

2020: The year everything changed

This year, in the face of so much difficulty and hardship for so many, the people of East Kent came together and continued to deliver local support and services, to campaign on behalf of pwMND, and to raise much needed funds in ever more creative ways. As we go into lockdown 2.0, please remember that, despite the small matter of a global pandemic, nothing will stop the East Kent Group from supporting people with MND.



2020 – The Year that everything went online

2020 was the year that everything became “virtual”, something none of us could possibly have imagined as the year began.

Now at the end of the year, and as we go to press facing another lockdown, we can look back with some pride at how we all adapted to new ways of providing support to those who so desperately need it.

Coronavirus meant that home visits were prohibited to protect pwMND who were shielding. This did not stop support from being provided though, with telephone calls and video calls

taking place instead of face to face visits.

Judy Keay, our Association Visitor, believes that one of the few benefits is that contact is more frequent via phone, email, WhatsApp etc. than when travelling distances to make visits was the norm.

East Kent Group support meetings also became virtual, taking place via Zoom.

Video consultations also took place

virtually, and one user's report can be found within this edition.

The East Kent Group committee did not stop meeting either, with these meetings also taking place via Zoom. Big plans are afoot for the group, with changes to social media sites, and new personnel joining the committee.

And not forgetting all of the amazing fundraising that has taken place this year.



A Zoom meeting taking place

An update from our Treasurer, Maureen Wallis - Funds raised for East Kent in 2020

In May, in light of the cancellation of many planned fund raising events, the group made a special appeal for funds.

It's safe to say that the response was incredible. Our Special Appeal has so far raised over £3513 plus £673 in gift aid. This includes £120 raised from the summer online quiz, with more funds to follow from the October quiz. Huge thanks go to quizmasters Elaine and Steve Coates and the many other contributors, including the family and friends of Simon Flack; the staff and customers of The Wrotham Arms in Broadstairs; and all the many others who donated anonymously in memory

of their loved ones.

Mick Rendell cycled 100 miles on 15th of August. He then cycled 46 miles on a tandem with his wife Jackie on 16th August. Together, they raised £1307 plus £226 in gift aid.

Clive Hudson's Million Metres target was reached in September and funds raised so far are £1250 plus gift aid of £138. Clive also raised a further £150 as part of the Mission 5000 challenge.

Mission 5000 was a target of 5000 miles to be walked, run, cycled or even rowed by volunteers during the period Sunday 13th September and Sunday 18th October. It represents

one mile for each person living with MND in the UK.

Many people raised funds as part of this challenge, including Emma Dowling, who has so far raised over £1710 plus £289 in gift aid, and Judy Keay, who raised £505 plus gift aid.

However....

One of the saddest impacts of Covid-19 has been the understandable reluctance of pwMND to attend appointments, or to have equipment installed in their homes. Fewer funds have been spent this year as a result, although funding was recently given for a Cromwell chair.

Please remember: these funds were raised by people in East Kent, for those living in East Kent with MND, and for their families and carers. If you need support, please contact your NHS Specialist Nurse Chrissie Batts, or Association Visitor.

Emergency Support Grants extension to 31 January 2021: Launched earlier this year, this grant was set up by the national MND Association to support people living with MND struggling with everyday living costs, such as grocery shopping or bills as a result of Covid-19.

An application form can be found online: <https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd>

MNDA - EAST KENT

mndconnect@mndassociation.org

www.mnda-eastkent.org.uk

MND Connect – 0808 802 6262

Mon-Fri 9.00am - 5pm and 7.30pm - 10.30pm (Local charge call)



A Million from an MNDA Warrior in East Kent

“Right... I have decided” he said.

“What have you decided?” I said curious, even though I was immersed in my breadmaking.

“I’m going to do a million!!”....

I was even more curious by now! A million pounds perhaps (well we are always trying to raise funds) but a MILLION? Our normal fund raising activities have been severely curtailed this year, no social gatherings, face to face quizzes, cake sales or group walks have been possible...so this seemed almost unachievable.

During this uniquely trying, Covid ridden, frightening, challenging time even a hundred would be fabulous....but a million? I looked at Clive with admiration....

