01253 702122:

Croft Bungalow
Croft bungalow in Derbyshire is a lovely adapted cottage with two bedrooms, two riser/recliner armchairs, a hoist, hospital bed, a disabled access bathroom, and a sensory/disabled access garden overlooking fields of sheep. The owners are thoughtful and helpful. Croft Bungalow, Birchover, DE4 2BL https://croftbungalow.co.uk

On site is a large heated indoor swimming pool with a hoist which enables pool entry and jacuzzi experience for all. The leisure facilities also include a sauna room, steam room and pleasant changing rooms with showers and roomy cubicles. Families can book exclusive use of the pool. Children are well catered for with a magnificent family room suitable for all ages.

The surrounding countryside has lots to offer with Portsmouth, Winchester, the sea within close proximity, and Jane Austin's house within easy reach.

The Able Stables, West Norfolk
https://theablestables.com. Keen to promote with MND community as the lady that runs it had a friend with MND.

Our Bench, New Forest
https://www.ourbench.co.uk Wheelchair accessible self-catering holiday accommodation.

Tudor Lodges, Looe, Cornwall
www.tudorlodges.co.uk All lodges accessible with tarmac ramping and included in price is availability of disability equipment. Several people affected by MND have used these lodges. Please contact to discuss availability and tariffs or visit website.

Windmill Barns Holiday Lets, Warwickshire
www.windmillbarns.com

Lower Laurel Farm: Summer Lane, Banwell, BS29 6LR
https://www.lowerlaurelfarm.com/

Boating holiday on the Norfolk Broads
https://www.nancyoldfield.org.uk/

The Bond Hotel, Blackpool
https://bondhotel.co.uk/
Provides care so carers can be relieved of caring role.

Calvert Lakes, Keswick, Lake District
This one is for the sporty types!
https://www.calvertkielder.org.uk/

Accessible Holidays/MND Scotland
https://www.mndscotland.org.uk/support/accessible-holidays/
Who can stay at our specialist holiday homes? If you, or someone in your group, has MND and lives within the UK or Ireland, you can book one of our holiday homes every 12 months free of charge. You can also get 50% off your second booking with us within the 12 months. If you don't have an MND diagnosis but have a disability or health condition, you can also stay in our specialist holiday accommodation. However, you will have to pay a fee to do this.

Planning accessible day trips and holidays
https://www.carerssupportcentre.org.uk/help-and-advice/out-and-about/holidays/

Holidays in Norfolk for people with disabilities
www.disabledholidays.com

GIVING CONSENT/PERMISSIONS

We do need your consent for contacting you via email, ie for local branch support meetings (face-to-face) or Association online meetings, financial support grant information, benefit services, local fundraising events, new services in the area and any other general information. The MND Association, and consequently the branch. needs to comply with the General Data Protection Regulations.

If you feel you have not given appropriate consents then please confirm your agreement that the branch can contact you.

Cynthia

Cynthia George

c.i.george@icloud.com

Christina Watson

It is disappointing to have to let you know Christina who joined the Cambridgeshire Team as a Support Volunteer for Carers has decided to step down for personal reasons. This is unfortunate as this was a new role and would have added valuable support and expanded the help the branch could offer in a different way.

Our thanks to Christina for the work she started and we wish her well for the future.

HOW TO DONATE to your local Cambridgeshire Branch

If you would like to help your local branch by making a donation there are various ways to do this:

CAMBRIDGESHIRE BRANCH JUSTGIVING PAGE

https://www.justgiving.com/team/TeamCambridgeshireMNDBranchx

TEXT TO DONATE

Text MND4CAMBS to 70085 to donate £5

Texts cost £5 plus one standard network rate message, to increase your donation add10/20/ etc

BACS PAYMENT

Account Name: MNDA-Cambridgeshire Branch

Sort Code: 30-96-09

Account No: 02968788

CHEQUE

Please make payable to MND Association Cambridgeshire Branch

For further details please contact

Brian Smith, Branch Treasurer
brian.smith@mndassociation.org 07711 206452

Cynthia George, Branch Chair
c.i.george@icloud.com 07515 534430/01954 202095

All funds raised locally go directly towards helping our members and family living with MND

CAMBRIDGESHIRE BRANCH - ABOUT US

The Cambridgeshire Branch of the MND Association offers support to all those in the county and surrounding areas who are affected by Motor Neurone Disease. This includes their partners, carers, relatives and friends.

