

4th Coastal Walk to D'Feet MND - POSTPONED

Unfortunately our 4th Coastal Walk to D'Feet MND has been postponed until Saturday 3rd October 2020.

Thank you to everyone who registered for this event and those who made a donation. £320 has already been raised.

We will be redesigning our posters as soon as we know we are able to hold the walk. Please keep checking the East Kent Group's website for updates: <https://mnda-eastkent.org.uk/wordpress/?cat=2>

The details of the walk are as follows:

There will be three walk options:

1. A long walk (approx. 24 miles)
Whitstable to Broadstairs.
2. A medium length walk (approx. 13 miles)
Minnis Bay to Broadstairs.
3. A short walk (approx. 6 miles)
Margate to Broadstairs.

There is an entrance fee of £10 which includes a tee shirt (collected on the day), training program, detailed plan of walk, and full insurance. Only registered



Lots of fun was had by walkers raising money on the D'Feet MND Coastal walk 2019

walkers can walk and they must wear the tee shirt for insurance purposes.

Each walker is requested to find sponsorship to support people living with MND in East Kent. There is no obligation to raise sponsorship but all support is greatly appreciated.

To register for the walk, please visit www.mnda-eastkent.org.uk/walk2020, complete the form, then follow the link to Just Giving to pay your entry fee of £10.

If you intend to set up your own JustGiving page, we are happy for you to do so. Please select MNDA as your charity and then please mention MNDA East Kent in your story to ensure that funds you raise are used for people

living with MND in East Kent. Once you have set up your JustGiving Page, please link it to our team at www.justgiving.com/team/coastalwalk2020 so we can keep track of the total funds we raise.

If you want to make a donation in support but not register please visit <http://www.justgiving.com/fundraising/coastalwalk2020>

Should you experience any difficulties please email: webmaster@mnda-eastkent.org.uk

The route is shown on the map below.

We thank our sponsors, with whose help we are able to raise substantial sums to help people living with MND in East Kent.

DOWNLOADS...

Training programs for the walks, the Walk Plan, sponsorship forms, posters and flyers can be downloaded below:

24 mile walk training programme
download PDF

11 mile walk training programme
download PDF

Walking Route and Plan
download PDF

Sponsorship Form download PDF

Poster download PDF

If you are able to display a poster, we would be grateful if you could print a copy and display it.

Greenwich
Kitchen

Premier
Signs & Graphics

Thanks to our sponsors

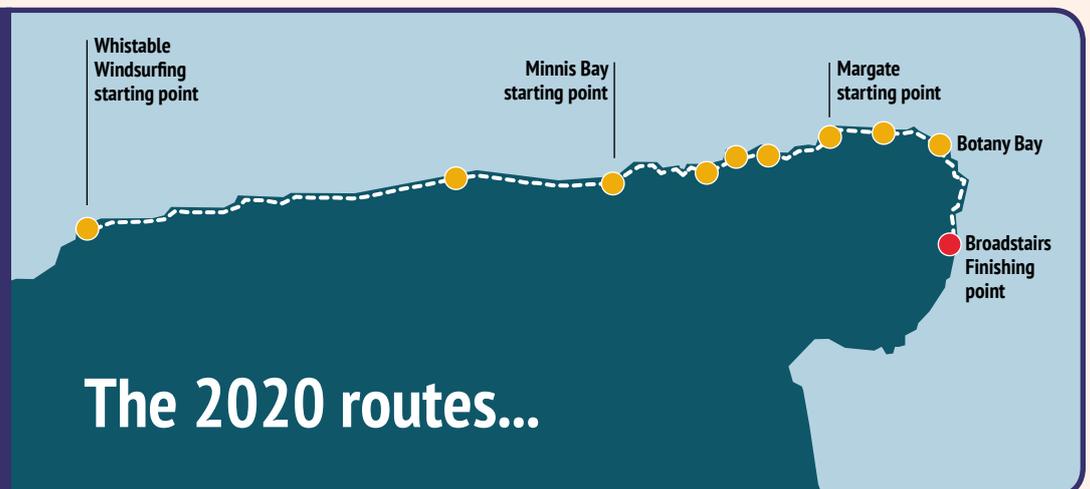
DIARY DATE for 2020

The 4th Coastal Walk to

D'Feet MND

Saturday, 3rd Oct 2020

You can register by visiting:
www.mnda-eastkent.org.uk/walk2020



The 2020 routes...

MNDA East Kent Group Fundraising

Wrotham Arms

Thank you to the Wrotham Arms, who continue to raise much needed funds for the MND Association East Kent Group, and raised a further £1242 at their New Year's Day Party.

Saltwood Run

For many years now the Saltwood Run has been a great fund raiser for MND Association East Kent Group.

The event is run on Boxing Day each year and was run in 2019.

We were delighted to receive a cheque for £1000 from the organisers and a further cheque for £250 from the Rotary Club of The Channel.

MNDA East Kent would like to thank both the organisers and The

Rotary Club for their continued support over many years, during which time they have contributed many thousands of pounds to support people living with MND in East Kent.

Carol Concert at Holy Trinity Church, Broadstairs

£820 was raised during a Carol Concert given by the Thanet Festival Choir on December 14th at Holy Trinity Church in Broadstairs. Those who attended said that it was a most memorable concert, beautifully sung and wonderfully conducted.

Hazel Halse, a member of the choir, gave a speech dedicated to a friend who sadly passed away with MND. The speech has been published in this edition and can also be found on the

East Kent Group's website.

2020 Planned Fundraising activities

Million Metres for MND continues, we had hoped to have a final flourish on Saturday 26th September, which may now not be possible due to Covid 19 and other plans are on hold. You can support this fund raiser for MNDA in East Kent by visiting <https://www.justgiving.com/fundraising/mndamillionmetres>

Planning is well progressed for our 4th Coastal Walk to D'Feet MND which will be held on October 3rd assuming Covid 19 is then under control and such events are allowed.