“A million pounds, that would be astounding” I said....he gave me one of those looks....

“Not pounds silly, I shall be cycling a million!!”...

“Miles or kilometres? That’s an awful long way whichever”....

Clive sighed and then explained he had set himself a target to cycle a million metres during this, his seventy fifth year to try and raise funds to support people living with MND living in our area, East Kent!!

It sounded almost impossible when he first told me...

but here we are, 10 months on and only 68,000 metres to finish what seemed an insurmountable task at the start!



Clive Hudson cycling in his shed

The secret to completing the gargantuan task is, of course planning, organisation and having a VERY understanding wife!! Come rain or shine, wind or hail, Clive has been pounding away every day on his bike.... and bit by bit, metre by metre the target is being met! Well....perhaps not in the way he would have chosen back in October 2019.....the cycle paths are so near and yet so far, we have both had to shield throughout the pandemic....who knew this virus would nearly scupper the planned ride last year? No....a bit of lateral thinking, and an old bike stand later the ride has been almost entirely completed in our shed!! So social distancing and

health needs have been met more than adequately. Clive has clambered on his trusty (rusty!!) steed every day and is nearly there. The almost daily plea “Have you seen my cycling shorts?” has been regularly met with “Where did you last put them?” The aching cramped legs are now rippling with muscles ...and a little money has been raised on the Just Giving Page to try and supplement the hugely reduced funds raised this year. Who knows...a million might mean exactly that.. we will just have to see on his 75th birthday on September 26th when this challenge is complete.

Lynn Hudson August 2020

Update

Clive met his target in September. Funds raised to date are £1250 plus £138 in Gift Aid.

Donations

<https://www.justgiving.com/fundraising/mndamillionmetres>

Original story

<https://mnda-eastkent.org.uk/wordpress/?p=3058>

Cycle Ride for MNDA

The Pru100 cycle ride was cancelled this year due to Corona Virus. Mick Rendell decided to cycle an alternative 100 miles in support of the Motor Neurone Disease Association, as a colleague has been diagnosed with the illness, robbing him and his family of the life they had together.



Mick and Jackie Rendell

Mick decided to ride on the weekend of the Pru100 event. He rode 100 miles on Saturday 15th August. Mick also persuaded his wife Jackie to ride Pru46 miles tandem on Sunday 16th.

In Mick's words in July 2020

It was my intention to ride the Pru100 event again this year and ride in aid of the Motor Neurone Disease Association of East Kent. I am riding on behalf of a colleague Craig Whitelaw who is

currently suffering from this debilitating illness. Craig was an energetic Broker Consultant and who is now confined to a wheelchair unable to walk or use his hands. In the past year Craig has been robbed of normal family life and has a wife and two young children who now have to watch their husband and father suffer.

I am (fingers crossed, touch wood etc) fit enough to do the things I want (mainly cycling) without issues and feel I can help people who can't by raising money for the worthwhile causes who

support them. The Pru100 like many events has been cancelled this year so I have signed up to do 100 miles around Kent (much harder than the Pru course) as an alternative. The Pru run 3 events, a 19 mile ride, a 46 mile and the 100 mile, so we have registered for two distances and I will ride the 100 miles on the Saturday solo and Jackie (my wife) and I will ride 46 miles on the tandem on Sunday.

Most of us are fortunate to still be fit and healthy and Craig is one of us, a member of our industry so please take the time to look at the link below and give generously where possible.

You can see the full story by visiting <https://www.justgiving.com/fundraising/mick-and-jackie-rendell1>

Note: Mick and Jackie raised an astonishing £1307 plus gift aid.

I decided back in January that I needed to do something constructive to help our friends Wendy and John, they had undertaken some amazing fundraising for the MNDA previously, and have told me how helpful the MNDA has been to them since Wendy was diagnosed in 2018.

I had a look at all the organised fundraising events and challenged myself to get fit to walk the Coastal Walk to D'Feet MND 2020 in June. I set up a WhatsApp Walking group with like-minded friends so that I could have support and company on some of my training - thanks to the following co-walkers: Claire, Ellie, Emma, Imogen, Jenny, Jess, brother Jonathan, Julia, husband Phil, cousin Sarah and Mia the dog, Sharon and of course Wendy and John.