We have Association Visitors attached to the Branch who have personal and direct contact with those living with MND. They offer support, help, and guidance to those living with MND and their families. They can help with navigating the way through the health and social care system.

We may purchase or contribute towards the cost of specific equipment where it is not available locally from the NHS or other statutory agencies, or where there would be an inappropriate delay in obtaining it, contribute to the rental of or adaptations to equipment to match individual needs, pay for professional counselling for people living with MND and their carers or contribute towards the cost of holiday and respite breaks which can be hugely beneficial to the family. We may pay for taxi transport to enable people to attend our regular branch social afternoons or to attend hospital appointments etc.

The Branch is entirely self-funding and run by volunteers, relying on income from fundraising events and sponsored activities or on donations from events organised by clubs, pubs and individuals.

Any financial assistance is provided through our financial support grant system and needs to meet certain criteria, further information can be found at: https://www.mndassociation.org/support-and-information/our-services

we need your help

The branch is regularly looking for volunteers. Can you help? Please get in touch to have an informal chat as we are sure we can match your skills to a volunteering role.

THE MND ASSOCIATION FINANCIAL SUPPORT GRANTS

Financial support grants are offered to anyone living with MND and their close family. All grants need to have an application form completed and supporting documentation provided as appropriate. Any grant funding needs to meet certain criteria and there is a maximum amount for each grant and in a rolling twelve month period.

MND Support (Care) Grant: This is available to anyone with MND. This grant may help towards home adaptations and equipment not available from statutory funding but is unlikely to be for the full cost. An assessment by a qualified health or social care professional needs to be undertaken and the application form signed by that person.

Quality of Life Grant: Applications may be considered to purchase equipment, services or facilities which help maintain independence, dignity, comfort and social connections or to promote the well being of the person with MND and immediate family.

Carer's and Young Carer's Grant: Supports the main unpaid carer (aged 16+) for someone with MND to allow them to take a break from caring duties and/or promote the well being of the carer or young carer and can be applied for up to twelve months post-bereavement.

Children and Young Person's Grant: Must be age 18 or under and reside with the person living with MND. A grant may be considered towards anything that helps the young person in their day-to-day life and can be applied for up to twelve months post-bereavement.

Cost of Living Support Fund: This one-off funding is currently available to a person living with MND who needs support towards household bills, food shopping, energy bills etc. This fund is under continuous review.

Grant application forms may be completed by the member living with MND, or any family member, Association Visitor, Health or Social Care professional on behalf of the person living with MND **except** the Support (Care) Grant which **must** be completed by a relevant Health or Social Care Professional.

For full details and application forms, please visit *https://www.mndassociation.org/support-and-information/our-services*

or contact
Maire Collins, Branch Financial Support Co-Ordinator,

mairecollins99@yahoo.co.uk

RESEARCH SUGGESTS 'HEALTHY FATS' COULD PROTECT AGAINST MND

Enhancing levels of 'healthy fats' like omega-3s in the brain could be beneficial in motor neurone disease (MND), according to new research published on 25 February 2025 in the journal, Nature Neuroscience

"The potential impact of healthy fats, like polyunsaturated fats such as omega-3s, on the risk of developing MND and the length of survival has been of interest to researchers for some time, but crucially the understanding of their impact has been limited. This research takes our knowledge on a step.

"So would giving people with MND the same type of fatty acid increase their survival rate? We don't know yet. But it is an avenue worth exploring. The researchers must now look at which fatty acids should be tested further, in what quantities they could be effective and how they should be administered, before they carry out a clinical trial.

