

## **Support for people living with MND through meetings**

### **Why they are important?**

For many branches and groups, successful support meetings are the front line of the support provided to those living with and affected by MND.

They are valued by people living with MND because they

- reduce isolation through the offer of friendship
- offer a chance to meet up with others affected by MND
- provide information
- offer a social event where they can feel comfortable
- and are a pleasant day out for both people with MND and the carer

The meetings also provide your branch or group with an opportunity to keep in touch with your members on a personal basis. However good your newsletter, website or social media is, nothing beats enabling people living with MND and their carers to meet face to face, share ideas, information, and support each other.

### **What style of meeting?**

Support meetings come in all shapes and sizes, and formats.

#### Open meeting

Called an 'open' meeting as the invitation is to all your branch or group members; those affected by MND, carers, past carers, HSCPs, and others interested in MND. It is an opportunity to meet and access the support offered by the MND Association and the branch or group, and offering an occasional speaker can be a major attraction at such a meeting. Ideally the meetings need to be held regularly in a suitable accessible venue.

#### Garden centre meeting

Many branches and groups now hold regular meetings in local garden centres and they are becoming increasingly popular. Not just because that they are often free of charge to use, but also because they are nice places for a day out and staff are usually very accommodating.

Branches and groups can negotiate a price for drinks and snacks to be covered by them for those attending.

There are large garden centres in most areas now, often on good transport routes making them easy to reach, and with a good provision of disabled parking and facilities.

The **Northamptonshire Branch** recently started running garden centre meetings which have been very popular with people with MND and their carers. However, the branch has also decided to continue with their more traditional open meetings so that they can stay in touch with those who fundraise for them and past carers.

#### Drop-in/ get together/ coffee mornings

Describing your meeting as a 'drop-in' can encourage people to attend. People feel more able to turn up when they are able to, not feel pressurised to attend at a certain time or stay the whole meeting. It is important to ensure a regular date is offered and the venue is easy to access with suitable parking and disabled facilities.

The **South West Surrey Branch** has traditionally run evening support meetings. John Haywood, Branch Committee volunteer said "The number of people attending the monthly evening support meetings was going down. In January the idea of an afternoon drop-in was put to the committee and agreed, and a venue at Guildford Cathedral was arranged".

A group of committee volunteers and Association Visitors worked together to organise and run the first afternoon drop-in which was held in April. Support was also provided from Helen Hawkins, Regional Care Development Advisor and Annabel Lotsu, Volunteering Development Coordinator.

The branch will for the moment continue to hold evening meetings so that people have the flexibility to attend at a time convenient to them, however the branch are pleased to hear of the difference that the afternoon drop-ins have made.

John said "We got some excellent feedback from people who attended the first drop-in and have had two further drop-ins with number of attendants increasing".

Annabel Lotsu, VDC, said "It really is encouraging to see branches and groups reviewing the different ways support can be provided for people affected by MND to ensure they are meeting their needs. The use of the term 'drop-in' has also encouraged people to attend. People have felt able to turn up when they are able to and not feel pressurised to attend at a certain time. The branch have been so encouraged by the positive response, that they are planning to continue the day time drop-ins and really do feel they are making a difference to local people affected by MND".

In 2006 the **Milton Keynes Branch** decided to turn open meetings to drop-ins.

Each year the Milton Keynes Branch hold 10 midweek lunch time drop-ins where people living with MND, health care professionals, carers, ex-carers, AVs and RCDAs met up over a buffet lunch. Drop-ins events are regularly attended by 20-40 people and the results have been astounding.

Charles Reece, Branch Chair, explains: "The success of the drop-ins have had far reaching effects on the Association's work. The regular contact between the committee, health professionals and people affected by MND has had a big impact on both expenditure and fundraising. More needs are identified more quickly, and the increased support we can offer has been reflected in more people connected to MND raising money for us."

### Support meeting

This is a regular meeting for people living with MND and their carers. This style of meeting can be focussed specifically to give support and advice for plwMND, giving a safe environment to address specific needs. Meetings which offer a combination of invited speakers and social time work well.