We have had some fun along the way despite lockdown, the transition from this and my very low level of fitness! My brother Jonathan, a veteran

Walking for Wendy!



Emma Dowling and friends

of all things challenging, offered to help me on the day by walking the 24 miles with me, and we were really hoping that the event would go ahead on the re-arranged date in October.

It was not to be, but Jonathan said "let's walk it anyway". I had already signed up for the Mission 5000 Challenge and so made the 24 mile walk part of a bigger



Wendy and John

mileage challenge.

The weather miraculously cleared up for us on Saturday 3 October and we started off at 7am from Whitstable in the dark, together with friends Ellie and Jess. They walked with us until Reculver then we had a long stretch on our own to enjoy the stunning Kent coastline.

We were met in Margate by my

children and Phil at around Mile 18 and a bit later Wendy and John joined us for the last couple of miles, which was fantastic. Seeing Wendy ahead of me waiting was emotional for both of us.

I really enjoyed the walking and I have experienced a huge sense of achievement in getting to my rather silly 250 miles total for the Mission 5000 Challenge as well as reaching my fundraising target. I ran out of time to walk all of my mileage so had to opt for using my static reclining bike in the garage - so it's a big, big thank you to Phil especially for giving me the time to complete it.

With friends and family I have walked to and around places that I haven't been before, we have had quality time together and I am really looking forward to doing the Coastal Walk again next year, I am hooked!! Walking with a big group of people will be great fun. Here's to next year everyone!



We've got a sack load of festive fundraising ideas this Christmas

THIS Christmas we need your support more than ever before to ensure we can support families affected by MND. That's why the Association's fundraising team has developed an assortment of festive fundraising ideas, with something suitable for everyone.

Busy parents with no time to spare can make a donation instead of writing and sending Christmas cards and share a branded Merry Christmas message on social media. Those who're seeking an adrenaline-filled challenge can sign up for

a December Dip and head to the coast to brave the chilly waves.

Alternatively, supporters looking to get creative can join our wreath-making workshop with RHS Chelsea gold medal winning garden designer Sue Hayward. Essentially, we've got more festive fundraising ideas than Santa has toys in his workshop!

To sign up or find out more about any of these events and ideas visit

www.mndassociation.org/festivefundraising



Make your own Christmas Wreath

Get creative and join us for a virtual wreath making workshop with Sue Hayward, RHS gold medal-winning garden designer.



Join our PJ Day this Christmas

Making a difference in the fight against MND just got cozy. On the 10th of December we're giving you a free pass to wear your festive pyjamas or winter onesie all day.



Make a splash this Christmas

Try something new this Christmas and brave the open water for our sponsored December Dip. Are you up for the challenge?



Make a Donation in Lieu of Christmas Cards

Donate to support the fight against MND instead of sending cards. In return you'll receive a virtual badge to share on social media and spread your festive wishes.



Take part in a Virtual Santa Run this Christmas

Tis the season to get your family running! Join our virtual 5k Santa run on the 5th and 6th of December.



Take part in a festive walk

Help to bring us a step closer to a world free from MND this winter, by completing your own Winter Walk.



Christmas Event 2020

Date: Saturday 5th December 2020

Time: 12pm - 2pm

Where: via Zoom (link to be sent to you closer to the date)

Dress code: We would love to see you in your best MND Christmas hat! We want to see who has been the most creative, with a prize going to the best one.



There will be lots of festive-inspired activities happening:

DRINKS:

We would love to toast each other at the end of our event, so get your favourite Christmas drink ready (perhaps a mulled wine or a mocktail).

THE QUIZ:

Keep your eyes peeled as we draw closer to the event, we will send out a printable answer sheet, for you to write your answers to the quiz on. There will be prizes for the winning team!

CAROL SINGING:

The lovely Canterbury Voices will be gracing us with their singing voices for a set of Christmas carols, to get us in the Christmas spirit (depending on any future lockdown regulations). For the last song, we would love everyone to join in together and sing 'We Wish You a Merry Christmas'.

