Mid Kent Matters



Summer 2025

DATES FOR YOUR DIARY

Support Group Meetings

Heart of Kent Hospice: 1st and 3rd Fridays in each month June 6th & 20th; July 4th & 18th; August 1st & 15th; September 5th & 19th October 3rd & 17th

Wisdom Hospice: Every other Wednesday of each month May 14th & 28th; June 11th & 25th; July 9th & 23rd; August 6th & 20th; September 3rd & 17th; October 1st & 18th & 29th

OPEN SUPPORT MEETINGS

Carers Meetings

1st Monday of alternate months

Monday 2nd June, Monday 7th July, ? August, 1st September

Contact Sue Copping s.copping@sky.com for full details and to be included on mailing list.

FUTURE LOCAL EVENTS

Wednesday 16th July: Informal Support Group Picnic Meeting at Aylesford Priory, 11am – 1pm. Contact details inside.

Medway Neuro Tech Fair -Stalls and Speakers, 4th September

Pilkington Building (UKC) 48 North Road Chatham ME4 4EL

Annual walk to D'Feet, Sunday 7th September, 10am

Contact Jen Sanders 07726 212688

Christmas Tea, Masonic Hall Maidstone, 6th December 2pm -Details inside MKM

Christmas Bazaar: 22nd November, Princes Hall, Rochester



FROM THE CHAIR



I hope like me you have had plenty of opportunities to get outside and enjoy the lovely sunny days we have had this Spring. The beautiful weather has inspired us to organise a couple of outdoor meetings this summer when I hope the weather will be kind to us and we can enjoy socialising in beautiful surroundings. Please see details of the Leeds Castle and The Friars meetings below.

If you are new to the branch please do come along and join us. We are a very friendly group and I usually have more fun and laughter at such events than I have during the rest of the week. We would love to meet you.

As always the branch has been very busy and we have had such a lot of support from various fundraisers and donations. So a huge thanks to all of you.

Your donations enable us to provide support when and where it is needed – which neatly leads me on to say, please, please do not spend any money on purchasing equipment before you have checked with one of the AV's or committee members – it may be that we can source the item, and if not, we can often apply for a grant to assist with the cost.

In the coming months we will be seeing and hearing more about the new 5 Year Strategy from the MNDA which will be focusing on the key areas of Treatment: Support: Influencing high quality care. We are hoping that one of the impacts of this strategy will be access to research trials for people in Mid Kent. This has always been an issue as we have never had a local hub where trials can be monitored. I am watching this space with a keen interest.

Hope to see you at some event later in the year Annette

OUTDOOR SUPPORT MEETING at The Friars, on Wednesday 16th July

We will be holding the first of this year's informal MND Support Groups at The Friars in Aylesford on Wednesday July 16th. We meet on the grass adjacent to the main Car Park at 11.00 and usually have had enough of each other by 1.00 (only joking!).

It's helpful if you can bring your own chair and most people bring along a picnic. Ice cream for dessert will be provided and you may be lucky enough to win a raffle prize!

Hope you can make it – no need to book, just turn up. Contact Sheila or Annette for further details.

CHRISTMAS TEA

Keep the December 6th free and come to the Masonic Hall, Courtney Road Maidstone ME15 6LF from 2pm to enjoy some fun with tea. We will collect numbers nearer the time.

Could YOU

be a Volunteer for the Branch?
We are keen to recruit some new committee members and hopefully some people who may like to train to become a volunteer visitor. If this is something you might be interested to find out more about, please contact Annette.

01622820710

annette.scott@mndassociation.org

TREASURERS REPORT



Welcome to the first report of our finances for 2025 and what a great start to the year we have had with wonderful fundraising events like our annual quiz hosted by The Dark Destroyer. We hope you all had a great evening and would like to say a big thank you to everyone who supported the event and helped raise over £2700!

