motor neurone disease association

Reading and West Berkshire

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News Letter



# A terrific tee off - for the love of Micky

We were beyond thrilled to receive a massive £18,220 cheque in memory of Reading golfer and legend Micky Denny.

The incredible total is thanks to the generous players and hardworking team who made Micky's 4th tribute golf day such an amazing success.

Delighted co-organisers Tony Stanley and John Mann said: "We all do it because of Micky. It's one big team."

Popular Micky, from Earley, lost his battle with MND in 2022, aged 63. And his friends have ensured his legacy continues every year with a fabulous golf day at his club – De Vere Wokefield Park, near Reading – to raise funds for other local families affected by MND.

This year's event attracted more than 100 golfers, and the cash was raised through an entry fee, hole sponsorship, a raffle and live auction held after the dinner. One very generous £5k donation from Richard McCarthy Homes was an amazing surprise and made such a difference, say the organisers.

John Mann said: "This is a fantastic way of not only giving us the opportunity to remember the legend that is Micky Denny, but also to raise money for an incredible charity, a charity which was there all the way for Micky from the day he was diagnosed to the day he sadly passed away. This is an opportunity for all of Micky's golfing friends to say thank you to the MND Association."




**The MND Dream Team and event organisers are pictured (L to R): Jane Gilbert, Ed Gryglaszewski, Barry Dodds, Nicky Denny, Jan Gryglaszewska, Allison and Tony Stanley, Mary Dodds, John Mann and Linda Green with Wokefield's Director of Golf Tom Burns.**

John also thanked fellow organisers Allison and Tony Stanley and Dave Cooper as well as the team at De Vere Wokefield Park Golf Club

He added: "Tom Burns and his team were fantastic. It just wouldn't have happened without them."

Micky's wife Nicky joined Branch committee members Jane Gilbert, Mary Dodds, Jan Gryglaszewska, Linda Green, Barry Dodds and Ed Gryglaszewski in a huge vote of thanks to all involved.

Nicky said: "It's an amazing total. Micky would have been very impressed and love the fact that so many people turned up on the day."

**Stop Press: The branch is delighted to hear that it has been chosen as SSE Energy Solutions' Christmas charity after a vote by more than 200 employees at its Reading site in Forbury Road. Both Micky Denny and a young mum now living with MND were much loved by their work colleagues at SSE's Thatcham office. More details to follow in the next issue.**

*Jane Gilbert*

# MND Warriors meet face to face

Our popular Drop-in support group meetings are the perfect place to meet with local friends who understand. And in October, virtual pals Kate Alderman, from Reading, and Dave Setters, who lives near Redhill, in Surrey, took the opportunity to meet up at the Calcot venue face to face.

Kate and Dave help to run the MND Warriors United Facebook group which has nearly 2,000 members worldwide.

It was created seven years ago for people with MND, their carers and family members who need advice and support. The creator and administrators of the group have been diagnosed with MND in their early 30s, and all share the same desire to fight.

They say: "We're all at different stages of the disease and have created a unique bond through our positivity."

Kate, who has had MND for 22 years, joined us with her friend and carer Laura Howard (pictured with committee member Linda Green).

As well as running the Facebook group with Dave, Kate also enjoys history of art classes online. Dave, who was diagnosed with MND in 2012, is very involved with a virtual collection of leading UK MND researchers and helps to influence how research funds are spent. He and Kate have only met once before in Oxford.

"I'm very lucky to still have my voice," says Dave who was joined by his wife Helen.



Everyone is welcome at our Drop-In meetings. Be sure to add our 2026 dates (see back page) to your diary!

*Jane Gilbert*

# Keep up the fight, says outgoing Chair Margaret

Branch stalwart Margaret Moss signed off her last Chair's Report in November with an emotional, heartfelt message to the Committee – keep up the fight, raise awareness and care for those affected by MND.

Margaret first stepped down in 2020 after 20 years in the role and returned later for a two-year interim period while the seat was vacant again.

During those years she has seen the branch grow from small beginnings to a strong, vibrant, passionate and talented group.

Margaret told the committee: "I have watched our invaluable Association Visitors provide care and advice over the years. I have seen the growth of the Drop-ins from half a dozen to 60 people.

"I have wondered at the development and growth of the branch's fabulous Newsletter.

"I revel in the range of events where supporters raise funds for us (and the branch support).

"I love the gathering of our members over the years – thank you lunches, tea parties, Jumbulance outings etc. Supporters are crucial to the success of the branch in so many ways – their quiet help does not go unnoticed."

Margaret thanked all those who had helped the branch over the years and mourned those lost to MND, not least her late brother Gerard Moran, the inspiration behind her amazing dedication.

