

Managing MND during self-isolation for coronavirus

1. Why are we offering this information?

We are trying to contact everybody with MND and their families during self-isolation for coronavirus. This information may help. We want to support you and find out:

- how you are coping during the coronavirus outbreak
- if you know the current Government advice and what this means for you
- whether your ongoing care has been arranged
- if you have the contact details you need, in case you need more support
- how we at the MND Association can best help you and your family in the circumstances.

2. Are you aware of the current Government advice?

You must keep up to date and check national advice regularly. The following web links will help you find government information about coronavirus.

If English is your second or other language, you may need help to understand the content. Contact your GP or your local adult social care services for support. They have a duty to assist with access to health and social care information. This may mean translation or help from an interpreter.

General guidance

England and UK:

www.gov.uk/coronavirus

www.nhs.uk/conditions/coronavirus-covid-19

Northern Ireland:

www.publichealth.hscni.net/news/covid-19-coronavirus

www.nidirect.gov.uk/campaigns/coronavirus-covid-19

Wales:

<https://phw.nhs.wales/topics/latest-information-on-novel-coronavirus-covid-19>

Information about shielding if you are vulnerable

Government guidance is that people with MND should be shielding themselves at home. You can find details here:

www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19

In summary, you are strongly advised to:

- stay at home until government advice changes – this means not leaving your home, even for family gatherings (contact loved ones by phone or online)
- get deliveries of food, supplies and medication to your door, so you can avoid any unnecessary face-to-face contact outside of your home
- only accept visits for essential support, such as healthcare, personal care or social care
- ask carers and care workers who enter your home to wash their hands with soap and water for at least 20 seconds on arrival, and regularly while they are there
- ensure carers and care workers know they must stay away if they have any symptoms of coronavirus (COVID-19) – such as a high temperature, a new continuous cough or if they start to feel breathless
- where possible, remain isolated in a different room from anyone living with you if they have any symptoms of coronavirus (COVID-19)
- use telephone or online messages if you need to contact your GP or other essential services.

How to register as extremely vulnerable

MND is included as extremely vulnerable, as the symptoms of motor neurone disease include problems with breathing. You can register as an extremely vulnerable to help you get access to local support. This could mean priority deliveries for food, medication and essential supplies.

Register at:

www.gov.uk/coronavirus-extremely-vulnerable

3. Do you know who to contact if you are unwell?

Find the NHS coronavirus helpline at: <https://111.nhs.uk/covid-19> and telephone the helpline on 111 if you have coronavirus symptoms that are worsening.

For more general healthcare support, there may be waiting times for a response. This is because of increasing pressure on NHS services at this time.

Many healthcare professionals have moved to support hospital wards due to the coronavirus outbreak. You may need to leave a message at their clinic for someone else to call you. You can also contact your GP for guidance.

Keep any contacts you may need close at hand. Make a list of the following details, where these apply to you:

- your GP
- your MND care centre or network, or your local neurological clinic
- any health or social care professionals you are in regular contact with (they may still be working in their normal practice or checking messages at certain times).

4. Do you know who to contact if you need urgent support with social care or equipment?

Those working in social care are also under increasing pressure to provide support in the community. You may have to wait for a response, but do leave messages by telephone or send emails if you need help.

Keep the following contacts close at hand, where these apply to you:

- family members or friends who could help in an emergency
- your local adult social care services (through your local authority in England and Wales, or your local health and social care trust in Northern Ireland)
- providers of essential equipment, in case you need support or guidance with this (this might include provider contacts for assistive ventilation, cough assist or suction machines, mobility equipment or other items such as riser recliner chairs).

5. Do you know who to contact if you need support with deliveries of food, supplies and medication?

Consider what support might be available in your local community for deliveries, but take care to use trusted sources. Explore options such as:

- online ordering for local supermarket deliveries – or click and collect schemes, where a family member or friend can pick up your order for you and deliver to your door (see section 2 for details about how to register as extremely vulnerable – this may help you get a priority slot for this)
- asking family members, friends or trusted neighbours to shop for you and deliver to your door
- finding out if your local pharmacy deliver prescriptions to vulnerable people
- checking what help is being offered by your local adult social care services (through your local authority in England and Wales, or your local health and social care trust in Northern Ireland)

- asking if this type of help is being offered through a trusted link with a faith or community group
- checking our growing webpage of possible local support at:
www.mndassociation.org/localcovidsupport

6. Keeping in touch

We can keep in touch if you would like us to do this, by email or phone. This may be especially helpful during the coronavirus self-isolation.

Let us know if you would like to be contacted by calling our MND Connect helpline, which is open Monday to Friday between 9am - 5pm and 7pm - 10:30pm.

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

Webpage: www.mndassociation.org/mndconnect

Useful links on our website:

Our coronavirus and MND webpage is constantly being updated:
www.mndassociation.org/coronavirus

Details about our MND Support Grants:
www.mndassociation.org/financialsupport

Details about our local support:
www.mndassociation.org/support-and-information/local-support

Support for children and young people:
www.mndassociation.org/cyp

This includes help for parents and guardians to communicate about MND and coronavirus, with resources to help keep children and young people occupied when staying at home. We also have a dedicated contact (through our MND Connect helpline – see above), who can help with a range of children and family questions.

7. You are not alone.

We are here if you need guidance or just someone to listen.

MND Connect helpline

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

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