Staying Connected – additional notes for volunteers contacting people with/affected by MND

The Coronavirus outbreak has placed many significant changes to our lives over the previous weeks, and it’s clear that people with and affected by MND will also be having to adapt and may be facing new challenges in accessing vital services and support networks.

Over the coming weeks we hope to make contact with all people with MND who are known to us to offer a friendly call and to let them know we are here for them. The purpose of our calls is to offer reassurance and an ear to listen, to understand any concerns or problems they may be facing during these challenging times and where possible provide useful support or guidance.

We have produced a checklist which can act as a conversation framework when making contact. There are seven key areas which we think it will be useful to cover during the conversation. These are:

- Introduction and purpose of the call
- Awareness of current government guidance
- Awareness of who to contact if feeling unwell
- Arrangements of action to take in case there is a disruption to care services or problems with equipment
- Access to essential supplies and medication
- Continued contact and communication with MND Association
- Closing the conversation

You will find details of some suggested questions and prompts in our checklist to help cover these areas. Whilst the checklist provides a framework for a conversation, the person you are calling may want to talk about a topic that we haven’t considered or may want to talk in detail about an area of their life that is giving them particular concern. In these cases, it’s important that we’re here to listen and use the checklist in a flexible and adaptable way to shape our conversation.

It is important to be aware that some of the people you speak to may be or become emotional and may be facing some extremely challenging situations or problems we can’t directly solve. Listening to these concerns and problems, however, remains a vital support service we can offer at this stage.

This is a challenging time for us all so please take time to consider your own mental health and support needs during this time. In order to provide the best possible support for others we need to make sure our own individual needs are also met as much as possible.
Planning the Conversation

- Before starting make sure you have read our checklist to see the kind of areas we’re hoping to cover in our conversations, remember this isn’t exhaustive and there might be more to discuss.
- Decide on your method of communication – initially this will probably be using the phone, or it might in future be using video calling technology such as Zoom or WhatsApp we have suggested in our recent communications.
- Make sure you have allowed yourself enough time for the call to have a meaningful conversation.

During the Conversation

- Ensure the person you are speaking to feels like it is an informal conversation and not a survey or interview, use the checklist as a guide but relax and see where the conversation takes you.
- Spend time listening and offering support and reassurance where required.
- Be positive, be realistic, being open and honest about areas where we can or can’t offer support and guidance. We have been clear about this in the checklist document.

After the Conversation

- Escalate any immediate concerns to your Area Support Coordinator (ASC) or other staff member who is supporting you to make these calls.
- Take some time to look after your own mental health and emotional wellbeing.
- Record relevant information using the Volunteer Portal where you are able to or feed back to your ASC or staff member supporting you and who is coordinating this work.

We’d like to say thank you for helping us with this important task.

Ensuring people with and those affected by MND know we are there to support them is vitally important, especially during these challenging times.