7-point checklist for staff and volunteer contact with people with/affected by MND

Please read this important note about safeguarding and the impact of COVID-19

All staff and volunteers have a responsibility to be aware of and report any concerns they may have about safeguarding adults and/or children at risk of harm.

The potential for individuals to be at risk of harm may increase in some households, because for some individuals ‘home’ may be unsafe. For example, research tells us that issues such as domestic violence and child abuse can increase during times of stress and anxiety, with the coronavirus contributing to factors that may result in a higher likelihood of the abuse toward women, children and pets. Also, social distancing and social isolation can be used as a tool of coercive and controlling behaviour by perpetrators and will also shut down usual routes to safety and support.

If you have any concerns about the safety of any adult or child, in your conversations with them, please follow the procedure detailed in the Association’s Adult and Children’s Safeguarding Policies

If you think an individual is at risk of immediate harm or danger, ask them to call 999 and ask for the Police, or alternatively make the call yourself.

Always escalate to your line manager – if you are a volunteer then this is your Area Support Coordinator (ASC) or MND Connect if your ASC isn’t available. If it is out of office hours, please contact the Association’s Emergency ‘On Call’ Service which operates Monday to Friday 5.00 p.m. to 11.00 p.m. and weekends and bank holidays, 10.00 a.m. to 10.30 p.m. The number is 03453 751855

Please remember Safeguarding is everyone’s responsibility

1. Introduce yourself and briefly explain the purpose of the call

- Hello, I’m [INSERT NAME AND ROLE], we are contacting everybody with MND and their families at this time to check how you are coping with the current coronavirus situation.

- We’d like to make sure you know about the current Government advice and what this means for you.

- We’d like to check you know about the arrangements for your ongoing care and support and what to do if you need to contact someone.

- We’d also like to ask how the Association can support you and your family.

- I have some questions I’d like to run through with you, is this a convenient time now for us to talk?
2. Are you aware of the current Government advice? You must keep up to date and check regularly.

Links here you might find helpful for further information:
UK: [https://www.gov.uk/coronavirus](https://www.gov.uk/coronavirus)  


If necessary, you may reiterate the current Government advice – people with MND should be “shielding” and following the instructions here:


You are strongly advised to stay at home at all times and avoid any face-to-face contact for a period of at least 12 weeks. Note that this period of time could change.

Visits from people who provide essential support to you such as healthcare, personal support with your daily needs or social care should continue, but carers and care workers must stay away if they have any of the symptoms of coronavirus (COVID-19). You may find this guidance on home care provision useful. All people coming to your home should wash their hands with soap and water for at least 20 seconds on arrival at your house and regularly whilst they are there.

1. Avoid all contact with anyone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough.
2. Do not leave your house.
3. Do not attend any family gatherings.
4. Do not go out for shopping, leisure or travel and when arranging food or medication deliveries, request that these are left at the door to minimise contact.

Use telephone or online services to contact your GP or other essential services.

Register as “extremely vulnerable” (currently England only). We have received confirmation from the Government that MND is considered covered under severe respiratory conditions. Therefore everyone with MND can click YES

You can get coronavirus support as an extremely vulnerable person. Register if you have a medical condition that makes you extremely vulnerable to coronavirus. For example, you’ll be able to ask for help getting deliveries of essential supplies like food. If you’re not sure whether your medical condition makes you extremely vulnerable, register anyway.

[https://www.gov.uk/coronavirus-extremely-vulnerable](https://www.gov.uk/coronavirus-extremely-vulnerable)
3. **Do know who to contact if you have concerns about your care and if you are unwell?**

You will need care to manage expectations here. Please be clear that we cannot offer clinical advice and we may not be able to directly resolve any issues discussed. We are aware there may be significant changes to services.