On January 27th, Clive Hudson

attended Chatham House School in Ramsgate, together with the organiser of the Coastal Walk to D'Feet MND, Cath Miller. They addressed the sixth form and were advised that the students will undertake a fund-raising event for the group during 2020.

Anyone can raise money for the MND Association by using the EasyFundRaising link, <https://www.easyfundraising.org.uk> and entering the MND Association as the cause you are raising funds for. Then simply click through to your online retailer as usual.

The MND Association has also published some ideas for raising funds during indoor isolation, which can be found on page 4.

Carol Concert

On Saturday 14th December, some of our East Kent Group members had the privilege of attending a Carol Concert given by the Thanet Festival Choir at Holy Trinity Church in Broadstairs.

It was a most memorable concert, beautifully sung and wonderfully conducted.

The concerts raised £820.00 for the MNDA and we are extremely grateful to all the members of the choir, Clifford Lister – the Conductor, Jim Clements – the Soloist and to the organisers. Many many thanks to you all.

During the concert, the most moving speech was made about the loss of a friend to MND. The speech is printed in full below. Please read it, we found it very moving.



CAPTION Thanet Festival Choir – conducted by Clifford Lister.

Elizabeth:

In June 2017 my clever, articulate, creative and very active friend Elizabeth, whom I'd known since we were both 18, was diagnosed with Motor Neurone Disease.

MND occurs when special nerve cells in the brain and spinal column stop sending signals to the muscles, which gradually waste away, leading to problems with walking, eating, drinking, speaking and breathing. The causes are not fully understood, there is very little that can be done to treat the disease, and most people with MND die within

two years of diagnosis.

The speed with which Liz deteriorated after that June diagnosis was horrific. By August she was unable to walk unaided. By late October she was virtually wheelchair-bound, and needed help with washing, dressing and going to the toilet. By the end of the year she was using a ventilator to help her breathe. By April 2018 she was starting to have difficulties swallowing and speaking, and had a PEG fitted – that's an endoscopic medical procedure in which a tube is passed into a patient's

stomach through the abdominal wall to provide a means of feeding when oral intake is not possible. It was, however, her breathing which came to dominate Liz's daily life as the illness progressed. She had to wear a face mask day and night, struggling for breath, constantly trying to adjust the mask with only a very limited ability to move her fingers and hands. She became terrified that she would choke to death. Her personality changed and she began to suffer from cognitive impairment, depression and panic attacks, sometimes turning against her partner, Keith, and her other carers and friends.

Liz's life became a constant round of appointments and visits – medical, social care, physio, occupational therapy, counselling, psychiatry – whilst at the same time she had to cope not only with her illness but with the disruption caused by the necessary alterations to her beloved home, including the installation of a wheelchair accessible wet-room and a lift, and – later, when she became completely immobile – hoists in her bedroom and living room.

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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)



Funds spent in East Kent in 2020

Approximately £900 was spent up to the end of February 2020 on various support grants.

A Coronavirus emergency grant of £250 has been granted. This is a new grant available at the time of publication <https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/>

This extra funding will be reviewed at the end of June.

The respiratory gas monitoring equipment has been ordered and it is hoped that an update on its installation can be made very soon. This equipment was paid for using funds raised during previous Coastal Walks to D'Feet MND.

East Kent College students support the MNDA

During December, Adrian Powell, Cath Miller and Clive Hudson, organisers of the Coastal Walk to D'Feet MND, visited East Kent College in Broadstairs to make a presentation to students about MND and the work of the MNDA Association.

The talk was attended by two year groups of students who were studying various aspects of IT.

The students enthusiastically responded and decided to organise events to support the MNDA Association in East Kent.

The first event was a local cake sale which raised £75.

The students have used this



East Kent College students volunteer to support the MNDA Association

money to raise awareness of the Coastal Walk to D'Feet MND by using Facebook advertising. The students had planned other events to support this project which have sadly had to be held in abeyance due to the Corona Virus Pandemic.

Another group of students had organised a 10K Fun Run from Minnis Bay to Reculver Towers. They had planned the project, completed all the papers for Thanet District Council, designed all the promotional material,

checked out the route and completed a registration package. Sadly, this event also had to be cancelled due to the Corona Virus Pandemic.

MNDA East Kent would like to acknowledge the effort put into these events by the students at East Kent College and wish them all well as they work remotely to complete their studies. We are grateful for their efforts and hope that this endeavour will be beneficial in their future careers.

Continued from page 2...

Dealing with the authorities involved was incredibly frustrating. Nothing seemed to happen on time, the various departments and organisations did not liaise with each other, and often the help that she and Keith needed was simply not forthcoming. Life was a struggle on all fronts. She frequently described it as 'hell'.

The help and support provided by the Motor Neurone Disease Association was one of the few shining beacons of light in this otherwise impenetrable darkness. The MNDA's representative in her area attends monthly meetings with the local authority Support Services, and was able to offer advice and help navigate a way through the seemingly endless red tape and incompetence. The MNDA advised on benefit entitlement and provided information about care and mobility options, including the sourcing and financing of a wheelchair-adapted motor vehicle. Funding for specialist posts in hospitals like Kings is provided so that dedicated MND clinics can take place. The MNDA also helps to fund specialist equipment, such as

custom-built electric wheelchairs and technical gadgets to help with speech and communication, and sometimes these are available for loan.

Indeed, when Liz and Keith decided to get married, in early December 2017, the MNDA was able to lend her an electric wheelchair in which to 'go up the aisle' as, perhaps inevitably, the customised one which had been ordered for her several months earlier had still not arrived. There are also local groups which offer social events and general support – such as the East Kent Group, represented here this afternoon – and online forums for sharing advice and tips about coping with many symptoms and side effects of MND.

MNDA assistance also proved invaluable when, in July 2018, Liz's care package was suddenly withdrawn on the inexplicable grounds that 'she did not satisfy the eligibility criteria'. This happened at a time when she and Keith had very few reserves of energy left with which to challenge it. Yvonne, the MNDA rep, was instrumental in fighting for the care package to be reinstated and helping to formulate their appeal,

and even came to their home to be there when the appeal assessors visited. The help and support provided by the MNDA in these appalling circumstances was essential and invaluable. I dread to think what could have happened without it.

