

Ongoing Support Contact Guide

For: All volunteers providing ongoing contact to people/families affected by MND.

How to use: There are 5 conversation areas which may be appropriate to refer to when you make contact. Each offers simple helpful questions and discussion points to use as required and guided by your conversation. You will also find further things you could say and links to information online which may also be helpful. Use alongside your notes from any previous contact to help you prepare for and make your contact successful.

1. Staying safe

Key questions and discussion points	Further information or things to say
<p>Are you currently self-isolating?</p> <p>Note: some people may know this as shielding</p>	<p>Most people with MND are self-isolating at the moment, following Government recommendations. If you are at higher risk, as with MND or Kennedy's disease, you are strongly advised to stay at home and await further guidance.</p> <p>Even as lockdown begins to ease, it is very important that you try to avoid the infection.</p> <p>For the time being, limit personal contact to those who live in the same household or those who are essential to your care. People who do need to be in close contact with you should also self-isolate as much as possible, and follow guidance to reduce risk of bringing infection into your home.</p> <p>This also means getting home deliveries of food and supplies, to reduce the risk of contact with coronavirus while shopping.</p> <p>We realise it is important to get on with living your life the best way you can. What you do next has to be your choice, but it may help to balance the risks when making decisions.</p>

	<p>If in doubt, contact a member of your MND health care team for guidance. They can advise on your symptom progression and any specific actions you can take if you need to leave your home for any reason.</p>
<p>Are you receiving any help because you're registered as extremely vulnerable?</p> <p>Note: the registration process and support available varies across England, Wales and NI. Please be aware of the specific circumstances in your area using the links opposite and below</p>	<p>We are extremely concerned that people with MND have not been included in the UK Government's list of extremely vulnerable persons in their guidance on shielding and protecting vulnerable persons from coronavirus. We believe this is important due to the complex symptoms of MND and its impact on respiratory health.</p> <p>If you have not had a letter confirming your status as extremely vulnerable you should discuss this with your GP or other healthcare/MND specialist as they can ensure you are registered.</p> <p>Further information is here: https://www.mndassociation.org/about-mnd/coronavirus-and-mnd/how-to-self-register-as-extremely-vulnerable/</p>
<p>Do you know where to find the most up to date Government advice about coronavirus?</p>	<p>It is important to keep in touch as advice may change regularly.</p> <p>UK: https://www.gov.uk/coronavirus</p> <p>England: https://www.nhs.uk/conditions/coronavirus-covid-19/</p> <p>Northern Ireland: https://www.nidirect.gov.uk/campaigns/coronavirus-covid-19</p> <p>Wales: https://gov.wales/guidance-on-shielding-and-protecting-people-defined-on-medical-grounds-as-extremely-vulnerable-from-coronavirus-covid-19-html</p>

2. Community support

Key questions or discussion points	Further information or things to say
<p>Do you have all the help you need with essential shopping?</p>	<p>With some supermarkets, you may need to be registered as extremely vulnerable to be added to their priority list. However, if you are self-isolating, others may add you to their priority list following a simple telephone conversation. If you have speech and communication difficulties, ask a carer, family member or friend to call on your behalf.</p> <p>Further information about all supermarkets is here: https://www.mndassociation.org/about-mnd/coronavirus-and-mnd/mnd-and-coronavirus/</p>
<p>Please make sure you only use voluntary help from trusted sources</p>	<p>Many local authorities, councils, and health and social care trusts have started to co-ordinate voluntary support for shielded residents. Find contact details as follows:</p> <ul style="list-style-type: none"> • See gov.uk/find-local-council to find local authorities in England and Wales • Search for <i>health and social care trusts</i> at nidirect.gov.uk to find local health and social care trusts in Northern Ireland. <p>Other mutual aid and volunteer groups are helping local communities during self-isolation. See also our webpage, set up to collect links about local support</p>
<p><u>In England</u> volunteers registered with the NHS are now available to help vulnerable people who are self-isolating</p>	<p>This includes support with grocery shopping, collecting prescriptions, NHS patient transport, and transport of medical equipment and supplies. GPs and healthcare professionals can refer you or you can find out more on their NHS Volunteer Responder web portal:</p> <p>https://volunteering.royalvoluntaryservice.org.uk/nhs-volunteer-responders-portal</p> <p>You can also contact a responder by telephone from 8am to 8pm on 0808 196 3646</p>