We have received some generous donations over the first few months of 2025 and our branch and 3rd party fundraising events have all been incredibly well supported. These have helped us to raise over £10300 and raised awareness of MND too! Thank vou to the committee members for their hard work and to everyone who helps organise, run and support fundraising events for Mid Kent. A special thank you to Eve Ovenden who organises a disco every year with funds raised coming to Mid Kent, over £2600 this year! Maidstone Borough council have given us £2000 in grants, which we have used to help people with increases in the cost of living. In total our income so far this year is £15533! Our thanks go to :- Brachers, Rotary General Gordon Maidstone. Club Masonic Lodge, Woodham Cards and Gifts, The Cavendish Café, Dan Coward. Levbourne School. Eve Ovenden, Maidstone BC, Medway Chequers Lotterv The Inn and Doddington. We also thank the fabulous committee members for the Quiz night, book sales and quiz sheets and of course to everyone for your support and general donations. Special thanks to those who donate regularly via standing order and thanks also go to everyone who uses Easyfundraising and who gift aid their donations,

Over the last few months, we have spent £24200 to support people affected by MND. Our care costs have

included quality of life grants, carers grants and therapies for people with MND and their carers. We have made contributions towards the installations and rental of stairlifts and of Bio Bidets. repairs to scooters and new batteries and covered the costs of deliveries and collections. From the Maidstone Borough Council grant we have supported people with grants to help some of the increases household bills. In addition. continue to cover the costs of the MND support days at both the Heart of Kent Hospice and Wisdom Hospice.

Thank you to everyone who has continued to support us with your online donations via our justgiving and tribute pages, by standing orders or bank transfers direct to our account.

There are changes coming into effect at the end of the year regarding cheques we pay into our bank account. We will be charged £1.00 for each cheque that we pay in to our account. We would be most grateful if you could consider the alternative ways to donate to MNDA Mid Kent, either by making a direct transfer to our bank account, or via our justgiving page to help us avoid these additional charges. (Details below). If you prefer to make donations by cheque we can of course still accept them and are of course grateful for all donations received.

Please get in touch if you wish to gift aid any donations that are made directly to our account, we receive an extra 25p for every £1 donated via gift aid which really does make a difference to our funds. As always we commit to using every penny raised or donated, to support others diagnosed with MND so no one feels alone. Your donations will help us to continue to provide support to people with MND.

Lynne

BLUE TOKENS

Hello all!

Some more good news, we have awarded the maximum amount of £1500 from Tesco (Groundworks), after our supporters posted the most blue tokens. Thank you to everyone who shopped there and gave us such a good result.

I just need to work out how to claim it now!
Lynne

CAMPAIGNS UPDATE

The main campaign for the next few months had been due to be the "relaunch" of Act to Adapt, but this has now been delayed until the autumn, as other, more immediate, priorities have taken over. The current priority is the difficulties plwMND are experiencing in getting access to Tofersen, due to NHS resource issues. There is more information on this on the Association website via the link below, which includes a petition for people to sign. https://www.mndassociation.org/get-

The Policy and Campaigns Team are currently gathering information and evidence for the new housing campaign, and will be setting up meetings with the Campaign Network in the near future. I'll keep you posted. If anyone would like more information on campaigning, or would like to be more involved, please let me know. Elaine Coates

involved/campaigning/take-

action/tofersen-petition

elaine.coates@mndassociation.org

LONG DISTANCE RUN FROM SOMERSET TO KENT



My nephew Andy Sambrook is a Long Distance Runner and this year he has asked for my blessing to run in memory of his uncle Allan, my husband who died 26 years ago of MND – in the early days of this group, when Joyce was our AV. Of course I am pleased for Allan and myself.

Andy plans to run in October, starting at Burnham on Sea in Somerset and after approximately 170 miles, finish at my house in City Way, Rochester. We spent family school holidays in Somerset, which left such lasting memories with everyone that we have since been there with all the grandchildren.

He has already started planning and organising his route etc to be ready. He is open to ideas and advice from anyone – and we will advertise his run on our website and here in MKM. He would be particularly interested to hear from anyone with experience of getting running vests.

If you are able to help in any way, please tell me and I will act as his link and pass the information on to him.

Linda Blagdon

HOLIDAY IDEAS



Although it is cloudy and cold as I write, we have already had several warm and sunny days which make us think about holidays. The places listed below have been used by a member of our group. She found them to be suitable for her needs, but of course, they might not be right for you and you will need to check that they meet your specific needs.