Prompts if needed to think about:
- MND clinic appointments and access to doctors (including GP) – are they aware of current arrangements?
- Do they have contact arrangements for MND Care Coordinator or Specialist Nurse or anyone else who usually coordinates care for them?
- Do they know how to reach other health and social care services they need e.g. district nurse, respiratory nurse, OT, dietician, speech & language therapist, physiotherapist, palliative care (if appropriate), routine blood tests? (e.g. Riluzole), psychologist etc
- Are their social care arrangements or care organised using CHC (England & Wales only) currently working as they normally would?
- **If you have concerns and cannot reach services contact GP / NHS 111**
- Advice re coronavirus here: [https://111.nhs.uk/covid-19](https://111.nhs.uk/covid-19)

4. **Have you thought about arrangements you could make if you didn’t receive any of your regular care services at home, if you needed additional help or if any equipment you rely on fails?**

Prompts if needed to think about:
- Knowing how to raise concerns with their social care provider and adult social care/local authority (HSC trust in NI)
- Do you have any back-up support from family/others to help with care?
  - Importance of maintaining “shielding” at home
  - How will you manage personal care, washing, dressing, feeding (including using a PEG or other feeding method if needed)?
  - What about using equipment e.g. NIV, cough assist, suction, hoist, wheelchair, riser-recliner etc?

5. **Are you getting grocery shopping and other items you need, including medication, and have you considered what support might be available in your local community?**

Caution! We cannot recommend or promote offers of local community support as we cannot guarantee they are genuine or safety in using them.

Prompts if needed to think about:
- Online grocery services? (supermarket etc or community support)
- Neighbours, family & friends? (left at the door to minimise contact)
- Are local pharmacies able to deliver medication?
- Faith and community group support [https://covidmutualaid.org/resources/](https://covidmutualaid.org/resources/)
- Online resources e.g. social media, WhatsApp, Facetime/Skype etc
6. Would you like the MND Association to keep in touch with you?

- Agree frequency of contact from Association and check preferred contact method and details – explain this may be done by MND Connect
- Where we have contacted someone who hasn’t previously given us permission to contact them we can take verbal consent using the questions on the form Updating Consent – ASC completes form (taking feedback from a volunteer where they have contacted), ASC scans and sends by email to Care Admin. More information here: [https://www.mndassociation.org/privacy-policy/](https://www.mndassociation.org/privacy-policy/)
- ASC to update MrC in notes section. ASC may allocate to an AV on MrC if the AV has agreed the contact support arrangement will be ongoing
- AV to update Volunteer Portal where AV has an established relationship

Further support to think about:

- Online information and resources, emotional support and wellbeing e.g. MND Association website, online forum, facebook, twitter
- **MND Connect** [https://www.mndassociation.org/support-and-information/our-services/mnd-connect/](https://www.mndassociation.org/support-and-information/our-services/mnd-connect/)
- Consider any needs which could be met by an Association support grant? [https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/](https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd/)
- Is branch/group support available (where provided remotely)?
- Are there any children or young people (CYP) in the household or wider family that are affected by MND, and may need additional support at this time, either because they are worried about the coronavirus situation or because they are off school or college?
  - MND Association resources for 4-10-year olds and 11-18-year olds on our webpage, including Young Connect Helpline 0808 802 6262
  - We have also added a list of resources for children and young people to our website, which are suitable for the coronavirus situation.
  - We have a dedicated CYP Manager, who is able to give you a call back if you would find this useful? She is able to discuss a range of children and family specific questions, including how you might talk to your child or teenager about the coronavirus.

7. Close the call

- Reiterate contact details for **MND Connect**:
  - Available Monday to Friday between 9am - 5pm and 7pm - 10:30pm
  - Calls are free from landlines and mobile phones within the UK
  - **Call**: 0808 802 6262
  - **Email**: mndconnect@mndassociation.org
- Remind to keep in touch with and follow Government advice
- Reassure we are always here if they need us – even if it’s just someone to talk to – and there is also further guidance on our website: [https://www.mndassociation.org/mnd-and-coronavirus/](https://www.mndassociation.org/mnd-and-coronavirus/)