

South Coast Bus Trip

June 2016

Writing more than a month after the end of this trip, gives a greater perspective on what was achieved.

First and foremost, the journey was extremely enjoyable, we travelled the full length of the South Coast from Broadstairs to Land's End. The journey took 17 days and we attended 19 events. We met lots of wonderful volunteers all along the coast, while attending the events. These were varied and ranged from music events, a zip wire off Bournemouth Pier, Cheer Leaders in Southampton, a reception at Exeter Cathedral, a quiz and a support meeting in Folkestone. A day by day blog of the journey can be found at www.mnda-eastkent.org.uk.

- Funds raised during the journey were over £10,000, which is of itself fantastic, but the event created much more:
- It showed us how branches and groups might work together for the common good, as a result there will be many future collaborations.
- It showed us how we can use social media together with volunteers to create greater awareness of MND. @mndaeastkent received over 50,000 Twitter impressions during June as well as over 7000 visits to our web site.
- We were able to crossover with Campaigns who helped by getting as many politicians as possible to attend events.
- We supported Silence Speaks, Shortened Stories and Championed the Charter, as we spoke to the various politicians and dignitaries who attended

This journey would not have been so successful without the support of the MND Association Board, four of whom attended an event. We were also given a grant from The Innovation Fund to contribute towards our expenses. The Innovation fund was created to encourage Branches and Groups to work together.



T Shirt on Display at Head Office & Sally Light

There will be a permanent reminder of the South Coast Road Trip when the signed shirt is put on display at David Niven House.

Pam Fry, Sarah Hampton and Rae Martin Smith worked tirelessly to make the journey and the events a success, without their help the trip would not have been so successful. We also received wonderful support from Hilary Fairfield, Cathy Finnis, Claire Tuckett and Jane Giles. Huge thanks to branches and groups East Kent, East Sussex, West Sussex South, Portsmouth and Area Group, Southampton Winchester and District, East Dorset & New Forest, West Dorset, Exeter, Torquay and Cornwall. You made our trip memorable and we loved every moment.



Clive and Lynn Hudson

Masquerade Ball

April

At the Little Silver Hotel delightful friendly country hotel a Masquerade ball was held.

The evening started with a Champagne Reception where we were able to buy Raffle Tickets, make bids for the Silent Auction and enjoy a glass of Champagne.

A wonderful 4 course meal was included which was enjoyed by everyone.



During the meal there was a Heads and Tails Competition for everyone who had made a £5 donation. This entailed everyone standing up and then selecting whether they were head or tail. A coin was tossed and the losers sat down. This went on until only one person was left who won a special prize.

There was also a raffle for the splendid table decorations.

After the meal there was an Auction with a great selection of prizes, there was much amusement as husband competed with wife and mother with son. Prizes included a Curved Screen TV, Balloon Rides, Exotic Car Weekends and hotel stays.

There was a quick raffle draw for a wheelbarrow of drink, difficult to get home perhaps, but no doubt a delight to drink.

The formalities ended with a presentation of a Certificate from MND Association Patron The Princess Royal, to Peta Ashby.

The evening ended with a disco which went on until 1 pm. In all a wonderful evening made more splendid by the raising of over £9322.47 for MND in East Kent.

Thanks to the organizing committee Kirstie Meredith, Peta Ashby, Christine and Oliver Johnston. Thanks also to everyone who attended for their fantastic friendship and generosity.

Spring Lunch

7th May

We had a great Spring Lunch Support Meeting with 42 guests in attendance at East Kent College in Broadstairs.

The college laid on a superb meal which was served beautifully by the students.



Peta Ashby presented a cheque for £9322.47 to our treasurer Hazel Watts, monies raised at The Masquerade Dinner Dance held in Tenterden. Our speaker was Sarah Martin, a research worker from Kings College Hospital who spoke about current research activities to find a cure for MND. The lunch ended with the customary raffle and after dozens of prizes were handed out we left to enjoy the remainder of a beautiful day.

A Fishy Story!