Before you book, it is advisable to speak to your OT to establish what equipment and whether you need advice on where to hire it or what portable equipment may be available on loan from our local store.

Please don't forget that we have grants available which will help towards these extra costs. Please speak to your AV or any Branch volunteer if you would like to know more.

I have listed below some of our member's tried and tested venues in case you want to try them.

Broom Hall, Richmond Road, Saham Toney, Watton, Norfolk IP25 7EX Broomhallhotel.co.uk

Greenbanks Hotel, Main Road, Great Fransham Dereham Norfolk NR19 2NA, 01362 687742 Also Greenbanks Barn – Self Catering with accessible accommodation. Ideal for Family Groups.

Wallops Wood, Sheardly Lane, Droxford, Hants SO32 3QY. 02392009999 Self-Catering cottages with accessible accommodation, wet room and indoor swimming pool with hoist. Equipment Hire possible (eg Hospital Bed and hoist) from Solent Mobility.

Center Parcs, Longleat Forest, BA12 7PU

Check out sites and accommodation at Centerparcs.co.uk – Consul OT for advice on hire of equipment

Treworgans Farm Holidays,

Tregorwans Farm, Ladock, Truro TR2 4QD 01726 883240.

Wheelchair accessible cottages with wet room, profiling bed, & ceiling hoist. Tregorwans.co.uk

LLechryd Farm

LLechryd Farm, Ffordd Glan t Mor Talybont LL43 2AR, 01582 883240 This was judged the best place our member visited. She made use of a Collapse Hoist she took with her and the changing places app.

Marsham Court Hotel, Bournemouth Marshamcourthotel.co.uk

Our Bench, 11 Lodge Road, Lymington SO4 8HH 07751064167 Bench Cottage, Garden Bench & Little Bench.

ourbench.co.uk - Very informative website which shows all 3 sites and availability - much of which is already booked!

You might also find the following online sites useful:-disabledholidays.com accessatlast.com changing-places.org/find

Sheila

LONDON MARATHON 2025 ET AL.





Stuart was obviously very happy to hand over the results of his future daughter-inlaw's marathon challenge after she completed the London Marathon this year.

AND ELSEWHERE OTHER MARATHONS WERE BEING RUN ...

Our son Timothy Hinks ran a marathon in Manchester on 27th April 2025. Timothy also ran a marathon for MNDA in Brighton last year - not to mention a further 2 Ultra marathons (which are 31 miles long) earlier this year. I am looking forward to watching it. We are very proud of him.

Jonathon and Carol Hinks



SUPPORT GROUP MEETING AT HEART OF KENT



On arrival and during the first coffee session, is the time to discuss problems and solutions, new developments and ideas, as well as general news and family happenings.



At a recent meeting, Linda's Eyegaze system was the centre of attention and raised a lot of interest and questions. In turn, Linda patiently showed us all how she used it This session for Karen, Doreen and Sara was the last of several.

MID KENT PRE-SUMMER AFTERNOON TEA



Once again we were lucky to be able to hold our Afternoon Tea in the roomy and accessible Bower Grove School Hall, where forty or so members and their families and friends enjoyed the usual fabulous spread from Moat Farm Kitchen, aka Jane, Julie, Jackie and Bev.



We were made to work for our goodies by two short quizzes with answers which all related to tea-time.

BORSTAL SPRING TABLE TOP SALE





Hardly any time elapsed between setting out some healthy and desirable plants and the first satisfied customer walking away. And what is even better is that the rain stayed away and we sold more plants than ever before.

YOU NEVER KNOW!

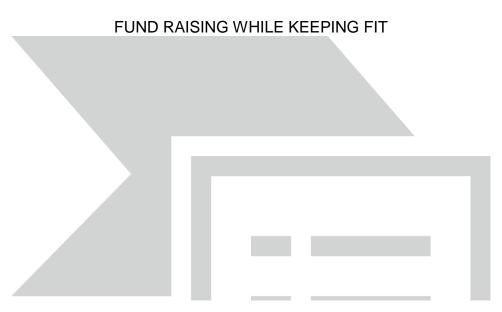
It is not often that a lengthy and unsuccessful clinic appointment can raise the spirits, but I had that experience recently -

There were ten people in the clinic all talking to pass the time and in due course, one person told me that she still has plants in her garden which she bought at one of my Garden Open afternoons. (How long ago is that? We held the last one when Tracey was Treasurer in c. 2018!) Soon after, another waiting patient told me that she still does Quiz Sheets because of a friendship with one of our early patients, so that must be since the late 1990s! Awareness lasts and works in many ways

Joyce



You may remember that after last year's Horticultural Therapy session at the Wisdom Hospice Support Group, Carol bravely promised to show us what progress her cuttings had made. And here they are! However, I'd like to know what plant food she used to produce the colourful snail trying to out-climb a fairy on a Christmas tree!