### Carers Meetings

Some branches and groups run support meetings not only for people living with MND but also specific separate meetings or sessions for carers only. Carers often find it difficult to talk about their feelings and concerns in front of their loved ones.

The Cleveland Branch began holding monthly carers meetings after they saw that many carers were not having their own support needs met anywhere else. "The aim of the carers support group is to give carers the opportunity to talk about their feelings, share their experiences with other carers, and generally to discuss things they may not want to talk about in front of their loved ones" says Branch Chair, Luke Rutter. "The group has been a great success with good support from carers. The format is informal, to encourage people to open up and discuss anything that is on their mind. The feedback from them has been encouraging".

Linda McNally who cares for her husband Tom, regularly attends the carers meetings and says, "We're a well-run group, all pulling in the same direction to make life that little more bearable. To any other branches or groups who don't have a carers group or are thinking of forming one, then do it. The rewards are many".

### Joint meetings with other branches/ group

There may be the opportunity to work in partnership with one or more branches/ groups on a joint support meeting event, bringing people together from a wider area in the right setting. For example three branches in South Wales came together at the National Botanic Gardens of Wales.

"This was a really successful event and was well attended by those with MND and their families from across the three branch areas" says Maimie Davis, Association Visitor and committee member of the South West Wales Branch who helped organise the meeting. "People found it very enjoyable to meet and talk to others in a similar situation surrounded by lovely scenery and we will definitely be doing this again".

### **Whatever the format there are key features that all successful meetings share.**

They are

- friendly and welcoming
- held in comfortable and appropriate surroundings
- held regularly and at a convenient time for people with MND
- supported by branch/group members, and Association Visitors. From time to time, regional staff may attend and encourage local health and social care professionals too.
- well planned and organised
- good fun.

These gatherings can take time to build up and their character will often depend upon the area your branch/group covers, how long it has been going and the contact you have with people with MND through your AVs and the local RCDA. Actively involving your RCDA, AVs and VDC in the planning and organising of your meetings for those affected from the outset will help ensure their success.

Discuss plans with your RCDA as they may know of several people living with MND and carers who would be interested in meeting with others. You may want to send out a small questionnaire first, asking pwMND what they would like. Or you could invite everyone to an initial meeting and ask them directly how they would like to continue meeting. Once they are used to coming along and have made friendships with others affected by MND there is often then a willingness to continue to meet.

Many branches and groups have found that daytime and weekend meetings are often more convenient for people living with MND and their carers, and less tiring than evening meetings.

### **Speakers at meetings**

If there seems to be a reluctance to come to social type meetings the alternative would be to offer a short programme of meetings with invited speakers. The right speaker can be a major attraction at a meeting, giving advice and information on topics which people living with MND may see as of benefit to them e.g. carers organisations, advice on benefits and grants, complementary therapies. Talks on research are always of interest, or you could invite the local Neurologist, Speech or Occupational Therapist, Physiotherapist or people working in the field of disability. Their involvement can often lead to improved links with local services. RCDAs, VDCs and other Association staff are also pleased to attend to speak about their particular role in the Association

Remember to ask those who regularly attend your meetings what they would be interested in hearing more about and when arranging speakers ensure they are aware not to make their talk too long or formal. It can be difficult for pwMND to sit for long periods of time and it is important to include some social time into the meeting for members to get to know each other, particularly if they are new. This can be done over a comfort and refreshment break after the talk.

Occasionally offering something different from the formality of a speaker is welcome, perhaps an arranged outing during summer months or perhaps a choir for a December meeting.

### **Getting the venue right**

Where in your area you hold your meetings is really important. You may find that where you are considering holding a meeting is not near where most of the people affected live, and that travelling to attend would be difficult. Discuss this with your VDC/RCDA as their knowledge of where people affected are in your area will help you identify the most suitable locations to enable more people to attend.

The **Staffordshire Support Group** are always looking at ways to improve the support they provide and have produced a map of their area with locations of people living with MND marked on so they can better plan where to hold their support meetings. Sheila Lamisère, Group Leader, says, “Staffordshire is a very big county, so we meet in garden centres in different areas to enable as many people as possible to attend. The map will help us identify the most suitable locations to allow more people to join us for what are very rewarding and enjoyable get-togethers.”