The other important aspect of the MNDA's work is the funding of research into the causes and treatment of MND, and possible cures. This is a cruel, truly horrible disease for which improved therapeutic treatment and a cure are desperately needed. Over the course of a year and a half I looked on helplessly as a lively, highly intelligent, active person declined into someone who was hardly recognisable as her former self, desperately trapped in a body which would no longer function. At the end of November 2017 Liz wrote "This disease is terrible. I cannot think of anything worse. It savagely and relentlessly destroys one bodily function after another. It gradually takes away the ability to participate in activities one has previously enjoyed. It takes away one's personal dignity and ability to manage, and controls one's life. It engenders fear of the future and of being able to cope."

In the end she struggled on for just over another year until January 2019, when she died quietly and suddenly, and thankfully not from the choking fit that she had so greatly feared.

The Motor Neurone Disease Association therefore plays a vital role in helping and supporting people who are afflicted with the disease, and their carers, and in funding research into treatments. Longstanding members and supporters of this Choir may recall that Eileen Vesey, the wife of our founder, died after a long struggle with Motor Neurone Disease. That was in 1987. There has been some progress since then, but not enough. There is still very little that can be done to alleviate the symptoms and a cure is a long way off. The MNDA is a charity and its important work is financed by legacies, donations and the efforts of fundraisers. It receives no money from the government or the NHS. Please help them to help people like Liz – and Eileen – and to move closer towards finding a cure by donating generously this afternoon. Thank you so very much.

Hazel Halse

One Million Metres for MNDA

An update from our
Chairman, Clive Hudson

This project began in late 2019, to raise funds to improve services for people living with MND and reduce the journey times to access those services in East Kent. Details can be found in the Autumn/Winter edition of the newsletter and on the East Kent Group's website:

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

Update April 2020:

Since this project does not require group activity it is possible to



continue cycling.

I am in an at-risk group so I am continuing to cycle at home on a static stand.

We had planned many fund raisers around the project including a Million Metre Finale on September 26th. This

would have involved 20 cyclists each cycling 50K ie 1 million metres, on that day. We will have to wait to see how the pandemic progresses before exploring that option.

To date, I have completed 550,00 metres, despite being unable to cycle

in December and January due to a chest infection. My target is 600,000 by the end of May, then 100,000 per month until reaching my target by 26th September.

I am pleased with this and feel I can complete the million metres by September 26th.

To donate towards this fundraiser, and for further updates, please visit:
<https://www.justgiving.com/fundraising/mndamillionmetres>

If you would like to join the team and raise more funds, perhaps by cycling at home or during the one hour exercise period allowed, please visit:
<https://www.justgiving.com/team/MNDAMillionMetres>

10 ways to raise funds during indoor isolation

We know our incredible #TeamMND supporters are dedicated to fight on behalf of people affected by motor neurone disease, whatever the circumstances. If isolation isn't going to stop you fundraising, we've put together a list of 10 fundraising ideas that are easy, fun and most importantly, perfect to do indoors.

1 - Tidying up

Use this time to have a clear out. Anything you don't want can be auctioned on eBay and funds raised can go to charity. Just be sure any potential buyers know they may have to wait a few weeks for delivery if you aren't able to get to a post office.

2 - Couch to Kitchen Run

Run around the house and garden to raise funds! Get the kids involved too. Pick a distance to run, set up a fundraising page, and share it on social media. Just make sure the lego has

been tidied away before you start! You'll also need a workout app such as Strava, or a smartwatch to track your distance.

3 - Starter for 10

Host your own quiz live on Facebook. Charge an entry fee for others to join, and the funds raised go to charity. Quick fire rounds will make it harder for contestants to Google the answers!

4 - All dressed up and nohair to go

Do a sponsored leg, arm, bikini, or full-body wax! Or a sponsored headshave. You could even go the other way and grow that moustache or beard.

5 - Climb Mt. Stairdon

Summit a mountain in your own home. Could you climb the 475 flights of stairs needed to reach the top of Mount Snowdon? Pick your own mountain, and Google how many flights of stairs it would take to reach the top. Set up a fundraising page and share your challenge on Facebook. You could even

get the kids to make your very own #TeamMND flag to place at the summit!

6 - Silence Speaks

Give your kids a challenge to raise money for a good cause. Can they be silent for an hour, or even longer? Our Silence Speaks event is a great way to get a bit of quiet time whilst also raising money.
www.mndassociation.org/silencespeaks

7 - Birthday Fundraiser

Do you have a Birthday coming up? Raise some funds by asking friends and family to donate in lieu of a birthday card or gift. You can do this on Facebook, or by setting up a JustGiving page.

8 - Roll with it

Use your excess toilet roll tubes to get creating. Maybe a bird feeder, a crown or even shape stamps! Sell them to family and friends and donate the proceeds.
For some great inspiration visit:

<https://redtri.com/things-to-make-with-a-toilet-paper-roll>

9 - Ready, Steady, Cook!

Use up those odds and ends in your cupboard and have a Facebook live cook off! See who can whip up the best meal with what they have. Maybe have a time limit too! Judging could make it even more exciting!

10 - Endurance

See how long you can last! Whether its skipping in the garden, press-ups, star jumps, or planking! Set yourself a target and share your progress online. Even better if you can wear our orange and blue colours as you work out.

Please tell us about your fundraising and sign up for a free pack
www.mndassociation.org/fundraiseyourway
fundraising@mndassociation.org
01604 611860



Award success for UK MND Collections

The MND Association has been awarded the prestigious 2019 UK Biobank of the Year Award.

The national accolade recognises the MND Association's work on the UK MND Collections, previously called the UK MND DNA Bank – a resource of biological samples collected from people living with MND and controls between 2003 and 2012.