The good news is that she will remain as a committee member, initially as



Vice Chair, to help guide her successor Andy Jones into the role.

"Thank YOU Margaret," say all The Dream Team!

*Jane Gilbert*

# Meet Andy Jones - Branch Chair-in-waiting

I have been given the huge privilege of succeeding Margaret Moss as Chair of the MND Association's Reading and West Berkshire Branch and will assume this role in the New Year.

I am extremely grateful for the warm welcome I have received from Margaret and her fellow "dream team" committee members over the last few months whilst I have been learning more about the work they do, and the support they give to people living with MND.

The local community has benefitted greatly from this support and the awareness they have raised. During this period, I have also got to learn about the many and varied ways in which the local community raise money for the charity to support people living with MND, and to fund further research into improved treatments and eventually, we all hope, a cure.

I live in Newbury with my wife, Sally, and I worked in the IT industry for over 38 years. During that time, I ran client contracts and services organisations both nationally and internationally. I was very fortunate to be able to take early retirement four years ago, and after a period of satisfying our thirst for travel, we have both been looking for opportunities to use our acquired skills to support the community in a voluntary capacity.

Sally volunteers for the Newbury Soup Kitchen and the local parish magazine, and I am the leader of Newbury Velo Cycling Club's




paracycling programme, where we give the visually and physically impaired the opportunity of cycling in the great outdoors, partnering with charities such as Berkshire Vision.

Previously, Sally and I have also served on the governing bodies of separate schools whilst our two children were in education, so we have a long history of volunteering in areas of interest where we feel that our skills and enthusiasm can help the community.

I played rugby for over 20 years, and, although we are fortunate that MND has not affected our family, I have been touched and inspired by the stories of the rugby family who have sadly had the disease, players such as Rob Burrow, Doddie Weir and now Lewis Moody. Who couldn't be inspired by the incredible fund raising by Kevin Sinfield!

So, when I saw that the branch was looking to fill the committee Chair role, I thought it was a good opportunity to use my professionally gained skills and experience to help a charity that was visibly providing such fantastic support to those living with MND. Thankfully, the branch also think that my skills would be of use, so here I am! I am humbled that they have placed their trust in me.

I am delighted that Margaret will remain on the committee and continue to provide her considerable experience in the support of the MND community, at the same time as giving me advice and guidance as I continue to learn. I will be at some MND events over the next few months and look forward to meeting you all and understanding what additional support the branch could offer you.

*Andy Jones*

## We can help in so many ways . . .

**We are the Reading and West Berkshire branch of the Motor Neurone Disease Association, and we are your local point of contact. You might be surprised at how we can help you and people living with MND, their families and carers. We do a lot more than just providing voice banking, fundraising and organising the social events you read about in this newsletter.**

**We are all volunteers and most of us have had a close connection with MND. We work with professional health care providers to try and ensure people living with MND get the best possible care and advice. We also have a few hard working trained volunteer Association Visitors (AVs) who can offer guidance and support.**

**Don't be shy, use the contact details so we can discuss with you how we might be able to help.**
**Email: contact@mndrwb.org Tel: 07760 854975**

# Countdown to Christmas with lovable Goldie

We're so delighted that Goldie the bear is back to light up our countdown to Christmas with his adorable antics.

Once again he will be helping loyal supporter Jacqui Warbey to raise MND funds and awareness every day until December 24th.

Jacqui, from Woodley, has come up with a host of clever fundraising events since losing her beloved husband Richard to MND in 2017, aged 56.

And she has spread awareness of the cruel disease far and wide helped by Goldie, Richard's childhood teddy. Together they have a Facebook group – Goldie's Advent Calendar – where a festive, fun photo is being shared to followers.

Jacqui says: "We hope his antics will make you smile and that you donate in recognition of our efforts in preparing each photo.

"Remember, this advent calendar is also calorie free!"

We can't wait to see what little Goldie is up to next.



Follow his antics at

www.facebook.com/groups/862192674948352/

to light up your festive season and check out

https://www.justgiving.com/page/goldie-bear-2025

Jane Gilbert

# Paddy's cake sale is another record breaker




**It's a family affair – (pictured L to R)**
**Sara, Tilly and Jo helping in the kitchen**

The Dream Team's Paddy Lunn has served up yet another record-breaking slice of cash from her annual cake and card sale.

Paddy, who sadly lost her husband Rod to MND, once more hosted friends and neighbours at her Sonning Common home helped by her wonderful family.

She writes: "The idea for the first sale, back in 2012, came off the back of Rod's winning design, while he was living with MND, for the Association's Christmas card competition.