Once you have identified where in your area would be best capture most people affected you need to find a suitable venue. This will depend on what type of meeting you are going to offer, but paramount on your list of requirements should be the needs of the people living with MND.

#### Points to consider

- Where the meeting venue is situated. Is it easy to find? Are there easy access routes to it via road, bus, or taxi links?
- Car parking. Is there easy parking and full disabled access. Are there designated disabled bays? Is there plenty of spaces for numbers expected to attend, and if not are there good nearby parking facilities?
- Accessibility into the building for people with MND- is there wheelchair access, ramps and doors with ease of opening. Remember larger electric wheelchairs need more room.
- Within the building is it easy to get around, especially for people in wheelchairs. Is there plenty of room to manoeuvre and is there a suitable lift if needed.
- Welcoming, comfortable looking place - with helpful and understanding staff.
- Toilet facilities. Check the disabled toilets especially. It may be worth asking one of your members who is in a wheelchair if they could go along to check, and give you feedback on the facilities from their perspective.
- Seating. What type of seating is available is it suitable for people with mobility problems, comfortable, stable and secure. Some people with MND may have difficulty getting into and out of chairs if their mobility is restricted.
- Refreshments. What is available? Consider offering hot and cold drinks, and availability of aids such as straws for those with drinking difficulties. Lighter cups or mugs with handles for those with difficulties holding normal cups. If you are considering offering some food, is there the option of a range of foods, particularly soft options such as soups.
- Security. Are venue staff on hand or easily contactable? Will they be available to support you in the unlikely event of any disruptive activity?

Our Venue Safety Checklist (available on the Volunteer Zone) will also highlight areas for you to note such as safety, first aid facilities and fire safety procedures. Ensure this checklist is kept up to date for each meeting your branch/group holds, and a copy filed. See the section on Risk Assessment for more information and advice.

Discuss with the venue what your requirements are. If it is a garden centre you may find that they have a quieter time during the day when it would be easier for them to accommodate you all, especially if there are some wheelchairs. Garden centres are very popular places for lunch so holding your meeting either late morning or early afternoon may offer a quieter time.

### **Planning ahead**

By planning ahead for your meetings you can ensure that they are suitably publicised and everyone informed.

Most branches and groups plan a year of meeting dates in advance, often meeting on a recognised monthly date such as “the second Tuesday in the month” so it is easy to remember.

The **Bristol, Bath, Weston and Winsley Group** have just been awarded £4,500 of lottery money to go towards funding their support group days. In order to ensure that this money is used to the best effect, the group have decided to ask their membership, via a survey, how they would like to see support meetings run in their area. Andrew Grundy, Group Leader says, “We are thrilled to have been awarded this money and are working hard to ensure that it is spent wisely. With the help of our AV’s we are asking those with MND what their thoughts are on how our support meetings are run. We are also very keen to look at providing transport for those who may struggle to attend the meetings as we believe that this is very important”.

### **Getting there**

Sometimes the reason why people with MND do not go to the meetings is simply because they can’t get there. They may not have their own transport and may not be able to afford taxis. Your branch or group can help by making it clear that you will meet the cost of transport and pay for travel expenses to enable people to attend. Ensure this is clearly put in your invitations to meetings.

### **Programmes, invitations and reminder notices**

The programme of meeting dates can be promoted in a variety of ways such as the branch or group newsletter, website, social media, and local press. Other options are to place a poster in the MND Clinic or Care Centre, and ensure relevant health and social care professionals are also informed and invited.

Close to the time of the meeting send out a personal invitation either by email or post. Include more details about the meeting, including details about the speaker if you are having one. Ask the AVs and your Branch/Group Contact to personally let the people with MND and carers they know about the meeting. Often a written invite followed up by a personal call will encourage someone new to come along. Remember to offer help with transport and always include appropriate contact details should someone need to know more details about the venue, directions etc.

Include the date for the following meeting in case anyone can not make this meeting but would be interested in knowing when the next one is.

### **Setting up**

Where ever your meeting is set, make it easy to find, especially for those who haven't been before. Put up some signs if necessary. If the meeting is within a garden centre situation, with permission, place some recognisable signage on the tables where everyone is going to sit, or ask some of the members helping with the meeting to wear their MND Association ID badge or t-shirt.