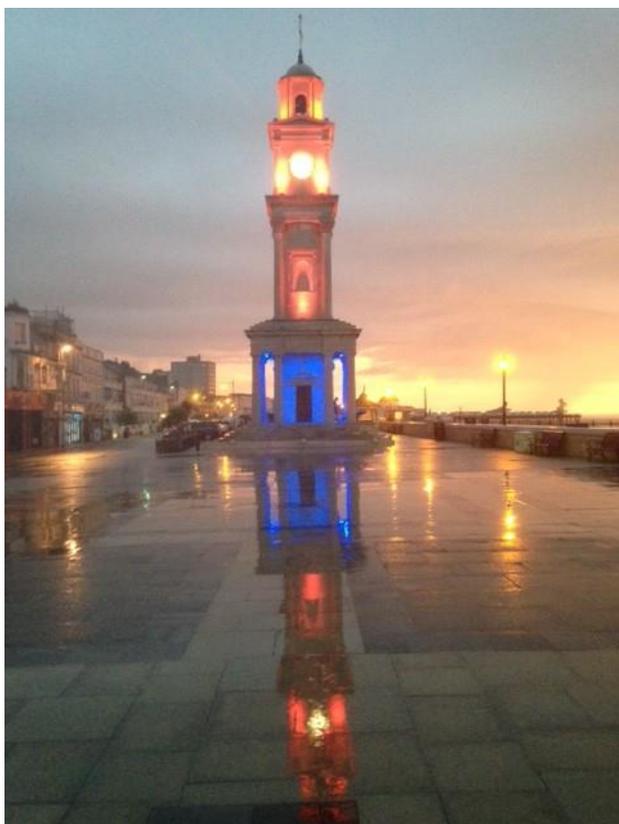
MND Association East Kent member Daren Edwards is a keen fisherman and regularly visits France seeking to catch large carp. On his most recent visit he caught the beauty shown below in a lake in the Champagne Region. It is a mirror carp and weighed in at 32 pounds and took over 20 minutes to land. For those who appreciate the finer points of fishing, it was using a 15lb mainline with 3 Tiger Nuts as bait. The temperature was 28C, difficult conditions but Daren had a great time. Daren would like to thank MND Association for the financial contribution towards his holiday trip.



Herne Bay Clock Tower lit up in MNDA colours

21st June

On Global MND Awareness Day Friends of Herne Bay Clock Tower lit up the Clock Tower in blue and orange. The clock tower was lit up for 3 consecutive nights. Seeing a landmark in Kent lit up for MND meant a lot to many. As the light faded the blue and orange lights became stronger and stronger and it was great to have a quiet moment to reflect on what this great awareness raising actually meant to people living with MND, past and present.



Podplus 3 Lakes Charity 5K

26th June

2016 Podplus 3 Lakes 5k Charity event took place at the Julie Rose Stadium, Ashford. The event raised £665 for East Kent Motor Neurone Disease Association. The charity was chosen after a prominent local runner of Podplus was diagnosed in 2014 and has shown bravery and courage throughout. The event is organized by local business Podplus Sports Shop & Injury Clinic who provide Physiotherapy, Podiatry, Chiropractic Sports Massage and Pilates.

The Walk, jog & run route passes three Conningbrook lakes in Ashford, and finishes outside the Podplus shop on the track of the Julie Rose Stadium. It is likely to be the last year of the event due to development of the Conningbrook site.

The finishers all received a Pink Lady apple courtesy of Coregeo Marketing, and custom made cakes from local company notjustcakes.co.uk, plus a custom memento. Nice Works events Martin Burke provided timing and race results. KMFM were in charge of our PB Bell, they also gave out Beach Balls and Frisbees, handed out water, medals and updated our twitter feed. Their help created a really happy finish line atmosphere and their support was invaluable.



Fighting MND with Dad

David Irving was diagnosed with MND in 2014? His family immediately set out to raise £5000 for MNDA East Kent.

David's family ran football matches, zip wire descents and road walks. Very soon they reached their target, shortly afterwards David sadly passed away and his indomitable family determined to increase their target to £10,000.

Marathons, road walks and other events followed. We are delighted to announce that they achieved their target of £10,000 raised in June 2016.

The family are determined to raise more funds to fight the devastating Motor Neurone Disease.



Quiz Night

The Wrotham Arms Public House, Broadstairs held a quiz night on 14th July.

The event was huge fun and raised £310.00 for MNDA East Kent.

We would like to thank all the customers who took part and Jackie from the Wrotham Arms for her efforts in organising this excellent quiz.

Last year the Wrotham Arms raised a total of £1635.50. To date in 2016 they have raised £1074.10. Jackie is confident she will exceed last year's total.

Huge thanks to all the customers and staff of the Wrotham Arms for raising these funds for the benefit of MNDA in East Kent.

PLEASE SUPPORT

Carly, Matthew, Simon, Gail, Rob & Tom in their Co-Op Charity Run

30th September

Several staff members of The Co-Op are running to raise funds for M.N.D Association.