"Since then, each November I have held a sale of notecards printed from his many small paintings both for Christmas and local scenes.

"This last sale proved a busy and enjoyable afternoon; on the dot of 2pm the doorbell rang and soon the house was full of friends and acquaintances buying homemade cakes, marmalade and chutney, Christmas cards, and notecards.

"My granddaughter Tilly sold raffle tickets while daughters Sara and Jo handed out tea and more cake! An artist friend had kindly donated some original paintings for sale and two were included in the raffle.

"By the end of the afternoon we had raised £985 which grew to £1137 a few days later from further donations and sales.

"A huge Thank You to everyone for their amazing support."

# Having a great time; wish you were her




If you think you've seen this heading and/or cartoon picture before you'd be right. So why am I, apparently, rewriting the same article - I'm not. In a previous newsletter - I can't remember exactly when and, to be honest I can't be bothered to check - we asked readers who have had holidays in adapted accommodation to let us know how/how well they were adapted and anything else they felt relevant. Since then, we've not exactly been inundated! So, I figured it's down to me ..... again!

A couple of years ago my wife and I decided that holidays were getting too difficult for us both. However, we missed them so, on the advice of our daughter, we booked and went on a two-week holiday in early September. That way we wouldn't feel that we had to go out every day. We stayed in one of three adapted cottages in the small village of Llanfynydd near Carmarthen, in the beautiful grounds of Stangwrach, a house owned by an absolutely lovely lady named Grace. The business is run by her and her two equally lovely daughters, one of whom lives on site with her and the other a few minutes down the road. Our cottage had three bedrooms, one of which was downstairs next to the wet room. It has hardwood floors throughout, so it's great for wheelchairs.




Whilst we had booked two weeks, nonetheless we went out most days. On one day out we were having lunch outside Subway in Carmarthen when we heard a very loud roar: it was a line of motorcycles roaring through the middle of the town - 108, I counted them!




Later on I was sitting in our vehicle when I became aware that a large yellow spider had crawled up my leg and onto my knee. I flicked it off. When we got back to the cottage I was sitting in my wheelchair - being 6' 3" tall I tend to stay in it when on holiday as I can raise the height of it to make it easier for me to get up from it - when over my knee came the same yellow spider. Persistent little blighter!! Again, I flicked it off. I didn't know we had large yellow spiders in this country. Maybe it was an illegal immigrant!!

On one of the days we didn't go out we spent the afternoon basking in glorious sunshine in the appropriately named 'sunroom'. Me in my wheelchair and my wife lounging on a comfy cwtch. I believe that's 'couch' in Wenglish (that's a cross between Welsh and English).




Whilst there we were able to enjoy the beautifully landscaped garden, which is in a dip, and includes a stream which cascades down over rocks, flows under the drive, under a small wooden bridge and out the other side. I understand that Grace, who is 85-years-old did/does much of the work herself. Maybe there's something in Welsh water. With the name Jenkins I must have ***some*** Welsh blood. Maybe that's why I've survived with MND for 28/29 years!




For more details about the accommodation visit **holidaycottagewales.com**.

If you are interested in any of the three cottages, firstly make sure that it is ***completely*** right for ***you***, then you can contact Grace on the email below:

**enquiries@holidaycottagewales.com**

Alec Jenkins

# Buckets to the rescue for wheelie clean cars . . .

Three cheers for Reading Joggers and Wokingham Road Fire Station's crew who rolled up their sleeves for a brilliant car wash fundraiser in September.

Together, they collected an incredible £900 to be shared between The Fire Fighters Charity and the MND Association Reading and West Berkshire Branch.

The event was part of Reading Joggers' year of fundraising in honour of two popular runners – Nicky Sayer and Andrew Lenaghan - who have both sadly lost their battle with MND.



Co-organiser Tracy Hawkins said: "For that reason, and as a fitting tribute to them, MND Association Reading and West Berkshire was chosen by the committee as its charity for the year."

Nicky Sayer's husband Dave told the joggers how the branch had provided support and friendship after his wife's diagnosis as well as funds for massage therapy which helped with her wellbeing.

He wrote on Reading Joggers' website: "The group has been absolutely brilliant, and it meant so much to Nicky and me to know that other people care and we were not alone."

Andrew Lenaghan's wife Caroline and daughter Kirsten told how avid runner Andrew had enjoyed the challenge of raising funds for the Association as his father had also had the disease. When he was diagnosed himself, he found the support offered extremely valuable as his condition progressed.

The Drop-in sessions really lifted his spirits, they said, as he was able to chat to people who understood what he was going through and the concerns that he had.