The award is in its fourth year and was presented by Amanda Gibbon, chair of the UK Clinical Research Collaboration (UKCRC) Tissue Directory and Coordination Centre Steering committee, and award sponsor, James Siddons from Greiner Bio-One, at the UK Biobanking Showcase, held at the University of Nottingham in November.

The application process is coordinated by the UKCRC Tissue Directory and Coordination Centre, with a panel of Steering Committee members shortlisting the winning biobank and honourable mentions.



Case studies for two projects that use samples from the MND Collections were submitted as part of the application. The judging panel was particularly impressed by the number of samples that had been released to researchers as well as the research impact and evidence of wider collaborations and engagement. They also noted the readily available practical information contained within the MND Collections section on our website for researchers interested in acquiring samples.

UK MND Collections began in 2003. Participants had two blood samples taken alongside clinical information. One of the blood samples had DNA extracted and stored for genetic testing. The second blood sample had the white blood cells

removed and stored in liquid nitrogen (a form of suspended animation) to act as a back-up sample to replenish the stocks of DNA if they were ever to run out (see poster 1 about the use of DNA samples from the MND Collections).

As the study progressed, researchers found that they were able to wake the blood cells up from their suspended animation and grow them in a dish to see the effect the DNA variations were having within the living cells.

Science has moved another stage further, and it is now possible to wake up these blood cells and persuade them to become induced Pluripotent Stem Cells (cells that can grow to make any other cell type within the body). These can then be converted into motor neurons in a dish. This enables researchers to see how the genetic variation in the DNA is causing the motor neuron to die as well as enabling the testing of potential drug treatments directly on the motor neuron (see poster 2 on the use of the cell line samples).

Dr Brian Dickie, the MND Association's

Research Director said: *"We are proud to receive the honour of being named the 2019 UK Biobank of the Year. The MND Collections continues to contribute towards the discovery of genes associated with MND, as can be seen from the announcement of a new gene on 25 November 2019. This award recognises the invaluable resource of biological samples that the MND Collections are able to provide to researchers around the world to help find the causes of MND and potentially a cure."*

The MND Association would like to thank all of the participants for donating the legacy of their time, blood samples and data, to all of the staff who worked across the many clinical sites to enable the collection of the samples and data and to all of the fundraisers who have raised the money to enable the MND Association to not only create this invaluable resource, but to help us continue to provide access to the samples and data to researchers around the world.

Introducing Gary

This is Gary, the face of our new campaign to encourage health and social care professionals to download our Red Flag Tool and consider whether their patients' symptoms could point towards a diagnosis of motor neurone disease (MND).

Gary is the brainchild of Purple Agency, a marketing communications agency which specialises in the health and wellness sector. He comes with the message



'You're more likely to meet someone with MND than you are to meet a Gary.'

Most people know someone called Gary yet you are more likely to meet someone with MND than to meet a Gary. The concept reinforces the message that MND is more common than many people think and so is a disease which healthcare professionals should be looking out for.

Gary offers some helpful hints for healthcare professionals who might

see a patient with undiagnosed MND. Visitors to the dedicated campaign page can learn more about the symptoms of MND, both in medical terms and in the words of people with MND.

The advert launched in mid-January and is being shown to physiotherapists, ear nose and throat specialists, speech and language therapists, occupational therapists and GPs working within NHS Trusts in targeted geographical areas, via the NHS intranet. The Association,

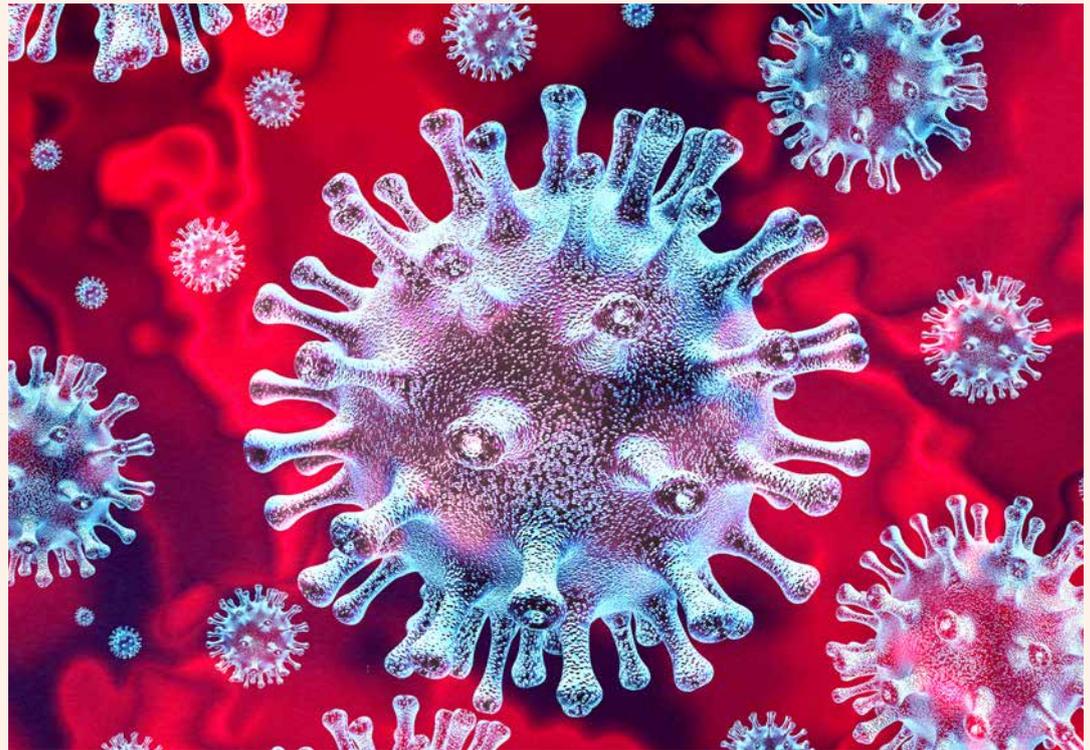
along with Purple, is working with a company called Fendix, which is managing the advertising campaign to ensure it is hitting the right audience.