They will be running from the Co-Op in River starting at 9.30 am, to the Co-Op in Mill Hill. This is a distance of roughly 10 miles. They are expected to arrive in Mill Hill around 11.15am.

Well-wishers are welcome at either Co-Op to cheer them on.



Campaigning

“Every year the Campaigns Contact volunteers meet up for a weekend of sessions, reflection and fun. We meet up to discuss campaigning issues and remember the year’s campaigning highlights and difficulties. It is always great to meet up with people who are campaigning for the Association across the country and to meet the Association’s staff from the Campaigns team and wider External Affairs Team.

There are sessions for volunteers who are beginning their campaigning roles and those who have been volunteering longer. Sessions included “Influencing decision makers”; “Local Campaigning”;

As a more experienced campaigner I was asked to help with the organisation of the event. This was great fun to do and a different sort of volunteering.

There were also evenings of campaigning films and a special message from Jeremy Vine thanking campaigning volunteers for being the voices of people who have no voice. It is always a special moment when we receive a message like this. Campaigns work can take a long time and be frustrating in the short term, but when you achieve a campaigning goal there is nothing better.

Over the summer Mark and I had the privilege of speaking to 150 students age 16 as part of their summer National Citizens Service programme at the University of Kent. We were talking about our volunteering story and what living with MND is like. We were encouraging them to take part in the national Silence Speaks campaign which is an active sponsored silence. You remain quiet, but you try to continue with your everyday tasks. It highlights how difficult it is to interact with others when you have lost your voice.

The students were very inventive and came up with great ideas to help support the M.N.D Association’s messages and Silence Speaks.



Mark and I also had a piece in the M.N.D Association’s national newsletter. Earlier on in the year, we had spoken to students at the University of Kent. You never know how your talk is going to go down, or indeed if it has made any difference. Again we spoke about volunteering and what Motor Neurone Disease is like.

A few months later, some of the students got in touch to say they were running a 10 km race for the Association. This was great news. Then only last month, another student contacted me to say she was going to start a PhD looking at neurology patients. She had been inspired by our talk. We had changed the direction of somebody’s life.

It was an amazing feeling. It is never easy to speak in front of people, but we have discovered that we all have a personal story. These stories are powerful. Who knows your story better than you, so if you get the opportunity to speak in front of any group, go for it.

You never know where it will lead.”

Katy Styles

Professor Ammar Al Chalabi wins prestigious award



Professor Ammar Al-Chalabi won a prestigious award at the American Academy of Neurology (AAN) research conference taking place in Vancouver, Canada.

Professor Al-Chalabi is an MND Association funded researcher and Professor of Neurology and Complex Genetics at King's College London. He is also the Director of the MND Care and Research Centre at King's.

The Sheila Essey Award is jointly given by the AAN and the ALS Association in the USA, and recognises an individual who has made significant research contributions in the search for the cause, prevention of, and cure for [amyotrophic lateral sclerosis](#) (ALS, a type of MND).

Prof Al-Chalabi received the award for his role in helping us learn more about the complex causes of MND, including the role of genetics in the non-familial form of MND.

"It is a wonderful acknowledgement of the work the present and past members of my team have done in ALS/MND research," Prof Al-Chalabi said. "I found out I had won by email, which I had checked on my phone while on my way to teach my medical students, so I was very excited and smiling a lot!" As part of the prize, Prof Al-Chalabi has been awarded \$50,000 to continue his research efforts into MND.

Explaining what he planned to use the money for, Prof Al-Chalabi said: "It will help to pump prime future studies and support early stage researchers to become fully fledged investigators too, both vital steps in our fight against MND."

NICE Guideline published

February 2016

The National Institute for Health and Social Care Excellence (NICE)* published its guideline on MND on Wednesday 24 February.

Sally Light, Chief Executive of the Association said:

"The MND Association strongly welcomes the publication of the NICE guideline on MND. This long awaited guideline has come about after more than four years of campaigning by the Association and our supporters.

"It is a hugely significant document that sets out in detail what good care looks like and how it should be delivered. It will shape future care and have a huge influence over the quality of life for people living with MND and their families and carers.

"We look forward to working with our members and supporters to ensure the NICE guideline on MND has a positive impact on the care and support available to people with MND, their families and carers in England, Wales and Northern Ireland."

The guideline covers MND care from referral and support at diagnosis through to organisation of care and includes managing symptoms and planning for end of life.