Sadly, in April this year, Andrew, a former chef at Reading School, suddenly passed away, aged 60.

Caroline wrote: "I can honestly say that the volunteers at MND Association have been amazing over the last eighteen months. My daughter Kirsten and I are incredibly grateful for the support they have offered us all."

For more details about Reading Joggers and its partnership with MND Association Reading and West Berkshire visit:

https://www.readingjoggers.org/

*Jane Gilbert*

# A gift for MND under the Christmas tree



Thank you, once again, Helen and Duncan Varley at Glenvale Nurseries in Southend Bradfield for bringing some festive cheer to local families affected by MND.

We're delighted to be one of the charities supported by their annual raffle held during the Christmas tree season. Helen and Duncan also kindly source the beautiful cyclamen plants gifted to guests at the branch festive tea party.

www.glenvalenurseries.com/christmas-trees

# Rockin' the night away for MND

The incredible Mighty Triple 'O' Band absolutely rocked it for MND helping to raise more than £2,000 to support local families.

It was an unforgettable evening full of music, laughter and community spirit. And it was all thanks to the amazing family of Derek and Sally Hince whose hard work made the sell-out night in September such a huge success.

Sally and Derek, who is living with MND, only returned from a Mediterranean cruise on the day of the gig at St Mary's Church in Purley-on-Thames but their children and grandchildren made sure they had a night filled with fun memories.

A delighted Sally said: "It was a lovely evening, our family pulled together. I wanted it to be light-hearted and bring out the fun, and I think that is what we achieved."

The dance floor was packed with about 120 people enjoying the brilliant sounds of The Mighty Triple 'O' Band featuring singer John Lockhart from Purley, who is Sally and Derek's son-in-law. He and the other five band members all gave their time free of charge. The use of the hall at St Mary's Church was also kindly donated.

Sally and Derek's two children, partners, and grandchildren, all helped with running the raffle, tombola, bar and soft drinks. And their friends and neighbours, joined members of the Women's Institute, a lunch club, local singing groups and several of our MND community to enjoy the sounds.

For Sally and Derek, the fantastic event was also about raising awareness of MND as well as donating funds.

"We have had so much support from the branch," added Sally. "And we did build some fun memories."

*Jane Gilbert*





**Friends Kylie Wright and Netty Glatter with grandchildren (L to R) Stan, Theo and Evelyn Lockhart, Tom and Harry Hince. (Lily Hince was unable to be there as she had started university)**

# Young Thatcham mum fronts national MND campaign

Our **Unlock the Door campaign** highlights the broken system surrounding housing adaptations. Too often, the Disabled Facilities Grant (DFG) scheme fails people with MND. Applying for a DFG is such a complex and slow process, and people with MND are being forced to live in unsafe and unsuitable homes.

Adaptations such as ramps, adjustable furniture, door-widening and stairlifts are integral to living with dignity and maintaining health and wellbeing. Too many people do not receive the support they need when they need it. We need to transform the system to deliver a faster and fairer grants process.

**Everyone deserves a safe home.**
**Use the link below to ask your councillor to fast-track accessible housing for people with MND.**

**Demand action**

https://act.mndassociation.org/2025-11-Unlock-the-Door

# Bravo to all our amazing athletes

**Our wonderful supporters never cease to amaze us with their many challenges raising vital funds and awareness of MND.**

One of them, **Lee Didcock** plans to follow in Kevin Sinfield's footsteps by doing his own 7in7 MND Challenge in May next year. Lee will be walking 7 marathons in 7 days from Liverpool's Anfield football ground to the Atrium Health Club in Reading in honour of his friend, dad-of-five Kevin Jefferies who is living with MND.

And he is expecting other friends of Kevin, from Spencer's Wood, to join in along the 192-mile route from May 16th - 23rd. This year they gave an amazing boost to Kevin by taking on the Surrey 3 Peaks Challenge and arranging a second annual reunion football match in Reading. Many of them also meet up regularly with Kevin and his wife Natalie at their local, the Farriers Arms, where there have been several MND fundraisers.

Lee, who lives in Windsor, has already been training hard for the long walk down south.

He said: "Kevin is one of my oldest friends, I have known him since I was eight-years-old. As he is a huge Liverpool fan and a football agent it's appropriate for us to start at Anfield. I know I will finish it and it's helping Kevin who thinks we are nuts. I also want to see Natalie smile."

Lee is aiming to walk onto Reading's Atrium football pitch on May 23rd for the finish and to start this year's fun reunion match.




**Lee takes a freezing cold bath to aid recovery after another long practise walk!**

All funds raised are being split three ways – 50% to MND Association Reading and West Berkshire, 35% to Kevin Jefferies' family support and 15% to MND Association Research.