Results from the Association's Improving MND Care Surveys in the past have shown that people with MND often see a number of health and social care professionals for a variety of symptoms before being referred to a neurologist and receiving a diagnosis. It is hoped the awareness Gary raises will speed up that referral process so people with MND receive a diagnosis and the correct support more quickly.

Early results from the campaign are excellent – on day one the advert received five times more clicks than the average for the channel. Results will continue to be monitored to help shape the continuing use of the advert while offline advertising space in specialist publications is also being considered.

COVID-19 and MND – a message from the MND Association

We are aware that the situation surrounding the spread of coronavirus may be causing people affected by motor neurone disease (MND) concern.



As always we are here to offer advice, support and to signpost to the most appropriate organisation. In this case our advice is directly mirroring that being shared and updated regularly by the NHS and the Government.

You will find that information here:

- NHS information
- Government information
- Public Health Agency (Northern Ireland)
- Public Health Wales

And for anyone travelling the Foreign and Commonwealth Office

Living with or caring for someone with MND

If you are living with MND or you are caring for someone with MND please discuss any specific concerns you have with your health and social care team. They will be able to give you advice and

information which takes into account your specific circumstances.

Meanwhile, the MND Association will continue to monitor updates and consider how they may affect people with MND, volunteers and staff.

What are we doing?

Having taken advice from neurologists and specialists working in our care network, it is clear that people with MND fall into the group for whom coronavirus could be particularly dangerous. Our priority as an Association is to do what we can to reduce the chances of spreading the virus.

With that in mind all MND Association branch and group meetings, get togethers and all events between now and the end of April have been postponed, as have Association organised events. Staff and volunteers are using technology – phone calls, email, Facetime and Skype for example - to support people with MND and their carers rather than meeting face to face.

“it is clear that people with MND fall into the group for whom coronavirus could be particularly dangerous”

We are extremely disappointed to have had to take these steps – we know how important the support network is for people affected by MND. Our teams will be working hard to ensure that everyone who needs and wants support will continue to receive it.

Other aspects of the Association's work will continue as usual with the aim of keeping any impact on people affected by MND to a minimum.

Answering your questions about coronavirus (COVID-19)

The current outbreak of COVID-19 (coronavirus) is an illness caused by a new strain of the virus. Other types of coronavirus can cause common colds, but COVID-19 causes fever and coughing.

As it can affect your lungs and airways, complications can develop for some people with underlying conditions.

You are considered at risk with COVID-19, if you have a chronic neurological disease, such as motor neurone disease (MND). You may have concerns if you are living with MND or Kennedy's disease, or you help to support someone with either condition.

Having taken advice from clinical experts, with experience in neurological conditions, we have provided answers to common questions on our website:

<https://www.mndassociation.org/mnd-and-coronavirus/>

However, as COVID-19 is a new virus, facts and guidance are still emerging and changing. We will continue to update this content as we find out more.



Despite people living with MND not being identified as extremely vulnerable persons we have received information confirming that people with MND living in England can self-register as extremely vulnerable.

Shielding and protecting vulnerable persons from Covid-19



Visit the following website:
www.gov.uk/coronavirus-extremely-vulnerable and follow the steps below:

1. After confirming you live in England, and indicating if you've received a letter from the NHS or not, enter your details as requested.
2. Tick "Yes I have one of the medical conditions on the list". We've had it confirmed that, in this instance, #MND will be classed as a 'severe respiratory condition'.

You can also register by calling 0800 028 8327.

If you live in Northern Ireland or Wales please follow the advice from the **Northern Ireland Department of Health** and **Gov.Wales**

The MND Association is extremely

concerned to see that people with MND have not been included in the Government's list of extremely vulnerable persons in their guidance on shielding and protecting vulnerable persons from Covid-19.

This despite MND being included in the previously published guidance on social distancing.

We believe that this has very concerning implications for people with motor neurone disease and we are calling on the Government to define people with MND as being extremely vulnerable as a matter of urgency.

If you have MND we recommend that you still register as extremely vulnerable at: www.gov.uk/coronavirus-extremely-vulnerable as this may help you get the best possible support.

For our latest advice on covid-19

for those affected by MND, visit mndassociation.org/coronavirus.

The MND Association has written an urgent letter to Secretary of State for Health and Social Care Matt Hancock urging him to include people with MND on the Government's list of extremely vulnerable persons.

We are urging our supporters to email their MP, calling on them to put pressure on the Government to add MND to the extremely vulnerable persons list.

Supporters can also tweet Matt Hancock directly.

Join the campaign at:
<https://www.mndassociation.org/get-involved/campaigning/take-action/get-mnd-on-the-list/>

#GetMNDonTheList

LINK TO BBC ARTICLE:

"Doddie Weir calls for people with MND to be added to the extremely vulnerable list" - 9 April 2020

<https://www.bbc.co.uk/news/uk/scotland-52218342>

A bit of light relief from lock down

QUIZ

Questions for grown-ups...

- Q1 'Live Aid' pop concerts are staged on July 13th 1985 in London and which other US city?
- Q2 Which English County has the shortest coastline?
- Q3 John F Kennedy became the 35th President of the United States in 1961 but what does the 'F' stand for in his name?
- Q4 Which Peter Benchley novel was made into a film in 1975 by Steven Spielberg?
- Q5 Who wrote Jurassic Park, which the Spielberg film was based on?
- Q6 What was the name of Apollo 11's Lunar Module that landed Neil Armstrong and Buzz Aldrin on the surface of the moon in 1969?
- Q7 What was the first music video to feature on MTV?
- Q8 What was the title of The Beatles' first film released in 1964?
- Q9 Who was the first monarch to live in Buckingham Palace?
- Q10 What sport would you associate with Newham and Essex Beagles?

RECIPE

Corned Beef Hash a la Botany Bay

This is very basic and can be modified by adding spices and herbs. Sweet chilli sauce is a favourite. The peas and carrots could be from a tin or frozen pack. Sweetcorn or beans could also be used.