If the venue allows, arrange the tables and chairs in a setting that will encourage people to mix. Groups of tables work well and offer somewhere to put refreshments. Wheelchairs are less obvious in these seating arrangements too. Garden centres are often happy to cordon off an area specifically for the meeting.

Make the space easy to move around in. Avoid low coffee tables and too many chairs as they can get in the way of wheelchairs. One large table often restricts people's movements around the room and can reduce the social aspect of a meeting.

Consider the temperature in the room and ensure it is comfortable.

### **Meeting and greeting**

First impressions count. This is particularly important for those attending for the first time, who will often be nervous and unsure. Arrange for a couple of people to take the lead in welcoming and introducing people, perhaps this can be done on a rota basis. If your AVs are aware of anyone new expected let those 'meeting and greeting' know so they can look out for them.

Once everyone has arrived encourage them to circulate by offering to introduce people to each other. Watch out for anyone left on their own and help them to meet others.

### **Provision of information and resources**

Consider making available a small selection of the Association's general information and leaflets. This could be offered in a file box which can be passed around during the meeting. If someone is having difficulty joining in a conversation, having something to read or look at can offer an alternative for them.

For example:

- Living with MND care leaflet
- What is MND care leaflet
- Information about other local groups and organisations that can provide support/help eg local sitting service, volunteer driver schemes, gardening schemes etc.
- Information specific to carers – local services and organisations. Places to signpost to especially relating to things such as benefits.
- Information about the Association's Forum for people living with MND

- Research – general guide leaflet
- Membership forms
- Thumbprint – latest
- Local branch newsletter
- Local branch/group leaflet
- MND Association publications list
- MND Connect magnets with the phone number.
- List of Regional staff contact details
- Fundraising information
- Selection of useful books relating to MND which could be loaned out between meetings

Discuss with your VDC/ RCDA/ RF what resources they feel may be helpful to have in the file/info box and nominate someone to take responsibility for ensuring it is kept up to date and appropriate.

Encourage the members to add their recommendations to the information box/file. Some branches and groups have a collection of useful hints, tips, and advice collected from members which is good to pass on to others.

Some practical resources that may be helpful are note pads and pens, tissues, large straws and serviettes.

### **Close of the meeting**

Saying goodbye and thanking people for coming is as important as the welcome. Leaving people with a sense of their being valued and your interest in them will encourage them to return again and again.

### **Afterwards**

Send any necessary thank you letters and include a 'write up' of the meeting in the branch/group newsletter, or on the website or social media. Try and include the personal experience or message of a person with MND or carer who has attended, and photographs of people enjoying themselves. By emphasising the warm and friendly atmosphere other people may be encouraged to give it a try. Do remember to check people are happy to have their photo taken and used in this way.

Arrange for any new attendees to receive a follow up call, either through their AV or the Branch Contact. This gives an opportunity to check out how they are feeling, if the event was to their liking and will hopefully make them feel interested in coming again.

If holding your drop-in at a garden centre don't forget to thank the staff for their help.



Our Chief Executive, Sally Light, recently presented garden centre staff with a certificate to acknowledge their ongoing support of the Northamptonshire Branch. The branch has held their popular drop-in sessions for people affected by MND at the garden centre restaurant since March 2013. The story was featured in local media.

Keep reviewing the meetings each year to ensure they are still meeting the needs of plwMND and carers in your area. Numbers of those affected fluctuate so you may find you need to move the venue to another part of the branch/group area. Or if the branch/group covers a large area there may be a need to rotate the meetings throughout the year to enable as many as possible opportunities to take part.

There may be a possibility of doing a joint meeting with a neighbouring branch/group. This can be discussed at your branch/group review with your VDC.

#### **Finally - Special dates to celebrate.**

Note the birthday of the start of your meetings and celebrate each year. Consider holding a Christmas lunch, or a thank you lunch during the year for everyone who has helped and supported (this can include Health and Social Care Professionals and use as a Long Service Award or Extra Mile Award opportunity). It's a lovely excuse for a party.

#### **For more information contact the Volunteering Team:**

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