If you would like to join in the walk, help with sponsorship or make a donation follow Lee and his friends on Instagram @mndchallenge – 7in7 for MND and check out the online donation page here:

**https://www.justgiving.com/crowdfunding/7in7mnd**



Huge congratulations to Bradfield's **Lily Pearce**, pictured with her dad Paul, who took on the Windsor Half Marathon in September raising a fantastic £2,490 for branch funds.

Lily, a charity events co-ordinator, was following in the footsteps of her dad who is living with MND.

She said: "Three years on from my dad's diagnosis, he is still proving to us what a real trooper he is.

"The Windsor Half was a great day. Dad used to take part every year for as long as I can remember. Now it's my turn. We are forever grateful for how supportive the Branch has been."

Last year Lily took on the tough London Marathon raising nearly £15,000 for the branch. And she admits that the hills of Windsor proved even more of a challenge this time.

Continued on next page

# Bravo to all our amazing athletes - cont




**Lily is pictured with family friends James and Lee**

Her proud dad Paul was also the inspiration behind jockey Oisin Murphy donating half of a £50,000 prize to the MND Association.

At the same time as clinching his fifth champion crown he held on to claim the UK and Ireland World Pool Jockeys' Championship. The competition awards points to jockeys based on the winner's World Pool Win odds in World Pool races run through the year.

Oisin, who lives in Lambourn, said: "The MND Association touches me as I have a family friend who is suffering at the moment." He gave the remaining prizemoney to the Racing Welfare charity.

Paul's wife Gail said they had seen the TV interviews and Paul was so chuffed by the generous gesture of their friend Oisin.

"Oisin sponsored Lily and he adores Paul," she added.

Visit Lily's fundraising page here:

https://www.justgiving.com/page/lily-pearce-

Bucklebury's **Kitty Gilbert** smashed her first half marathon run around London's landmarks in October raising a wonderful £2,543 to help local families affected by MND.

Kitty, took on the big Royal Parks Half challenge in memory of her beloved granny Pamela Wyatt who lost her battle with the bulbar palsy form of MND 26 years ago.

"What a day! It was a lovely run past all the landmarks," said Kitty, who had a finish time of 2:17:56. "I was only 17 minutes behind former England footballer John Terry!"

Kitty, who works in London as a Head of Marketing, says she found her big run debut tough from 15k onwards.

"The cheering crowds carried me through," she said, " and I am thrilled and proud to have raised more than £2k for the Reading and West Berkshire Branch."

Kitty's mum, branch Publicity Officer, Jane Gilbert and her husband Derek said they felt like they had run a marathon dashing around the parks to try and spot her among the 16,000 runners. For the record, the 120 Team MND runners raised an amazing £118,514 between them.

Jane said: "We're very proud of Kitty and delighted that she has decided to run next year's Hackney Half raising funds to help fight MND."

Check out Kitty's Royal Parks Half donation page here:




**A wave from Kitty around halfway mark**

https://www.justgiving.com/page/kitty-gilbert-1

Continued on next page

# Bravo to all our amazing athletes - cont

Avid cyclist and fundraiser **Bob Wearn** was inspired by The Bard to ride The Shakespeare Way in memory of his dear friend and ex-colleague Peter Colvin.

Peter, who was a leading light at Burghfield Sailing Club, sadly died in 2020 and Bob says he has seen first hand the brilliant work done by the Branch in supporting Peter and his family.

When he first heard about The Shakespeare Way – a 175-mile route between Stratford-upon-Avon and The Globe Theatre, London – he was instantly hooked and resolved to ride it one day.

He and his brother Pete set off for the three-day ride on September 19th and have raised £998 to help the Branch support other local families.

Bob, from Windsor, said: "The ride went pretty much without a hitch, and we only got lost a couple of times. The trickiest bit was probably going through Abingdon as the cycleway has been set up to go East to West, and we were doing the opposite way.

"We had three long days but the bikes performed well and helped ensure we hit up the hills ok! More hills than I was expecting really on the first day out from Stratford en route to Oxford.

"According to Sustrans the route length is 175 miles, but we did 185 miles! Plus of course we had to cycle back to Waterloo Station and again from Windsor Station to my place.

"We were very lucky with the weather - it only rained for about an hour around Telford."