A vegetarian version could be made by substituting chickpeas or mixed beans for the corned beef.

Another alternative would be to mash the potatoes and use this as the covering.

Method

Par boil potatoes and allow to cool.

Cook carrots.

Fry onions until soft

Remove corned beef from tin and cut into 2cm cubes, put in the bottom of a large ovenproof dish.

Cover with peas, cooked carrots and fried onions.

Spread tinned tomatoes on top.

Chop potatoes and lay on top

Sprinkle grated cheese on top.

Cook in oven at 160C for one hour.

INGREDIENTS

1 tin of Corned beef

One large onion

4 oz peas

4 oz carrots chopped.

Tin of tomatoes

2 oz cheese

4 medium potatoes



PUZZLE

Springtime Wordsearch

S	G	G	E	R	E	T	S	A	E
L	X	B	U	N	N	Y	K	U	Z
A	W	L	I	D	O	F	F	A	D
M	F	O	B	G	T	P	J	V	S
B	Y	N	B	T	G	M	H	F	R
S	K	S	U	N	S	H	I	N	E
I	V	L	I	F	I	X	Q	O	W
M	I	R	F	T	J	A	Y	R	O
P	P	D	S	W	J	I	R	D	L
S	J	S	K	C	I	H	C	C	F

- | | |
|-------------------|------------------|
| BUNNY _____ | LAMBS _____ |
| CHICKS _____ | RAINBOW _____ |
| DAFFODIL _____ | SPRINGTIME _____ |
| EASTER EGGS _____ | SUNSHINE _____ |
| FLOWERS _____ | TULIP _____ |
| FUN _____ | |

GREEN FINGERS

Get busy in the garden...

Here is an idea if you have bought too many potatoes and find you have a few sprouting.

Put 10 cm of soil in a big container. This could be a plastic sack or any large container at least 45cm wide and 45 cm deep. I use old compost sacks, rolled down and with holes in the bottom.

Place 5 or 6 sprouting potatoes on the soil, then cover with soil. Then water well.

As the shoots come out just continue to add soil up to the leaves. Continue to do this until the container is almost full. If using compost sacks, just roll up the sides as you add more compost.

Water daily so that the

soil at the top is kept moist.

After 10 – 12 weeks you should have potatoes to harvest. You can check this by removing some soil around the stalks and you should find some small potatoes.

These will be new potatoes and if you leave them you will get larger potatoes.

The final size will be determined by the size of the original potatoes planted.

Why not also grow some spring onions from seed? They can be planted in a small drill of soil now, and need no other help apart from a bit of watering. They should be ready at the same time as the potatoes.

Then, make your own potato salad-yum!



JOKES FOR KIDS

Q: Why did Tigger go to the bathroom?
A: To find his friend Pooh.

Q: How did the hammerhead shark do on his test?
A: He nailed it.

Q: The red house was red. The blue house was blue. What colour was the green house?
A: It wasn't, it's transparent.

Q: How much money does a nose have?
A: One cent.

Q: Why was 8 afraid of 7?
A: Because 7 8 9.

Hello everyone!

I'm Carly the cat and I'm one of the MND Buddies!

I'm so excited to be appearing in *Thumb Print*! Clare, who puts together this magazine for your grown-up, asked me if I would like to write for you and I couldn't wait to get started!



I love painting, making things and using lots of crazy colours and I've been working super hard to put together a page of the magazine which I hope you will enjoy reading too. I haven't done it all by myself though - my buddy Penni-May has helped me and you can read all about her on the opposite page - isn't she just purr-fect?!

Don't forget - the MND Buddies are always here whenever you need us - you can find us at www.mndbuddies.org, but don't forget to ask your grown-up before going online!

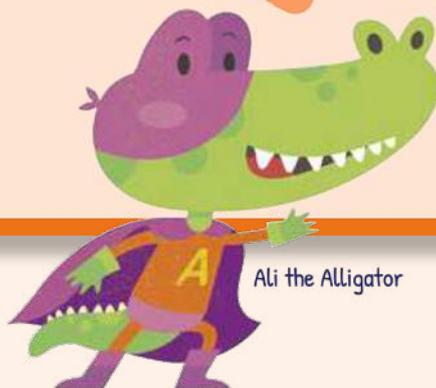
"I hope you enjoy everything that Penni-May has written for you and I can't wait to see you again soon!"

Lots of love,

Carly x



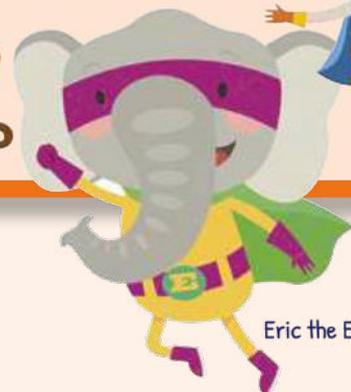
Meet my other buddies



Ali the Alligator



Max the Monkey



Eric the Elephant



Rini the Rabbit

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)



Come and meet our new MND Buddies!

Hello Everyone!

"My name is Penni-May and I am 12-years-old.

"I enjoy drawing, well, all sorts of art, I enjoy sports – mainly running, rounders, cricket and gymnastics.

"I love school, I have lots of friends and I enjoy so many of my lessons but there's some I could happily live without!

"I have had this amazing opportunity to write for Thumb Print because 17 years ago, my dad started to get symptoms of MND that sadly took over his body. He has had it all my life.

"I always wished there was someone there for me to talk to because I worried if I talked to Mum and Dad it might upset them, but I know now that they like me to talk to them about it. For



all the children out there keeping emotions to yourselves, please don't because you don't need to be afraid to talk to someone. Nobody will judge you.

"I don't really like to talk about the condition as it upsets me a little. We just deal with every day as it comes and always hope for the best.