RAFFLE:

And of course, what is a Christmas party without a raffle? Everyone attending our virtual event will be entered into our raffle. All prizes will be delivered by email or by post. Prizes will include biscuits, chocolates, wine, and gift vouchers. Not to be missed!



SEND US YOUR DETAILS:

We kindly ask you to send the full name of you and your guests and an email address (so we can send you your lovely prize) to ChristmasRaffle@mnda-eastkent.org.uk so a raffle number can be assigned to everyone! Winners are to be announced after the carol singing!

There is no charge for the Christmas Extravaganza, however, if you wish to donate to MND East Kent, please visit our JustGiving page at (<https://www.justgiving.com/fundraising/mnda-east-kent-special-appeal>).

We look forward to seeing you at our Christmas event. Remember to send us the contact email of all guests to ensure you are entered into our Christmas raffle.

**SEASONS GREETINGS, EAST KENT GROUP
OF THE MND ASSOCIATION**



Thank you to our outgoing Chairman, Clive Hudson

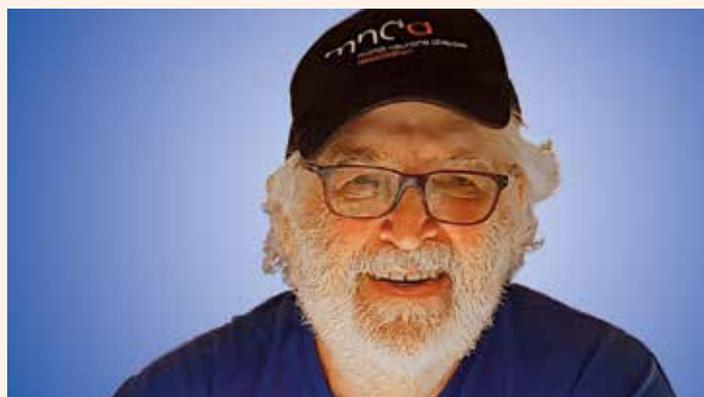
Clive decided to step down as Chairman of the East Kent Group in September, but continues to be an active member of the committee, especially in fund raising.

Clive truly has been a warrior in raising funds for, and increasing awareness of, pwMND in East Kent, whether that be cycling countless miles from his shed, organising multiple events or bringing people together for the benefit of all.

We'd like to say a huge Thank You to Clive on behalf of all those with MND in East Kent.

Message from our AV, Judy Keay:

Amongst all the East Kent Group Meeting minutes etc. the earliest I have been able to locate is a meeting held on 12 November 2014 which stated that 'Clive took the minutes'. He, obviously, did such an efficient job that he was soon promoted to being Chair of our Group. It wouldn't be possible to list all the things Clive has done since that



Clive Hudson, former Chairman of the East Kent Group

time, partly and importantly, because he has just got on and done them.

These can be organizing events such as Walk to d'Feet MND, two Dragon boat races against Mid Kent at Moat Park, our

annual Christmas and Spring lunches at the Yarrow Hotel in Broadstairs for pwMND and their families. Also, there is Clive's support of other fundraising events from the Saltwood Boxing Day

Run, student events, various quizzes and a whole range of other initiatives.

Clive has himself taken on fundraising events with the latest being his million metres cycle ride, and some years' ago the South of England bus trip calling at various other MNDA Groups and Branches en route. I know I simply haven't and can't list everything here but, added to Clive's fundraising activities, it is important to recall his website and Newsletter work and involvement in Support Meetings and a whole host of Association meetings and conferences.

Clive will be a hard act to follow but it was reassuring to know that he doesn't plan to totally disappear off the horizon.

Judy Keay

Could you be our next Chairman?

As Group Chair, you will:

- Ensure continued delivery and development of our local work to support people with MND and their families
- Plan, prepare for and facilitate committee meetings
- Ensure appropriate decisions are made in a timely way when required
- Support Group volunteers in planning and coordinating

Group activities

- Ensure Group volunteers are aware of and follow the Association's policies and procedures
- Induct and mentor new volunteers
- Work in partnership with staff to recruit new volunteers
- Act as an ambassador for the Association and as a host at Group events.