To quote The Bard – All's Well That Ends Well

Bob's fundraising page can be found at:

https://www.justgiving.com/page/robert-wearn-12

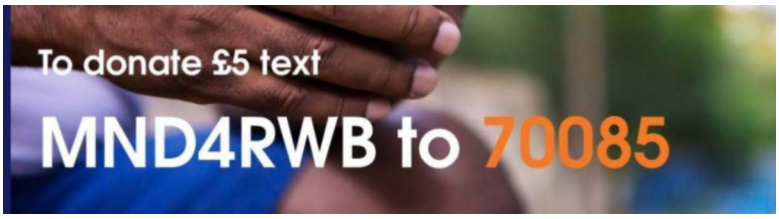
*Jane Gilbert*




**Bob (pictured right ) with brother Pete all set to start in Stratford-upon-Avon**




**Bob's finish at Shakespeare's Globe Theatre, London**




**Get in touch with MND Connect on 0808 802 6262**

**MND Connect is available Monday to Friday between 9am - 5pm and 7pm - 10:30pm.**
Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills. You can also email mndconnect@mndassociation.org

# The ‘terrible trio’ get crafty

On Saturday, October 19th, Lin Jenkins, Julie Dix and I made our way to the Thatcham Leisure and Craft Fair which had rather a different set-up this year. There were still tables inside St Mary’s Church, and I was lucky enough to have one of those, but instead of having the gazebos on the green in The Broadway they were in the church yard.

The fair opened at 10am and for the first couple of hours there was a steady flow of visitors - then it went very quiet. Lunch time, we thought, but it never really picked up again. I think we know from previous years that people get out and about early in Thatcham!

We managed to sell a reasonable amount of stock taking about £200 between the two stalls and met some lovely people, including the Mayor of Thatcham, Councillor Petra Pemberton. It all helped to raise awareness of MND.

Committee member Katie Cooper and her mum Carol Coker dropped by, and Carol was very surprised to find that the lady helping her daughter on the stall next to mine, was somebody she knew in her youth. There was a lot of reminiscing.

Lin also had a lovely surprise in the afternoon when her sister from New Zealand, who had only landed at Heathrow at 6am that morning, suddenly appeared in front of her. I wish I had been there to capture the moment.

A special ‘thank you’ to Katie Cooper who was able to arrange free parking for us very close to the church.

A couple of weeks later I was at a Charity Christmas Market in the lovely St James the Less Church in Pangbourne. This used to be an annual event and was revived this year on a smaller scale.

There were only four or five charities there but the lure of delicious refreshments brought the locals out.

Our Christmas Tea Party was another great opportunity to sell MND merchandise and a variety of donated items. There were two busy spells at the start and again at the end but in between I think people were too busy chatting, eating and quizzing! However I took over £170 which is a great amount to add to branch funds.

My last event for this year was at St Mary the Virgin Church in Bucklebury where once again I received a very warm welcome from everyone. This event always seems to be buzzing and I’m sure the locals look on it as an opportunity to catch up with friends they haven’t seen for a while

A visit to Glenvale Nurseries on my way home to buy a holly wreath and have a chat with the lovely Helen and Duncan Varley, who do so much to support the branch, was a lovely way to end the outing.

Thank you to everyone who donated items to sell and to those who came along to shop and chat. Some of the delightful and very popular tree ornaments made by the amazing Kim Facer and her friends are pictured on the right. The money raised all goes towards supporting people affected by this horrendous disease.

Mary Davidson









# A sprinkling of Christmas magic

This year's Christmas Tea Party was a real cracker packed with magical memories for our MND community.

Events lead Mary Dodds and the amazing Dream Team of volunteers sprang into action at historic Purley Barn on December 2nd laying on a festive spread of delicious treats for 100 delighted guests.

An early surprise visit from Santa brought smiles to the children's faces and joyful tunes from Wokingham singer Simon Williams made the party go with a swing.

During the busy afternoon two birthdays were celebrated, a bumper raffle raised £542 and there was fierce competition among quizzers searching for answers to a clever brain teaser set by Alec Jenkins, who is living with MND.

Our delighted guests all went home with cyclamen and mini panettone gifts as well as a few prizes kindly donated by our amazing supporters.

Afterwards Mary Dodds thanked the big, hardworking team of volunteers saying: "Your efforts have created lasting memories for our MND community."

Behind the scenes Carol Coker sold seven beautiful home-made Christmas cakes raising £155 in memory of her husband John. And festive wreaths created by talented flower fairies Dottie Channing-Williams and Lorna Murphy also boosted funds to help the branch support local families affected by MND.

Finally, a big shout out to: Helen and Duncan Varley of Glenvale Nurseries, Southend Bradfield, Angela Rose, Tesco's Team Support and Community Champion, Big Yellow storage, Reading, and James Pascall-Smith, of Johnsons Hotel Linen of Reading, for kindly laundering all the tablecloths. Every little helps . . . and what a big difference it makes.