Other separate guidelines from NICE that affected people with MND previously focused on the use of the drug Riluzole and non-invasive ventilation (NIV) for people with MND.

The new guideline incorporates guidance on NIV, replacing the previous version but is much broader in context, while the Riluzole guidance remains separate.

There are four main NICE documents published:

- The full guideline - 319 pages
- The short guideline - 47 pages
- Appendices to the full guidance - 468 pages
- Responses to comments received during the consultation - 187 pages

The short guide is likely to be the main reference tool for professionals. It focuses on recommendations to clinicians and practitioners about what they should do when caring for people with MND, urging a joined up approach where different specialists work together to improve overall quality of life.

The full NICE guideline discusses some of the reasoning and rationale behind recommendations in full and will be a hugely influential reference tool.

Nice Guideline Continued

In follow up to this guideline a national Quality Standard has been published in August.

Quality standards set out the priority areas for quality improvement

They cover:

- areas where there is variation in care
- topics across health and social care.

Each standard contains a set of statements to help improve quality. It also tells how to measure progress against the statement.

NICE develop them independently, in collaboration with health and social care professionals, practitioners and service users. They are based on NICE guidance and other NICE-accredited sources.

Quality Standards are developed for those wanting to improve the quality of health and care services.

For example:

- **Commissioners** - use the quality standards to ensure that high-quality care or services are being commissioned.
- **Service providers** - use the quality standards to monitor service improvements, to show that high-quality care or services are being provided and highlight areas for improvement.
- **Health, public health and social care practitioners** - use audit and governance reports to demonstrate the quality of care, as described in a quality standard, or in professional development and validation.
- **Regulators** - for example, the [Care Quality Commission](#).

Quality standards are not mandatory but can be used in the planning and delivering of services to deliver the best possible care. They support the government's vision for a health and care system focused on delivering the best possible health outcomes.

<https://www.nice.org.uk/standards-and-indicators>

Chrissie Batts, Specialist Nurse is working with Dr Prathibha and the Clinical Governance team at E.K.H.U.F.T to review the services within East Kent using the assessment tool recommended by NICE. This will then be presented to the Medical Director and team for East Kent Hospital trust in September.



More information about these important guidelines please access via these links:

A guide by M.N.D Association has been developed which can be accessed at:

<http://www.mndassociation.org/wp-content/uploads/01A-Nice-guideline-on-MND.pdf?baab72>

NICE Quality Standard:

<https://www.nice.org.uk/guidance/qs126>

NICE Guideline:

<https://www.nice.org.uk/guidance/ng42>

Carers Week in June proved to be successful for the M.N.D Association with a cumulative positive effect over the week. On Tuesday 7 June, the Association attended a parliamentary reception – accompanied by campaigns volunteers Heather Smith, and Katy and Mark Styles representing people living with MND and their carers. In all, they spoke directly to about 12 MPs including Justin Tomlinson MP (Minister for Disabled People) and got across some powerful messages about the challenges they and others in their position face.

Just a few of the key facts from our carers survey of 2015 that were shared:

- Over half of carers of people with MND provide more than 100 hours of care per week. Just one of those carers provides care worth a minimum of £89,440 per year.
- Almost two thirds of MND carers don't receive any benefits or allowances
- 56% of MND carers are retired, while 29% balance their caring responsibilities with remaining in work.
- 38% are unaware of their right to a carer's assessment, while only a third has actually had one.



I'm not a Carer, or am I?

Do you support a partner, family member, friend or neighbour who is ill or disabled? Are you the person that listens and encourages them or helps with things they are unable to do? Do you provide practical help such as shopping or food preparation or taking medication? You might help someone to get washed and dressed or ready for bed. You do all of this because you care, and you may be a husband or wife, a son or daughter but you are also a Carer. There is information and support available to you, for you.

Carers' Support are here to listen, and provide information and support to you. Our team of Carer Support Workers are available by telephone, text, e-mail and even Skype. We understand there are times when you need a friendly ear, or are unsure what to do and need some information. We also understand it can be difficult dealing with the range of professionals supporting the person you care for and the amount of information you receive from different sources, we can support you with this.

We also offer opportunities to meet with other Carers and take part in activities and training specifically for Carers. This year we have offered a range of activities such as Carers' Lunches, Afternoon Tea, Golf Sessions, Craft Sessions, Theatre trips and first aid and manual handling training. We can assist with care for the person you support to enable you to attend and also arrange transport.