This is an excellent opportunity to develop and utilise your leadership

skills and get involved with your local community. We are looking for someone reliable, warm and empathetic with the ability to motivate others. Leadership skills and experience of chairing meetings would be an advantage, along with good organisational and listening skills.

The Group Chair will usually work for approximately 7-10 hours a week and facilitate on average 6 committee

meetings a year and be involved in perhaps another dozen meetings during the year.

You'll be inducted into the role and informed about the Association. As part of this, you will receive e-learning, face-to-face training and mentoring.

For more details please contact: ahmed.abeldayem@mndassociation.org

My changing Association Visitor role in a new Coronavirus world

Association Visitor Co-ordinator, Judy Keay

How different is the world in which we now live? As with much else, my AV role has changed in ways I could never have envisaged or even thought feasible. Fundamentally, the role is the same except in how support is delivered.

Avs still have an important and unique role in supporting people living with MND and their families by ensuring they receive the support and services they need. We offer free and confidential emotional support and information about the Association and other services provided that help people to make informed choices - choices and decisions that so often need to be made in advance of need, not once a need has arrived.

There are two things which have helped me when offering support and advice. The first of these is that I attend the East Kent Multi-disciplinary Team Meetings along with healthcare professionals and others key to effective support for pwMND in our area. Plus, of course, there are times when I work with health and social care professionals to



AV Co-ordinator Judy Keay

resolve problems. Secondly, my husband lived with MND for 14 months and, as his carer, I learnt quickly important skills needed for 'going on a mission' i.e. fighting battles.

In pre-Covid days, I would make my visits to people who live within the 800 sq. miles of East Kent every 3-4 weeks. Visits would often be followed up with phone calls or emails when I'm 'on a mission' to find out information or sort out a problem. A possible advantage now is that I contact each person fortnightly or more often if necessary. To date, contact has been via phone, email, WhatsApp, text, and, on one occasion via Zoom (set up by a carer and certainly not by me!). Once these forms

of contact are established, I do sense people feel much freer now to contact me with questions and concerns. Set against this are things I feel strongly are the greatest disadvantage:

- a) not being able to hug, hold a hand, put an arm round someone's shoulders.
- b) being unable to see and fully grasp the current situation, development of the disease, etc.
- c) missing the opportunity to develop a relationship between the person with MND and their family which comes from being shown family photos, gardens, hobbies, etc. I've learnt so much from this 'sharing' about art, roses, music, Man U and more.

About Judy's role

Judy and her AV role is an incredibly important part of the multidisciplinary team with her knowledge and experience, not just with Motor Neurone Disease but with her life experiences. She has 'worked' with me for a number of years and brings a different dimension and perspective as she is not a medical professional which I think people - patients and families appreciate.

Christine Batts,
MND Specialist Nurse

There have been two pluses arising since Covid:

- 1) Chrissie, our special Specialist MND Nurse, and I now have regular weekly phone (and once a virtual meeting!) calls - these enhance and update our patient information. Hopefully, this will be something that we retain post Covid as it is certainly an advantage to all concerned.
- 2) Alison completed her AV training at the beginning of the year and has taken on some contact/email work. I can't wait now for Alison to be able to visit and get to know pwMND in their own homes.

If I reflect on the above, there are many things that I can't wait to see the back of but there are also one or two newly tried/developed areas that I want to retain as enhancing the service East Kent AVs are able to offer.



Chrissie Batts, MND Specialist Nurse

Video Consultations

One of our members wrote the following report about the services being offered during the current pandemic crisis.

Due to Covid-19 my normal clinic was cancelled. I was offered a video consultation instead.

This would be with the same consultant and specialist nurse that I would have seen. The only stipulation was that I had to have a smartphone (ios or android). If I didn't have a smartphone there was a contact number to call to advise them.

On the day of my appointment I received a text message with a link that I had to press at the time of my

appointment. This opened a video screen on my phone where I could see the consultant and specialist nurse in a room.

The video quality was very good and the audio was clear. I had no buffering issues. Although I have a very poor mobile phone signal I have a very fast internet connection so I tend to run everything through my internet connection.

I felt that I had had a proper consultation and had covered everything that I wanted to ask (I had made some notes beforehand). I didn't feel rushed.