*Jane Gilbert*




**West Berkshire Council Vice Chair Cllr Stephanie Steevenson with Tony and Allison Reynolds-Stanley who co-organised Micky Denny Memorial Golf Day**




**Gifts for our lovely therapists Kathryn Wits, Linda Turner and Amanda Munday**



**Lorna Atkins-Murphy displays her hand-tied wreath which boosted funds**




**Chloe receives her gift from Santa**




**Nicole Vokins and mum Dottie Channing-Williams (right) with their beautiful festive arrangements for the raffle**

# More pictures from our Christmas Tea Party



**Linda Butler (left) from Linda Butler School of Dance is pictured with Graham Attridge and Angela Hay. Linda taught ballet to Angela's son and gave a big donation to the branch after staging a show at South Hill Park**



**The Dream Team take a few minutes off for a photo shoot!**



**A nice smile from Cailo as he receives his gift from Santa**




Thanks to Big Yellow, Reading, for supporting Reading and West Berkshire MND Association

# Singing loud to help fight MND

A Tilehurst-based women's choir will be hitting the high notes at its Christmas concert on December 17th raising money and awareness for a heartfelt cause. See flyer on previous page.

Sadly, several of Vivace Voices' singers have been affected by losing friends or family to MND in recent years. And one of them, Liz Aldersley, kindly nominated the Association in memory of her friend Mick Foster, who lost his battle with the disease in June.

We are grateful to Mick's wife Lin and daughter Sarah for sharing their story with Vivace Voices on its website and online donation page (see below).

The choir's charity lead Rachel Fitz-Desorgher said: "Every term we perform a concert and raise money for a local charity. For Christmas we are supporting the MND Association's Reading and West Berkshire Branch.

"MND is very much in the news right now due to the rugby player Lewis Moody having been diagnosed with this incurable and life-shortening disease."

The concert at St Mary's Church, Burghfield, near Reading, will feature a fabulous mix of popular, lesser-known festive songs as well as some 'join in and sing' carols, followed by a buffet tea and raffle. Tickets are £5 by cash or card on the door.

A few days later, on December 19th, the choir will be singing carols at Asda in Lower Earley, from 11am-1pm, with a collection in aid of the branch.

Rachel added: "I really hope you can help us to support this small but mighty local charity in its inspirational work supporting those living with Motor Neurone Disease."



**Mick's Story**

Mick was diagnosed with motor neurone disease in 2022. His wife of 56 years, Lin, recalls that her once active husband who had enjoyed playing golf for many years and had more recently taken up bowls, had been poorly with Covid in 2020 and then, when he was well enough to get back to driving, she noticed that his foot was unusually 'heavy' on the accelerator. Soon afterwards he started to experience weakness in his legs and so began rounds of hospital visits with Lin and Mick making endless trips back and forth for tests.

It took a full two years of visits and tests before the devastating diagnosis of motor neurone disease was made. Lin, Mick and their family had to come to terms with the knowledge that there is, as yet, no cure for this degenerative disease affecting the brain and nerves and that inevitably leads to death.

Lin describes how the local hospital caring for Mick put her in touch with the Reading and West Berkshire branch of MND Association. She says: "They have been, and continue to be, an incredible source of support. Connecting with others who are facing similar challenges has offered us both practical insight and emotional support."

Mick was a very tall man, standing at 6' 5", and so faced some particular challenges as he became more disabled - extensions were needed on his bed and wheelchair, and even using a taxi was tricky because of his height. Lin's local MND Association helped by providing the family with essential information, helpful advice and the reassurance that they were not alone.

As the steady physical and mental decline caused by MND took its toll on the whole family, the MND Association were able to offer respite care which Lin says "gave us much-needed time to rest and recharge, as well as complimentary massages to help ease the physical and emotional strain. They are always there - nothing is ever too much trouble."

Sadly, Mick died in June this year and Lin is still getting used to the silence in the house now that her life companion is gone. The Reading and West Berkshire branch of MND Association continues to be there for Lin and her family - "being part of this community has made a lasting difference in our lives - they truly become an extension of your family."

For more details visit:
www.vivacevoices.uk

To donate visit:
https://www.justgiving.com/page/vivace-voices-reading-5

*Jane Gilbert*

# The Warriors' epic Kennet and Avon Canal Walk – Thank You!

A huge thank you to everyone who supported our walk from Great Bedwyn to the Plough on the Green raising £6,263 for the MND Association.

**The Plough on the Green, Newbury** – Thank you to landlady Kirstie Lane, her staff, and customers for donations, hosting our finish line, and letting us collect at the bar.

