

Newsletter

Getting MND on the list of those extremely vulnerable to Covid-19

Despite the support of over 5,200 people, over 120 MPs and nearly 40 clinicians and high-profile celebrities, the government has failed to heed to the Association's concerns and recommendation to add MND to its list of conditions clinically classified as vulnerable to Covid-19.

Only those who have developed respiratory or bulbar symptoms are added to the list currently.

Deputy Chief Medical Officer Dr Jenny Harries said that *'patients with MND should continue to be recommended by GPs/specialists for shielding on a case by case basis, to reflect the varying degrees of severity of Motor Neurone Disease.'*

The overwhelming support in such a short space of time has been truly remarkable and something the Association wants to thank every individual for. And despite this setback in England, the campaign has led to the Northern Ireland Executive adding MND to their extremely vulnerable list.

You can hear Sally Light, Chief Executive's response to the government here.



However, there is still much more to be done to ensure all people with MND are registered as extremely vulnerable and can access the support they need at this time.

Firstly, everyone known to the Association who is living with MND is being contacted to ensure they have access to the support they need right now. 3,000 calls in, and still going nationally. Additionally, the Association is:

- Working with its Care Centres and the Association of British Neurologists to ensure clinicians register their patients with MND as extremely vulnerable
- Encourage people with MND not yet registered in England to self-

register as extremely vulnerable via the online registration process (see below for details). Although his process is not available to people with MND in Wales, they can contact their GP to be registered

- Work with the Department of Health and Social Care (DHSC) and the Chief Medical Officer's office to engage with the Royal College of General Practitioners to encourage GPs to register their patients with MND

- Work with the Department for Environment, Food and Rural Affairs and the DHSC regarding the support available to the wider vulnerable group to ensure that anyone who is not registered as extremely vulnerable can still access the help they need, such as super-market delivery slots

- Work directly with supermarkets to secure delivery slots for people

- Ensure people with MND and their carers are made aware of the NHS volunteer responders programme and are registered.

#GetMNDonTheList

How to register as extremely vulnerable to Covid-19

1. Visit www.gov.uk/coronavirus-extremely-vulnerable and follow the steps shown below.
2. After confirming you live in England, and indicating if you've received a letter from the NHS or not, enter your details as requested.
3. When answering the third question, tick "Yes I have one of the medical conditions on the list" OR "my GP or hospital clinician has told me to 'shield'".
4. If you do not have someone to help access food, please remember to tick 'No' to the question 'Do you have a way of getting essential supplies delivered at the moment?'

You can also register by calling 0800 028 8327. Please note that online registrations will be checked through your registered GP.

For further information, see the link below:

www.mndassociation.org/about-mnd/coronavirus-and-mnd/how-to-self-register-as-extremely-vulnerable/

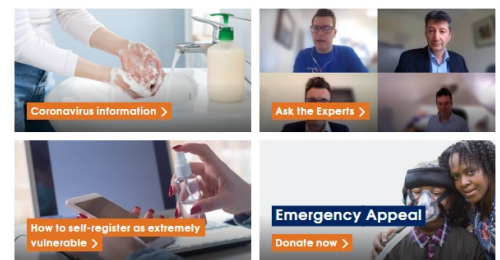
What you need to know about Coronavirus

The national Association's site has everything you need to know about Coronavirus, from what support is available, how to access it and what fundraising is needed at this time. The site is continually being updated so do keep checking back.

www.mndassociation.org/about-mnd/coronavirus-and-mnd/

Coronavirus and MND

Living with motor neurone disease (MND) or Kennedy's disease is challenging, but you may also be worried about the impact of coronavirus (COVID-19). We are here for you, with information and support. We are continuously updating this content, with expert advice.



Fundraising @home – your support is needed more now than ever!

The Covid-19 pandemic has had an unbelievable impact on every UK charity's ability to fundraise, and therefore their ability to support the most vulnerable when they need it most.

You may have heard of the 2.6 challenge? #TwoPointSixChallenge This is just one initiative to try and save charities income. Any activity you like from running 2.6 miles, to doing an online workout with 26 of your friends. Every small fundraising activity really is a matter of survival to the work of all charities right now.

So how can you fundraise for our branch? Here are a few ideas!

- Virtual pub quiz with friends and family
- Birthday fundraising

- Climb Mount Stairdom - climbing the equivalent of Mount Everest
- Run around your house and garden to rack up the distance
- Sponsored silence #silencespeaks
- Auction off all those things you don't need and donate the money raised.

Thank you for your ongoing support.



Sustaining the MND Association in extraordinary times

Not only do those with MND need our support more than ever, but so does the MND Association as a whole to in order continue to provide that very important support.