Having a parent who isn't well is hard, as I don't always get to do things that other families would do or experience. But I have had some 'once in a lifetime' opportunities that not many other people would not have had. In 2014, I went to The O2 in London and walked out on the court at the ATP Tennis Tour while holding onto Spanish player, David Ferrer's hand and the biggest tennis ball I have ever seen! We then got to watch the match between him and Rafa Nadal – the atmosphere was amazing! I have also been round Silverstone in a Ferrari – it was so fast I think I nearly threw up!

"The MND Association organises events and recently arranged The Big Picnic which all the family and our friends could go to and have a fun day out without having to think about the condition or our worries.

I also go to a Young Carers Club which allows some time out with children in the same situation as me. As a family we enjoy going away in our campervan,



Eric the Elephant, drawn by Penni-May. Visit the 'See it' section on MND Buddies at www.mndbuddies.org to submit a picture of your own.

More about me!

Name: Penni-May

Age: 12

Favourite subject at school?: Art and food tech

Favourite food?: Definitely pizza!

Favourite movie?: Jumanji

Favourite book?: Harry Potter or Diary of a Wimpy Kid

Favourite pop star?: Rick Astley and Olly Murs

What would you like to be when you grow up?: I would like to be a baker and make cakes, chocolate sculptures and patisserie

Have you met my friends Isaac, Erin and Elih?



They are the stars of a new video which my friends in MND Education, Emily and Kaye, have put together to help your grown-up learn more about the information which is available to help you. You can watch their film at bit.ly/MNDBuddiesVlog – don't forget to get your grown-up's permission first!

Would you like to be our next MND Buddy?

If you would like to write for the next edition of Thumb Print please get in touch with editor, Clare Brennan at clare.brennan@mndassociation.org or on 01604 611877. You can also get in touch via Twitter: @mndaeditor.



Technology breakthrough offers hope for people silenced by disability

New Artificial Intelligence (AI) technology that will allow people with motor neurone disease (MND) to have a conversation in their own voice, even after losing the ability to speak, has been created by a collaborative group of some of the world's leading experts.

The Motor Neurone Disease Association has partnered with Rolls-Royce and its data innovation catalyst, R2 Data Labs, and some of the world's leading technology companies, including Accenture, Dell Technologies, Intel and Microsoft, to pool technology and expertise to improve the lives of those living with extreme disabilities.

For the first time, those living with MND will be able to have a conversation through a computer using their own voice, words, colloquialisms and accent, without pausing to type answers or being restricted to a prescribed set of words.



The new technology, called Quips, uses voice-banking and AI to learn a person's unique language style and use it in conversation.

Nick Goldup, Director of Care Improvement for the MND Association, said: "MND affects the nerves in the brain and spinal cord which tell muscles what to do. As the disease progresses people lose the ability to move, eat, speak and eventually to breathe. The technology available to help people communicate has changed little in the recent past – most people will be familiar with Professor Stephen Hawking's computerised voice which

he programmed using his eyes. This technology will allow people living with MND to communicate closer to 'real time' than they can with existing technology."

Quips is in its early stages, but Rolls-Royce is aiming for it to be implemented into some of the leading augmented and alternative communication packages that already exist, such as those used by Professor Hawking.

Quips listens to the conversation, suggesting words and phrases that the user is likely to want to say, based on its understanding of their previous

conversations. The user can quickly select sentences which are read out in their own voice instantly, with their own accent and local colloquialisms, without gaps for typing. It even includes slang and can adapt to different situations and people, such as work, home, or even the pub.

Nick said: "Having your voice stripped away is one of the most brutal aspects of MND. Technology that allows people to retain those things that make them unique – their voice, speech patterns, intonations and word choices – is a huge leap forward in enabling someone to retain their dignity and their sense of self. This is really exciting technology – and of course its potential use expands much further than just people with MND."

Stuart Moss, an IT Innovation strategist at Rolls-Royce, lost his father to MND on Christmas Day 2014. He started the Next Generation Think Tank earlier this year, alongside the MND Association. Stuart said: "This technology is the first step in what I hope will be many innovations to come from the Next Generation Think Tank."

Registration for priority services from the utility services:

It is important that people with MND register for Priority Services to ensure that, in the event of a breakdown of service, they will be treated as priority for resumption of service, e.g. generator in the event of an electricity power cut.

Please contact as follows:

UK POWER NETWORKS PRIORITY SERVICES.

Register at:
<https://www.ukpowernetworks.co.uk/power-cut/priority-services-register>

Or phone: 0800 029 4285

BRITISH GAS PRIORITY

Register at: www.britishgas.co.uk

Or phone: 0800 294 86004

For other gas providers, phone your gas supplier's phone number

SOUTH EAST WATER PRIORITY

Register at: <https://www.southeastwater.co.uk/get-help-for-priority-customers>

Or phone: 0333 000 2468

SOUTHERN WATER PRIORITY

Register: www.southernwater.co.uk

Or phone: 0800 027 0800

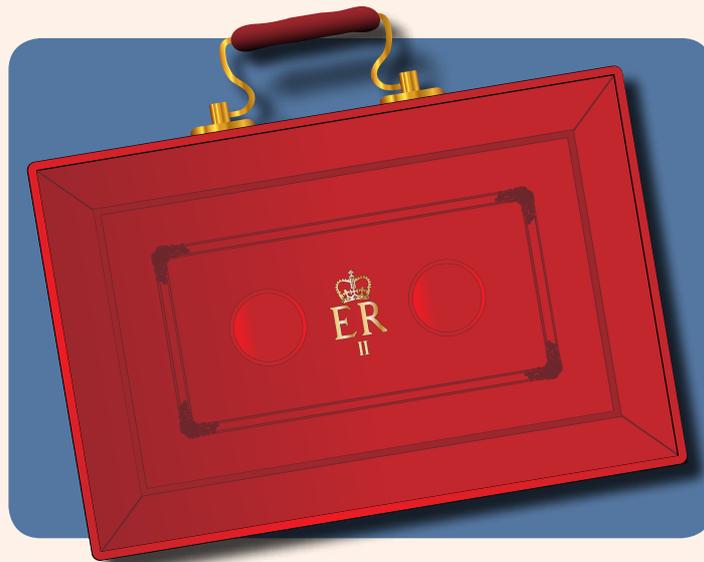


Budget 2020 roundup

On March 11, Rishi Sunak MP delivered his first Budget as Chancellor of the Exchequer.

