

Support through communications

Why do we need to be in touch with people outside of our meetings?

Many people with MND and their carers will attend your support meetings. However, there will be many others who for whatever reason cannot get along to them. For some the thought of meeting others affected is quite a challenge, particularly when first diagnosed. Many fear seeing others who have progressed further in the disease at a time when they are struggling to come to terms themselves with what is ahead.

Others may have reached a stage in their disease where they are no longer able to leave their homes, or they may have moved into a care home or hospice.

Even for those who can attend the regular meetings, having some means of staying in touch between meetings can be a great help and support. Take time to consider what other ways your branch/group could be in touch with people with MND and carers to ensure they are aware of the information and support they can receive from you.

Most branches and groups consider having at least one or more of the following forms of communication to their members

- Branch/group website linked to the MND Association's main website
- Branch/group newsletter
- Branch/group Facebook page
- Branch/group Twitter account

If your branch/group is considering developing any of these it is worth spending some time looking at what other branches and groups are doing and consider the following

- what does it tell you about their branch/group, its members and activities?
- what are they offering in information and support for people with MND and carers?
- what useful local information, signposting and contacts are offered?
- what are they sharing about other aspects of the Association such as research, campaigning?

Whatever you are planning to develop there is guidance on how to go about it and how to get the best from your communications available on the Volunteer Zone.

Once you have identified what it is you would like to do then it is advisable to find someone who can take the lead on the planning and development. You may already have someone within your branch committee or group team who is interested and has the skills needed to take on the role such as Newsletter Editor, Web Master or Digital Media Officer. If not, then we can help you with the recruitment for this.

Branch/group newsletters

Producing informative and interesting newsletters are an excellent way of keeping in touch with your membership, particularly people with MND, their carers and families.

Sending them out to local Health and Social Care professionals is a valuable way of keeping them informed too. Offer them a few extra copies to pass onto their colleagues, or to take along with them on visits with pwMND who they are supporting and who have yet to hear about the branch/group.

Think about the experience of being in touch with others at a support meeting. Think about the information which would be discussed and shared there. How can you replicate that informative and supportive experience in print?

A good newsletter offers balanced read across a range of topics. Here are some you may wish to consider

- Branch/group activities
- Articles which feature local people with MND/carers sharing how they are coping, perhaps with practical and emotional hints and tips to help others
- Forthcoming fundraising events
- Campaigning and influencing – are there local issues affecting people with MND?
- What's happening in the world of research? Is there a new development to share?
- Event listing/diary - giving details of forthcoming meetings, date, time, place and importantly the accessibility.
- Local contacts information and signposting to useful local organisations, e.g. Carers organisation

We know of many people affected who never came along to a branch/group meeting but who said how valuable they found the newsletter as a way of keeping in touch.

Branch/group websites

It is not essential for your branch or group to have a website, but we are actively working to increase the network of branch and group websites as more and more people are using the internet for their personal research into MND and the support that is available.

Branch and group websites are a very useful resource for keeping people informed of the support available locally. Websites enable you to reach people at any time of the day and give you the chance to publicise your branch or group to a wide audience, most of who will have specifically searched for local information.

Ideally, a branch/group website should be treated in a similar way to a branch or group newsletter in that it should provide people with MND, their carers and families with additional local information that would not necessarily be available on the Association's website. This avoids duplication of information and effort, but you must ensure your branch/group website signposts visitors to the Association's website for the most up-to-date information on MND, care services and research.

Branch/group social media

Developing a social media presence can help raise the profile of your branch or group. Facebook in particular is fast becoming one of the most popular social networking tools on the web.

Many branches and groups now have a Facebook page which they use to publicise the events and activities that are happening locally. It is being used by them as a tool to communicate with their members, volunteers, potential volunteers and others with an interest in the Association.

People with MND and carers are also using it as a means to keep in touch and support each other. After meeting up with people at a meeting they can link up by the branch/group Facebook page and keep in touch in between meetings.

Remember

Whatever means of communication your branch/group set up it is important to keep it regular, up to date, interesting and relevant for those you need to keep in touch with.