Carers that have attended these courses, have really found it helpful to be able to talk freely with other people in similar situations and many have kept in contact and continue to support each other.

Did you know Carers are also entitled to an assessment of their own needs? We are able to carry out Carer's Assessments on behalf of KCC.

If you would like more information about any of this information or a Carer's Assessments please contact us.....

Telephone 01304 364 637

e-mail support@carers-doverdistrict.org.

Also on facebook or visit our website www.carers-supportcdt.org.uk

Improving MND Care



The full results from the M.N.D Association 'Improving motor neurone disease (MND) Care' survey are now available.

It is the largest survey of people living with MND in England, Wales and Northern Ireland and the association is extremely grateful to the 919 people who took the time to complete the survey earlier this year.

The results will help to understand where to focus future efforts and resources.

The survey was last carried out in 2013 and gave some important insights which then led to the publication of [End of life: A guide for people with motor neurone disease](#).

The [Red Flags tool](#) was also created to help GPs when considering a possible diagnosis of MND.

The results this year show improvements in a number of areas:

- **Awareness of MND:** More people have heard of MND at the time of diagnosis.
- **Diagnosis:** The diagnosis experience itself has improved. More people are having tests explained to them, the opportunity to ask questions and to receive the diagnosis in a private place.
- **Care:** An increased number of people have a named person co-ordinating their care.
- **Regular monitoring of breathing:** More people are having their breathing regularly monitored with increased access to both non-invasive ventilation and machines, including 'cough assist'.

The survey will help inform the next five-year (2017 – 2021) strategy, which is currently in development. This means that focus on some of the areas require improvement.

According to the survey:

- **Time until diagnosis:** 1 in 5 people still wait a year or more to be referred to a neurologist.
- **Social care:** The services that help with day-to-day living, usually provided by local authorities. There is a need for better early support for adaptations including anticipating needs, assessed by well-informed therapists and social care professionals.
- **Information:** We need to better promote information available to support people when facing the later stages of MND, including end-of-life decision-making.
- **Support:** Further improvements are needed to the support available to children, young people, family members and friends who care for people with MND.
- **How we communicate:** We need to recognise and adapt to the ways people with MND wish to receive support and communication and do more to meet expectations in this area.
- **Co-ordinated Care:** NHS and social care providers need to better co-ordinate the different services that a person with MND requires. We will further raise awareness with those working in the health professions and drive improvements using the NICE Guideline on MND.

Overall, satisfaction with services provided by the Association remains high, with over 80% of people rating as either excellent or good. However, the Association want to further improve what they do, whilst also challenging health and social care providers too.

Once again, thank you to those who took the time to complete the survey.

M.N.D Association website

<http://www.mndassociation.org/wp-content/uploads/Improving-MND-Care-Survey-published-on-website-120716.pdf?baab72>



Beach within Reach is a small Thanet (Kent, UK) based charity that provides all-terrain wheelchairs to some of the beautiful beaches and surrounding countryside around Margate and Broadstairs.

The wheelchairs will be available during summer 2016 on 7 of Thanet's sandy beaches, but you can also call us to chat about use away from the beach. They are free to loan to anybody who has mobility impairment, providing you can bring along some I.D to prove who you are and complete a simple form for our records.

There is no charge for using the wheelchair but we are a charity run entirely by volunteers and would appreciate any donation you are willing to give. We need to raise £40,000+ in order to replace all of our existing chairs and ensure that we can provide all terrain wheelchairs to Thanet for the next 10 years.



East Kent M.N.D Association do not endorse this service: information provided by a person with M.N.D

Support Meeting – Folkestone

As part of The South Coast Road Trip we enjoyed a brilliant support meeting at the Memorial for The Few at Capel Le Ferne.

We had a brief presentation about the Memorial from Clive Butler, while we had tea and coffee. It was great to see so many PwMND and their carers.

We then visited the Scramble Experience Exhibition an incredible interactive Video, audio and equipment Exhibition.

The Memorial is a wonderful place very evocative and totally wheelchair friendly.

Accessible by bus from Dover or Folkestone right to the door.

Huge thanks to Clive Butler for organising our visit.



Our Group at The Memorial for The Few



Clive Butler informing us about the Scramble Experience

Gaynor Lloyd became Chairperson of the M.N.D Association East Kent Group in 2015. She has helped run support meetings, taken part in lunches and introduced us to her dog at fundraising activities. She has decided to move away from the area. We thank her for her valuable contribution to the East Kent Group wishing her well in her new home.