This year's Budget focused on two major themes: short-term stimulus measures to reduce the economic impact of the coronavirus, and longer-term investment in infrastructure, including transport and housing. The Budget contained over £30 billion of new spending commitments in total, making it the biggest-spending Budget for many years.

However, there was disappointment for those hoping that the Budget would include proposals for long-term social care reform, as called for in the MND Association's 2019 election manifesto. It was confirmed that last year's announcement of an extra £1 billion of funding for social care will continue for every year of the current Parliament, but this level of funding can do no more than prop up a struggling system. The need for a new, sustainable funding system for social care remains as urgent as ever, but this difficult but essential task appears to have been delayed once again. There was also no mention of extra support for the millions of unpaid



carers who provide essential care to people living with MND and other conditions.

More positively, the Chancellor announced a £6 billion funding boost for the NHS over the current parliament. The Chancellor also pledged that the NHS and social care services would receive all funding required to respond to the coronavirus outbreak and announced a £5 billion fund to help public services respond to the virus. The Budget also included significant

new investment into research and development, including a 15% funding increase next year.

The Budget included an announcement of major investment into housing development, but no clear commitments on accessibility standards for disabled occupants. Given that the Government has promised to consult on new accessibility standards later this year, this was a missed opportunity to put accessible housing at the heart of the new investment proposals. We

will be responding to the consultation, which is scheduled to begin in the next few weeks.

On welfare issues, the Budget included changes to Employment and Support Allowance (ESA) and Universal Credit due to the coronavirus. Contributory ESA will now be payable from the first day of time off work, rather than day eight. Universal Credit claimants will no longer be required to physically attend appointments with a work coach. In addition, Universal Credit advance loans, available during the five-week wait for the first payment, will now be paid back at a lower rate over two years rather than one. We continue to call on the Government to scrap the five-week wait altogether. If you or anyone you know requires assistance with Universal Credit then the Association has a dedicated benefits advice service. In light of the coronavirus the Government has also updated its advice for Universal Credit claimants.

Despite limited coverage within the budget, we will continue to campaign on the issues that matter to people living with MND, including welfare, health, social care, carers, accessible housing and research.

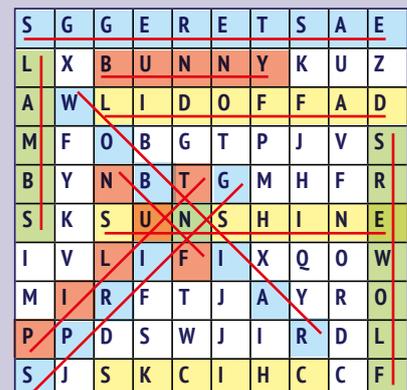
ANSWERS FROM PAGES 7 & 8

Quiz questions for grown-ups... (Page 8) - the answers

- | | |
|---------------------|-------------------------------------------|
| Q1 Philadelphia | Q7 Video Killed The Radio Star by Buggles |
| Q2 Durham | Q8 Hard Day's Night |
| Q3 Fitzgerald | Q9 Queen Victoria |
| Q4 Jaws | Q10 Athletics |
| Q5 Michael Crichton | |
| Q6 Eagle | |

The answers for Springtime Wordsearch (page 9)

- | | |
|-------------|------------|
| BUNNY | LAMBS |
| CHICKS | RAINBOW |
| DAFFODIL | SPRINGTIME |
| EASTER EGGS | SUNSHINE |
| FLOWERS | TULIP |
| FUN | |





Online Information and Support

Anyone recently diagnosed with MND in East Kent and needing advice and support can contact our local Association Visitor, Judy Keay (Judy's contact details are listed in this newsletter). There is also 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/mnd-and-coronavirus/>

Additional financial support grants are available at this time, in the form of a new Emergency Grant of up to £250 to support people with things like bills, extra food, hygiene costs and entertainment costs. Details can be found at: <https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/>

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, and personal stories:

<https://www.youtube.com/watch?v=qUJZCRGGBdBs>

<https://www.youtube.com/watch?v=KmmWACyU0tM>

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

3. Also on YouTube is the MND Coronavirus Ask the Experts #1 <https://youtu.be/OM2BqdC4N34>

4. 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/>

MNDA EAST KENT DIARY

DATE	EVENT
Wed 8th Jul	MNDA East Kent Committee Meeting
Sat 25th Jul	Support Meeting Thanington
Wed 9th Sep	MNDA East Kent Committee Meeting
Sat 19th Sep	Cream Tea – Strode Park
Sat 26th Sep	Million Metres Bike Ride
Sat 3rd Oct	Coastal Walk to D'Feet MND
Sat 24th Oct	Support Meeting Capel Le Ferne
Wed 11th Nov	MNDA East Kent Committee Meeting
Sat 12th Dec	Christmas Lunch, Yarrow Hotel Broadstairs

Note: All events to be confirmed in light of Coronavirus – please check the East Kent Group website for updates: https://mnda-eastkent.org.uk/wordpress/?page_id=591

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	Lynn Hudson		lynn.hudson@mnda-eastkent.org.uk
	Janet Raeburn		
	Kim Metcalfe		
	Alison Cooper		
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Regional Fundraiser East	Roger Widdicombe	01908 508398	
		07918 745244	roger.widdicombe@mndassociation.org
Central Volunteering team		01604 611681	volunteering@mndassociation.org
Thumbprint online			www.mndassociation.org/membership
Online Forum			forum.mndassociation.org
MND Connect - National Help line		0808 802 6262	mndconnect@mndassociation.org
National office:		01604 250505	enquiries@mndassociation.org
MND Association website			www.mndassociation.org

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