3. Care and services

Key questions or discussion points	Further information or things to say
<p>Are you able to get in touch with health and social care professionals when you need to?</p>	<p>Please discuss specific health concerns with your GP or relevant members of your health and social care team. They will be able to give you advice and information which takes into account your specific circumstances</p> <p>Think about:</p> <ul style="list-style-type: none"> • Do you know how to reach all the health and social care services you need? • If you have concerns and you cannot reach services contact NHS 111
<p>Are you in contact with your MND clinical care team?</p>	<p>Think about:</p> <ul style="list-style-type: none"> • MND clinic appointments and access to doctors (including GP) – are you aware of current arrangements? These may be video or telephone appointments for example. If you've not heard anything for a while you should get in touch • Do you have contact arrangements for your MND Care Coordinator or MND Specialist Nurse or anyone else who usually coordinates care for you? When was the last time you spoke to them?
<p>Do you have all the care and support you need at home?</p>	<p>Think about:</p> <ul style="list-style-type: none"> • Are your social care arrangements or care organised using Continuing Healthcare (CHC – England & Wales only) currently working as they normally would? • Do you have any back-up support from family/others to help with care? • How will you manage personal care, washing, dressing, feeding (including using a feeding tube)? • What about using equipment e.g. NIV, cough assist, suction, hoist, wheelchair, riser-recliner etc? <p>If you have a professional care worker who becomes unable to support you, contact the care agency first for guidance.</p>

	<p>If the agency cannot provide alternative support, contact:</p> <ul style="list-style-type: none"> • Your local authority for help in England and Wales – see gov.uk/find-local-council • Your local health and social care trust in Northern Ireland – search for <i>health and social care trusts</i> at nidirect.gov.uk
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4. Wellbeing, family & carer

Key questions or discussion points	Further information or things to say
<p>How are you feeling?</p>	<p>Adjusting to different routines and expectations can cause worry. Not seeing people you would normally see on a regular basis is hard. Being bombarded with news items about coronavirus can increase personal anxiety and it's often difficult to judge if reports are based on facts.</p> <p>It's okay to feel uneasy and only to be expected. Yet, there is a much wider understanding about the potential for stress at the moment, as everyone is affected. This means a great deal of shared support is available through websites and other media. BUT, it's important to seek information from qualified or trustworthy sources.</p> <p>There is lots of information we provide here: https://www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/</p> <p>Many organisations are offering support if you feel anxious about the coronavirus outbreak or having to stay at home. For example MIND: https://www.mind.org.uk/information-support/coronavirus/</p> <p>Or the NHS: https://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-anxiety-tips/</p> <p>If you feel consistently low or under stress, you should contact your GP for advice.</p>

<p>If you are caring for someone, with MND how do you feel you are coping?</p>	<p>Try to find out about support in your area, particularly through adult social care services. A good place to start is the website for your local authority/council in England and Wales. In Northern Ireland, look for information from your local health and social care trust.</p> <p>Find contact details as follows:</p> <ul style="list-style-type: none"> • See uk/find-local-council to find local authorities in England and Wales • Search for <i>health and social care trusts</i> at gov.uk to find local health and social care trusts in Northern Ireland. <p>You can find detailed carer support in our guide Caring and MND: support for you</p>
<p>Do you need any support for children or young people staying at home?</p>	<p>We have lots of information on our parents and guardians page, including links that may help with support and activities for the younger members of your family.</p> <p>We also have a dedicated member of staff* who can help by talking through concerns directly with parents and children/young people themselves. Would you like us to put you in contact with her? (*Laura Willix, our Children and Young People’s Service Development Manager – contact: 01604800633 laura.willix@mndassociation.org)</p>

5.MND Association support

<p>Key questions or discussion points</p>	<p>Further information or things to say</p>
<p>Our financial support grants are still available, and we’ve also introduced a one-off emergency grant to help with additional living costs, as a result of coronavirus such as food shopping or bills</p>	<p>In response to the coronavirus pandemic, we are currently offering a one-off emergency grant up to the value of £250.</p> <p>We do not normally accept claims for equipment or goods before they are purchased, but we will consider these in the current crisis. This will be reviewed at the end of June 2020: https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/</p>

<p>Remember you are not alone.</p> <p>If you need guidance about information, services or just need someone to listen, please contact our MND Connect helpline for support</p>	<p>MND Connect is available Monday to Friday between 9am - 5pm and 7pm - 10:30pm</p> <p>Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills.</p> <p>Call: 0808 802 6262</p> <p>Email: mndconnect@mndassociation.org</p> <p>Note: if appropriate encourage use of the MND Association website, or online forum, Facebook, Twitter</p>
<p>Would you like us to keep in contact with you? Or would you prefer to make contact with us if you need to instead?</p>	<p>Note: discuss with your ASC any concerns you might have about managing ongoing contact. For example level of expectations, your time commitment etc</p> <p>Note: this could be asking people to contact MND Connect or yourself if you're happy to be contacted</p>
<p>When should we contact you contact again?</p>	<p>Note: agree this if you're going to make contact again</p>
<p>Would you be interested in joining an online support meeting? Have you joined an online meeting before?</p>	<p>Note: have details to hand about any suitable online support meetings in your area – or discuss with your ASC if people are interested and there isn't currently an opportunity available</p> <p>Note: you may need to encourage people to think about using one of the remote meeting technology providers such as Zoom, Microsoft Teams etc and we can help people to set this up and get going</p>

Please remember to update the Volunteer Portal record for the person you've been in contact with, or contact your ASC to make sure the record is updated

Thank you for helping us keep in touch with people!