We would also like to welcome Clive Hudson as our new Chairperson, who writes:

“In July I was honoured to be appointed Chairperson of East Kent MND Association Group and I look forward to maintaining and improving the services we provide in East Kent.

I have agreed to stay in post for at least 3 years and intend to prepare plans for those years to achieve objectives we set ourselves locally.

Our group is composed entirely of volunteers. We have a committee of group members who do various duties such as fund raising, providing support, campaigning and administration.

The life blood of our Group and our association is fund raising, without it we cannot provide support to people with MND (pwMND). We cannot campaign to raise awareness of MND and we cannot fund research to find the causes of the disease.

We are lucky in our group to have dedicated caring people like Chrissie Batts, our Specialist Nurse and Judy Keay our Association Visitor. They work tirelessly to support people living with MND, but cannot do so unless they are provided with funds for training, for travel, for providing support in various ways to pwMND.

We have brilliant campaigners in our group, such as Mark and Katy Styles who campaign at all levels from local government and local hospital boards right up to the very top of our Government at Westminster. This work needs funds; we have to raise it locally for them to be able to work locally and we need to contribute towards the national costs of campaigning.

Key to everything are volunteers, without volunteers we can achieve nothing.

We need **YOU** to help in any way possible, perhaps running a coffee morning, a quiz, organising a concert or a barbecue, indeed anything that piques your interest.

Even if you do not have time to organise something you may be willing to help out. “

If you have ever been affected by MND or are willing to help, please join our register of volunteers by contacting webmaster@mnda-eastkent.org.uk

Are you a member?

The M.N.D Association help fund multi-disciplinary medical teams that provide the highest levels of co-ordinated care.

Through national and local campaigning and lobbying, awareness of MND is raised.

Also lead in the funding and promotion of MND research.

In East Kent the group provides support through maintaining these aims. Also arranging patient support meetings at different venues across the geographical area, all patients, families, carers and friends are welcome to attend.

Member benefits:

- A welcome pack, including membership card.
- Link to your nearest branch or group.
- [Thumb Print](#) – Quarterly magazine.
- Attendance and voting at our AGMs.
- Invitation to our conferences and events.

Membership options

People living with MND	No fee
Carers, spouses and partners of people living with MND	No fee
Individuals	£12.00
Families*	£18.00
Reduced rate**	£6.00
Life***	£250.00
Overseas membership	+ £10.00

Support meeting

The next support meeting is on Saturday 24th September 2016 from 11.00 a.m. to 1.00 p.m.

It will be held at the Iron Room, Village Hall, Faversham Rd, Boughton Lees, Ashford, TN25 4HP.

These meetings are very informal with family and friends being most welcome. It is an opportunity to meet other members, your local committee, together with Chrissie Batts who is our dedicated MND nurse based at Kent and Canterbury Hospital.

If you have any questions, want to share experiences, obtain advice or just fancy a cup of tea or coffee, then please do come along. We very much look forward to seeing you

Diary

Date	Event
10 Sept	MND Association, AGM East Midlands Airport
24 Sept	Support Meeting. Iron Rooms, Boughton Lees TN25 4HP
30 Sept	Co Op Charity Run, River to Mill Hill Deal
1 Oct	Volunteer Recruitment Day, Whitefriars, Canterbury
18 Oct	Annual Parliamentary Reception, Westminster
12 Nov	Support Meeting, Red Cross Hall, Folkestone
3 Dec	Christmas Lunch Support Meeting, East Kent College, Broadstairs CT10 1PN
26 th Dec	Saltwood Boxing Day Run
1 st Jan	New Year Party, Wrotham Arms, Broadstairs
More info www.mnda-eastkent.org.uk	

Branch Contacts		Phone	Email
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Secretary			secretary@mnda-eastkent.org.uk
Treasurer	Hazel Watts		treasurer@mnda-eastkent.org.uk
Association Visitor	Judy Keay	07580 517533	judy.keay@mnda-eastkent.org.uk
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Volunteer Co-ordinator	Claire Tuckett		claire.tuckett@mndassociation.org
Regional Care Advisor	Cathy Finnis		Cathy.finnis@mndassociation.org
National office		01604 250505	enquiries@mndassociation.org
Thumbprint Online			www.mndassociation.org/membership
Online Forum			forum.mndassociation.org
MND Connect – Help Line		0808 602 6262	mndconnect@mndassociation.org
MNDA National Website			www.mndassociation.org
The National Website offers support, information and advice to people living with MND, their carers, health and social care professionals and volunteers.			