Jo Coyle, one of our Dieticians took up the 30 Minutes-a-day Keep Fit Challenge. In fact she actually did closer to an hour a day and raised some money for MND at the same time. Jo came to a Wisdom Hospice Support Group meeting, where the members gave her generous support and she was able to show off her fund raising medal at the same time.

QUIZ EVENING MAY 2025

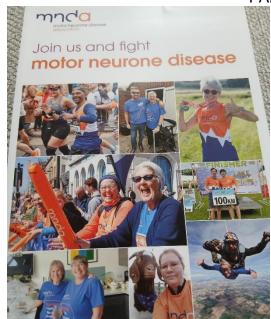


Dave Pannell and his team The Monks of Chanctonbury were thrilled to come 3rd out of 27 teams at this year's quiz and the icing on the cake was having the above photo taken with Shaun. If like me you are wondering why they chose their name, I can tell you, having already asked Dave on your behalf! He writes

About 10 years ago we used to go on a family holiday to a house in East Preston, West Sussex called Chanctonbury. We did a pub quiz down there and decided that The Monks of Chanctonbury had a good, mysterious ring to it. And so we used it again!!

Yet again Shaun's quiz attracted plenty of interest and gave lots of enjoyment as well as raising an amazing £2700 for Mid Kent Branch.







Elaine and Ali were pleased to find themselves on some publicity from National Office – albeit in the bottom left hand corner!

GIRLS NAMES REVISITED

I've searched through all my kith and kin To find some names that might fit in There's sister Kate and Aunty Sue

But these don't fit with any clue. John

I made a silly mistake when typing this sheet and asked for it's return on January 25th (which as someone pointed out was only a few days after they received it). Most people guessed that I'd meant May 25th and over 50 sheets were returned. I keep thinking I'm getting too old for this, but I'll try to keep going as long as I get returned sheets! Some returners have been with us for more than 20 years.

The answers are

- 1. Annette
- 2. Linda
- 3. Christine
- 4. Jane
- 5. Winifred
- 6. Abigail
- 7. Jan
- 8. Carol
- 9. Brenda
- 10. Marilyn
- 11. Joyce
- 12. Doreen
- 13. Lesley
- 14. Sheila
- 15. Elizabeth
- 16. Patricia
- 17. Elaine
- 18. Wendy
- 19. Phyllis
- 20. Dorothy
- 21. Beatrice
- 22. Barbara
- 23. Evelyn
- 24. Amanda
- 25. Penelope
- 26. Alice 27. Diane
- 28. Janice
- 29. Helen
- 30. Emma
- 31. Alison
- 32. Bertha
- 33. Florence
- 34. Sandra
- 35. Laura
- 36. Valerie
- 37. Joanna
- 38. Millicent
- 39. Sharron
- 40. Rebecca
- 41. Theresa
- 42. Shirley

- 43. Polly
- 44. Norma
- 45. Virginia
- 46. Sybil
- 47. Debra
- 48. Fiona 49. Heidi
- 50. Fay
- 51. Caroline
- 52. Charmian
- 53. Mabel
- 54. Fenella
- 55. Ingrid

The next sheet "Famous and Infamous Men" will be ready soon.

Jean

100 CLUB NEWS



Thank you to all the people who contributed to our 100 Club 2024/25 which was so successful we renamed it 100+ Club with 115 active numbers! This is a fun way to donate to MNDA Mid-Kent Branch with the chance of being one of our monthly winners.

Numbers are drawn every month and as you can see from our list of winners some people and numbers are luckier than others!