An issue was that normally before the appointment I would have blood/lung function tests at the hospital and then discussed at the meeting.

This could not happen.

Another issue is privacy. It's important

that you are somewhere quiet and can talk freely. Likewise it is important at the hospital that it is treated as though the patient is physically in the room.

I would certainly like to use the system again.

When we are in more 'normal' times perhaps we could be given a choice of hospital attendance or video consultation.

Video consultations - a nurse's view

Chrissie Batts, MND Specialist Nurse, who was part of the above consultation, added the following:

"Since the start of the Covid-19 virus which has caused havoc in our lives, we have all had to adapt. Being a technophobe with little knowledge, this has been even more of a challenge.

Usually, I would meet people living with MND at home or in the clinic, having face to face discussions. As clinics and home visits became suspended, I was asked to trial the new system that EKHUFT were introducing to support consultations.

I trialled this with a couple of colleagues prior to breaking it out to patients!

I surprised myself as to how easy this system is to use, so am encouraging other nurses to use this system. Obviously it isn't the same as meeting face to face but, at the present time, it is solving a few difficulties.

If you have used the system with me please let me know your thoughts which I can share with the IT team".

Kent's Campaigns Manager, Katy Styles, founder of an unpaid carers group recognised for campaigning efforts

A grassroots volunteer-led group based in Canterbury, Kent has won a national award for its efforts to improve the support available to unpaid carers.



We Care Campaign was founded by Katy Styles, an unpaid carer to her husband and mother, in May 2018 and has been lobbying all the main political parties to put in place a National Carers Strategy.

The campaign estimates unpaid carers provide the equivalent of £132 billion in care a year. However, despite there being more unpaid carers than ever before, We Care argues their rights are being eroded and an increasing number are being left with little support.

On 30 September, the campaigning group won Best Digital Campaign at the coveted Sheila McKechnie National Campaigner Awards after securing support from politicians for a National Carers Strategy ahead of last year's General Election.

In the run-up to the election, We Care ran the digital "Sticking Plaster" campaign that encouraged carers and carer groups to engage with their local parliamentary candidates about the many challenges facing unpaid carers. Carers were encouraged to share their stories, ask questions at hustings events, and were encouraged to vote.

The campaign used local events to identify individual carers and build



on a sense of community. Individual carers are often isolated and creating a sense of community was a target in itself.

Online tools and resources were also produced to help carers engage with their local parliamentary candidates.

As a result of the group's work, the Labour Party included the call for the creation of a National Carers

Strategy in its 2019 General Election manifesto. Additionally its work has come to the attention of large national charities and We Care is now working with Oxfam GB on its work on poverty and unpaid carers.

Katy Styles at We Care, says: 'Winning the Best Digital Campaign Award in the year the world went digital is something rather special. For a group of unpaid carers and allies, who will never meet physically, digital campaigning has been a lifeline in building our community and for raising our collective voice with political decision makers. Unpaid carers have never been more isolated than they are now nor been asked to do so much, with such little support. It is, therefore, even more vital to use all the tools we can, both online and offline to raise the plight of unpaid carers with those who have the power and influence to make the lasting change we need.'

Counselling service launched for young people

Children and young people affected by motor neurone disease (MND) can now access professional counselling within days rather than months thanks to a collaboration by two charities.



Research by the Motor Neurone Disease Association found children whose close family members had been diagnosed with the terminal illness were having to wait up to 18 months to access vital counselling services. The new support service, developed in collaboration with the UK's leading children's charity Barnardo's will slash that waiting time to just five days.

The tailored counselling is available for children, young people and their families. It is based on the Barnardo's 2020 Family Support Service which has supported hundreds of families dealing with the challenges of the COVID-19 pandemic. The new service has been adapted specifically for families affected by MND.

Young people can access the counselling at any stage they need support – from the diagnosis of a loved one to post-bereavement. The sessions are held online or over the phone.

Barnardo's therapists will also support and empower parents, giving them the tools, knowledge and access to resources to help younger children who may find it difficult to engage with sessions virtually.