**Paul Pointer** – Shared our giving page with his clients, who donated generously.

**The Crucible Sports & Social Club, Newbury** – Sasha-Marie, AJ, and Clay brought their friends on board. Julie and Jason Canning, their family, staff, and customers raised amazing funds - Julie even shaved her head! Meeting Sasha's mum Kim Ryan, who was living with MND, at the finish line was truly moving. Sadly, Kim lost her brave battle with MND in October.

**Family and Friends** – Special thanks to my sister Melanie for travelling from Great Yarmouth, and to my nephew Kyle, who ran the full 15.2 miles in just 2h 13. The rest of us walked it in under seven hours. Huge thanks also to all who collected sponsorships and joined us.

**Community Support** – Thanks to the Greenham community, Hermitage colleagues, friends Marcus and David (plus their dogs!), and Newbury Train Station staff for free travel to the starting point.

**The Congerton Family** – Haydon for setting up the giving page and banners, Bradley for QR codes, and the whole family for their support.




**Chair-in-waiting Andy Jones (second from left) receiving the magnificent cheque in September from all The Warriors**

**MND Association Reading and West Berkshire Branch** – Special thanks to Mary Dodds for her help, resources, and encouragement on the day.

The walk was a great success, the weather was kind, and it was a day full of pride, community, and hope. Together, we've shown that *when we come together, we can achieve great things*.

**By Andrew Johnston (who lost his beloved mum Joan to MND four years ago during Covid)**

# Local author's novel way to help fight MND

Newbury born and bred David Sheppard is sharing his musings on life – Eighty Years Later – to help raise funds for MND.

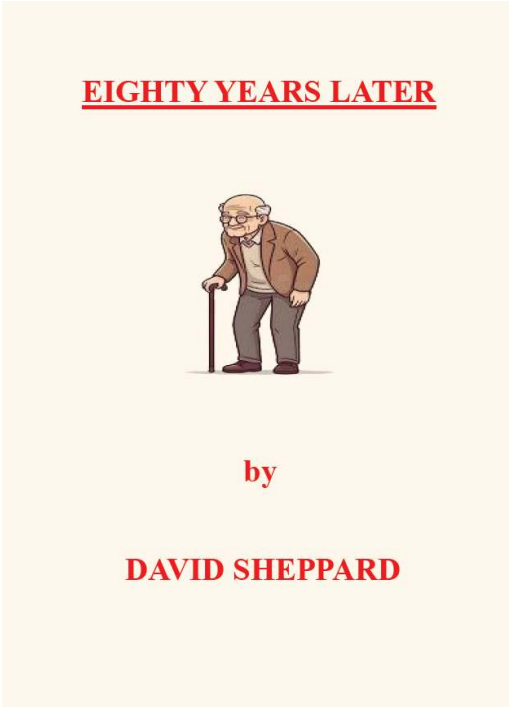
David, who has a dear friend living with the disease, is selling copies of the book for £7 each at markets in Compton and Aldworth on December 13th and 20th.

He says: "This book is not meant to be autobiographical, but there will be mentions of some of my life "experiences".

Not afraid to be controversial, he says it contains his views and opinions formed over his last 80 years.

David will also be raising awareness of MND in West Berkshire and is kindly donating all proceeds from the sales to the Association's Reading and West Berkshire Branch. For more details or to buy a copy email: **revshep45@gmail.com**

*Jane Gilbert*



**Dates for 2026:**

- 20th January
- 3rd March
- 14th April
- 26th May
- 7th July
- 22nd September
- 27th October

## Drop-in Meetings - An open invitation

You are warmly invited to our Drop-in Meetings

**The Calcot Centre, 3 Highview, Calcot,**

**Reading RG31 4XD**

**12.30 - 2.30pm**

These meetings are an opportunity for you to share experiences and thoughts, meet with friends who understand. We would be very pleased to see you. Please feel free to bring a relative or friend - all are welcome.

RSVP to secretary@mndrwb.org or call 07760 854957.

A selection of sandwiches will be available.

The venue has wheelchair access, toilets and car parking on site.

From junction 12 of the M4 head on the Bath Road (A4) towards Reading. You will pass Sainsbury's/IKEA on your left and in a few hundred yards at the next roundabout take the first exit onto Royal Avenue. Take the 4th road on your left, Highview, and the centre is on the left (signposted). Click here to view venue in Google maps,

To connect with us on Facebook please click on the following link:

https://www.facebook.com/mndrwb/

## Newsletters

**If you would like to change the way you receive newsletters (post or email) or if you do not currently receive your own copy and would like to be added to our mailing list (post or email) please contact**

**Kerrie Newton: secretary@mndrwb.org**

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