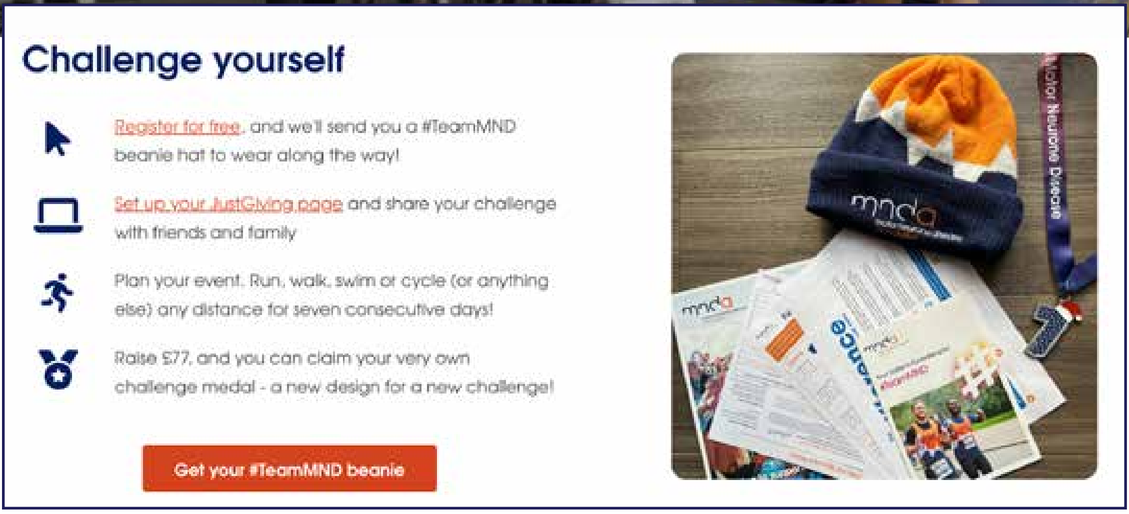
"We hope that further research and testing in humans will paint a clearer picture on the impact of diet on MND and other neurodegenerative diseases. In the meantime, we would advise anyone with MND to speak to their healthcare professionals before making any changes to their diet."

Dr Nick Cole
MND Association
Head of Research

7 in 7 Challenge

Are you inspired by Kevin Sinfield? Take on your own 7 in 7 challenge!

REGISTER
https://fundraising.mndassociation.org/event/7-in-7-challenge



Challenge yourself

- Register for free, and we'll send you a #TeamMND beanie hat to wear along the way!
- Set up your JustGiving page and share your challenge with friends and family
- Plan your event. Run, walk, swim or cycle (or anything else) any distance for seven consecutive days!
- Raise £77, and you can claim your very own challenge medal - a new design for a new challenge!

Get your #TeamMND beanie

> *"The thing about MND is the goal posts are constantly moving... but you just have to adapt as you change. It's all about living life to the full."*

2025 DATES FOR CAMBRIDGESHIRE SOCIAL AFTERNOON GET TOGETHERS

Wednesday 2nd April 12.30pm AGM	Hemingford Abbots Village Hall
Thursday 01 May	Cambridge, Great Shelford, David Rayner Centre
Wednesday 04 June	Hemingford Abbots Village Hall
Wednesday 02 July	Peterborough, Whittlesey Masonic Hall
Wednesday 06 August	Hemingford Abbots Village Hall
Thursday 04 September	Cambridge, Great Shelford, David Rayner Centre
Wednesday 08 October	Hemingford Abbots Village Hall
Wednesday 12 November	Cambridge, Histon & Impington Royal British Legion Hall
Thursday 04 December	Cambridge, Great Shelford, David Rayner Centre

These are social meet-ups for those living with MND, their partners and carers which provide an opportunity to chat and make new friends in a relaxed and friendly atmosphere. There is also the opportunity to meet the team who support the Cambridgeshire Branch - committee members, Association Visitors and general volunteers. All team members are volunteers.

CAMBRIDGESHIRE BRANCH CONTACTS

BRANCH CHAIR AND BRANCH CONTACT

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To find out more about the Cambridgeshire branch visit
www.mndassociation.org/cambridgeshire

www.facebook.com/cambsmndbranch