Laura Willix, Children and Young Persons Service Development Manager

for the MND Association said:

"Parents with MND have always told that us one of their biggest worries is the impact of their diagnosis on their family. The disease can progress rapidly and children and young people in need of help cannot wait months, and in some cases years, for vital support. Our new service will give children fast access to counselling sessions as soon as they need it. They can talk openly about their worries and fears to a counsellor with specialist MND knowledge who will help them deal with the difficult times ahead and hopefully go some way to alleviating the worries of the loved one facing the disease."

Sarah Wilkinson, Operations Manager at the Barnardo's LINK Therapeutic Support Service said:

"We are absolutely delighted to be working with the MND Association; having the opportunity to support children and young people to manage the challenges and anxieties that they may be facing. Both Barnardo's and the MND Association clearly share core values around strengthening family relationships and promoting safer childhoods. By working in partnership, I believe we can make a real difference to the families we work with."

The service has been funded by the James Milner Foundation as part of its commitment to support children and young people affected by MND. support a lot of children and younger people and reduce the time it takes for counselling support at a time when they need it the most".

James Milner said:

"Both myself and the James Milner Foundation have seen first-hand the devastating affect that motor neurone disease has, not just on the person who is unfortunately having to live and fight the disease but the person's family and children. The James Milner Foundation collaboration with Barnardo's and the MND Association can hopefully support a lot of children and younger people and reduce the time it takes for counselling support at a time when they need it the most".

If you are interested in the service, please contact Children and Young Persons Development Manager, Laura Willix at cyp@mndassociation.org.

MNDA EAST KENT DIARY 2020/2021

DATE EVENT

Sat 5th Dec

Online meeting

Virtual Christmas Event

Note: In light of Coronavirus all future events to be announced via the the East Kent Group website and Facebook page - please check for regular updates: https://mnda-eastkent.org.uk/wordpress/?page_id=591

Online Information and Support

Anyone recently diagnosed with MND in East Kent and needing advice and support can contact our local Association Visitor Co-ordinator, Judy Keay. There is a wealth of information and online support available to patients with MND and their families and carers:

1. For the most comprehensive information relating to all aspects of MND, please view the national MND Association website:
<https://www.mndassociation.org/>

Specific information relating to Coronavirus can be found at: <https://www.mndassociation.org/about-mnd/coronavirus-and-mnd/mnd-and-coronavirus/>

MND Connect, the Association's support helpline, is available on **0808 802 6262**

Monday to Friday 9am to 5pm and
7.00pm to 10.30pm

2. The local East Kent Group of the MND Association website is:
<https://mnda-eastkent.org.uk/wordpress/>

The East Kent Group of the MND Association Facebook page is:

<https://www.facebook.com/profile.php?id=100007065881601>

A series of videos can be found on YouTube, detailing the support available locally, as well as personal stories:

<https://www.youtube.com/watch?v=qUZCRGGBdBs>
<https://www.youtube.com/watch?v=KmmWACyu0tM>
<https://www.youtube.com/watch?v=GWD0c7fppNg>

3. A series of videos where experts answer questions about Coronavirus can be found on the national website:
<https://www.mndassociation.org/videos/ask-the-experts/>

4. Disability Relief for Council Tax.

If you have adapted your main home to meet the needs of a disabled person who lives there, you may be able to apply for a reduction in your Council Tax Bill.

To get a reduction the property must have at least one of the following:

- a) an extra bathroom or kitchen needed for the disabled person
- b) a room other than a bathroom, kitchen or toilet which the disabled person needs and uses
- c) enough floor space indoors to allow the use of a wheelchair which is needed for the disabled person

The first step is to apply to your local Council who, once an application has been made, will arrange a visit to confirm details of your application. If confirmed, your tax band will be reduced to the next band down. There could even be a backdated refund.

5. Support with Southern Water bills: Southern Water have raised the income threshold to receive a discounted bill until the end of March.

Contact them online at:

southernwater.co.uk/contact-us or via free phone **0330 303 0270 (9am to 7pm, Monday to Friday)**

Or via live webchat from their web homepage at southernwater.co.uk

6. Finally, a really useful blog for all carers, including government advice and Emergency Plans can be found at:

<https://maudandmum.com/carers-versus-covid-19/>

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The National Website offers support, information and advice to people living with MND and their carers