Our 2024/25 Year ends in June and subscriptions for 2025/26 will be due! Sadly this year MND claimed the lives of several regular 100 Club Members so I have many numbers available.

We would be pleased if you are able to renew membership and equally welcome new members.

Membership is still £25.00 per number per year! All details on flyer enclosed with this edition of MKM.

Winning Numbers are :-

February 2025

1st 81 Lin Barnes 2nd 111 Derek Munt

March 2025

1st 81 Lin Barnes 2nd 111 Derek Munt

April 2025

1st 4 Geraldine Campbell

2nd 111 Derek Munt

Sue Copping

WAYS TO DONATE

JustGiving - you can donate via our JustGiving page www.justgiving.com/fundaising/mid-kent-branch-mnd-association

Bank Transfer - Please contact our Treasurer for further information: lynne.eldred@mndassociation.org

Standing Order – Please contact our Treasurer for further information lynne.eldred@mndassociation.org. Please add something to the reference if you wish this to be a general donation or in memory of someone. If you wish to gift aid your donation, please complete the form in the link below and email to our treasurer.

Gift Aid – if you wish to gift aid any donation please complete the form (see the link below or contact our treasurer for a form) and send to our treasurer either by email (lynne.eldred@mndassociation.org
https://www.mndassociation.org/sites/default/files/2023-01/mnda-gift-aid-form 0.pdf

Easyfundraising - this is an excellent way to raise funds for the Branch, every time you shop online, without it costing you a single penny more. Simply <u>register on the Easyfundraising website</u> Motor Neurone Disease - Mid Kent Branch <u>Fundraising | Easyfundraising</u> and remember to shop via the website and you can earn funds for the Branch.

Text - you can donate via text message - you can donate £5 by texting MND4MIDKENT to 70085 (costs £5 plus one standard rate message). £5 is the Default value for the text but if you wish to donate more, simply add that value after MND4MIDKENT (eg MND4MIDKENT 10 to donate £10)

Old Coins- we can exchange your old British coins or foreign currencies (notes and coins). Just pass them on to our treasurer or any committee member or you can choose our charity at leftovercurrency.com <u>Leftover Currency - Donations to MNDA</u> Mid Kent Branch

USEFUL INFORMATION

Motor Neurone Disease (MND) is the name given to a group of related, but widely varying, diseases affecting the motor neurones in the brain and spinal cord. Motor neurones are the nerve cells that control muscles; hence their degeneration causes weakness and muscle wasting.

MND is usually regarded as progressive but the rate of progression varies greatly from person to person and between the three main types of disease. In the UK it is believed that there are about 6,000 people suffering from MND at any one time.

WE MAY BE ABLE TO HELP YOU!
BEFORE YOU SPEND MONEY ON A PIECE OF EQUIPMENT, CHECK WITH THE APPROPRIATE PROFESSIONAL. IF IT IS SOMETHING THEY DO NOT PROVIDE, SPEAK TO YOUR ASSOCIATION VISITOR or ANNETTE SCOTT.

Mid Kent Branch covers the ME postcode area except ME13, and includes DA11-13

Mid Kent MNDA website www.midkentmnda.org

BRANCH OFFICERS

PRESIDENT: Professor David Oliver

VICE PRESIDENT: Mr Colin Thompson, colinwthompson@btopenworld.com CHAIRMAN: Miss Annette Scott, 01622 820719 annette.scott4@btinternet.com

SECRETARY: Mrs Joan Simpson, 01634 686685 joan.simpson@mndassociation.org

TREASURER: Mrs Lynne Eldred, lynne.eldred@mndassociation.org

CAMPAIGNS: Mrs Elaine Coates, 07884355423 <u>elaine.coates@mndassociation.org</u> LOCAL CONTACT: Mrs Joan Simpson, 01634 686685 <u>joan.simpson@mndassociation.org</u>

FUND RAISING:

DIGITAL SUPPORT: Mr David Smart, david.smart@mndassociation.org

MKM: Miss Jean Lear, 01634 404378 jeanlear@btinternet.com

MND Specialist Nurse: Kelly Chubb kelly.chubb1@nhs.net

AREA SUPPORT CO-ORDINATOR: Sarah Smith 01604 800651

sarah.smith1@mndassociation.org