Head Office, have estimated that between £3.5 million and £5.5 million will not be generated this year, having a major direct impact on everything from research, campaigning through to actual support of those with MND and their carers. That is a big dent and impact! That is why we are asking everyone to do what they can to help at this time, however small.

And this goes for us a branch to. This is why we have responded to Head Offices internal crisis appeal to continue to enable essential services for those affected by MND and to sustain the financial viability of the Association as a whole.

We have donated £5,000 to Head Office for this very purpose.

We are all in this together.

By pooling our efforts and resources to help those who rely upon us we are confident, together, we can continue to provide the vital help and support people with MND need now and into the future - both locally and nationally.

Valiant Charitable Trust donation of £10,000 to support local people

Courtesy of Liam and Anna Dwyer, who many of you will know, our branch has received a generous gift of £10,000 from the Valiant Charitable Trust.

The Trust gift money to causes of their choosing and we have been lucky enough to receive one.

The gift came about through a personal and long-standing relationship with

Liam and Anna. The Chair of the Trust, Lady Valerie Diana Dixon says:

"Anna and Liam are such an inspiration to us and when we meet up they are always positive."

The money is specifically to be used to support those locally living with MND, so will be held in restricted funds for this very worthwhile purpose.

You can still donate via the Giving Lottery and Recycling for Good Causes

There are still two great ways you can donate and support the Branch just by having a clear out or being in with the chance to win some money.

- 1. Giving Lottery**
Want to have a chance to £25k? Then go to www.givinglottery.org.uk/support/mnda-west-sussex-north-branch and buy your tickets. 60% of the ticket sales will come to the Branch, and every ticket has a 1 in 50 chance of winning a prize every week. One person from our branch won £25, and kindly donated back to us (thank you!)



- 2. Recycling for Good Causes**
Recycling for Good Causes use a network of experts to resell your donated items with the proceeds going to our Branch. You can recycle anything from old cameras, jewellery, currency and stamps, game consoles, laptops, mobile phones and tablets. You can store up your items and give it to us at the next social, and we'll arrange the recycling on your behalf. For more information about how it works, visit: www.recyclingforgoodcauses.org.



Support MND carers by signing our open letter

#supportMNDcarers

Head Office are campaigning for improved support for carers during this unprecedented time. With more pressure on carers, coupled with less support or respite available than normal, improvements are urgently needed.

The Association specifically want to see improved access to testing and PPE, an increase in Carers Allowance, and clear guidance that helps protect unpaid carers and those they care for as lockdown restrictions begin to be lifted.

Please join the call to #supportMNDcarers through the COVID-19 crisis by signing the open letter <https://www.mndassociation.org/support-mnd-carers-by-signing-our-open-letter/> and share your experiences.

The letter will be delivered virtually during Carers Week (8-14 June) to the Minister of State for Care Helen Whately MP, Deputy Minister for Health and Social Services in Wales Julie Morgan MS, and Northern Ireland's Minister of Health Robin Swann MLA.

Treasurer's List of Monies Received & Spent

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Thank you to everyone for their contributions. The below are the cleared funds received for the first quarter 2020.

(All information was the best available at time of going to press).

MONEY RECEIVED

Money from activities:

The Ark - Bring & Buy Sale	£69
Fundraising - Giving Lottery	£51
Jenny Rimmer - Sussex Hat Hire	£1,252
Sale of Christmas Cards	
(Total for Xmas cards was £335)	£165
St Edwards Wives Group, Burgess Hill	
Charity Raffle	£140

Donations and Gifts:

Jean Patterson	£10
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Donations and Gifts in memoriam:

Brighton Road Baptist Church Horsham	
Womens Evening Fellowship	
(in mem. Audrey Smallwood)	£85
Mrs Jean Fox	
(in mem. Maurice Bracey)	£160
Alan Lester	
(in mem. Brian Emmett)	£250

Other income:

Bank Interest	£115
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MONEY SPENT

Financial Support for members & carers:

Private Ambulance Transfer Services	
(one return trip)	£320
Quality of Life Grant (two grants)	£1,000
Carers Spa Day	£315
Annual Transfer to National Office	
- to Care	£5,462
- to Research	£8,193

Expenses:

Visitors - Travel Allowance	£81
Purchase of MNDA Banner	£25

PUBLISHED BY: West Sussex North Branch of the MND Association.

The views expressed in this newsletter are not necessarily those of the MND Association. If products and services are mentioned, these should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.

We would like to keep in contact with you about the important work we do. If you do not wish to receive further information please contact a member of the Committee.

MND Connect

The number is
0808 802 6262