



# Multiple System Atrophy Trust

## A Guide to running effective Support Groups

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## 1. The Basics of Support Groups

We have created this document after discussions with Support Group Leaders and is provided to help enable you all to feel more confident within your roles. This section covers the basic information that will be common to all support group meetings. Throughout the rest of the document we expand on these ideas and cover additional information about things you might consider depending on your meeting schedule. We have also added in some helpful tips on how to make your meetings as useful and enjoyable as possible for all those involved.

Basic meeting arrangement	Things to consider
<b>Setting up your room</b>	<ul style="list-style-type: none"><li>• Try to arrive at your meeting venue around half an hour or so before the group starts so that you have plenty of time to set up the tables and organise yourself. Ask the person doing refreshments to arrive at the same time so the supplies can be sorted and the kettle is on before people arrive!</li><li>• People will often arrive early to the meeting so please make sure they can get into the venue or alert somebody that they have arrived. Some orange balloons or an MSA Trust T-shirt can help to identify where your room is.</li><li>• Set up the tables according to how you want the meeting to be run. For example, if you have speakers attending you may want some smaller tables arranged facing the front. However if you don't have a speaker you may wish to have larger tables laid out for open discussions.</li><li>• Remember to arrange the room so that there is enough space for wheelchair access and for people to move around the room and go to the toilets easily.</li><li>• If you haven't already, please complete the Trust's Venue Check List form and return it to us. If it is a new venue ensure you are aware of where the toilets and fire exits are.</li></ul>
<b>Materials</b>	<ul style="list-style-type: none"><li>• We will send you some information leaflets and guides before your first meeting but please do request more when these are running out. It is always a good idea to have some of the Trust's information resources at your meetings. A lot of the time people like to take the guides and leaflets to give out to family members and healthcare professionals.</li><li>• You may also like to display posters about the next meeting in your local hospital waiting room or health centre. Please contact the Office to discuss the production of these.</li><li>• If you would like to send out a draft meeting agenda with your support group invitations please let Emma know so she can include this on the emails and letters.</li><li>• Some groups like to hold a raffle, either to cover the cost of the meetings or to give as a donation to the Trust. If you would like to find out about more fundraising activities or events your group could get involved with please contact our Fundraising team in the Office.</li></ul>

<p><b>Introductions and welcome</b></p>	<ul style="list-style-type: none"> <li>• Ensure that the register is completed either as people walk in or it is sent around the room for people to sign. This is important in case of an emergency and also needs to be forwarded on to the Trust following the meeting.</li> <li>• Make sure that all members of the group are aware of where the nearest exits are in case of an emergency, also inform people if there is a fire drill expected on that day. Please ensure they also know where the toilets are.</li> <li>• Explain to people as they arrive about the meeting schedule and where they might like to sit. If possible sit any new members with regular attendees in order to help them feel at ease . see further notes below on this.</li> <li>• At the very start of the meeting you might like to give a brief introduction about the meeting agenda for the day and say something about yourself. You might then like to go around the room to allow people to give brief introductions of who they are and where they come from. This allows others to see who lives nearby and may have similar experiences with local services.</li> </ul>
<p><b>Discussions</b></p>	<ul style="list-style-type: none"> <li>• Often the set up for discussions will be different depending on which meeting scenario you have organised e.g. if a speaker or a nurse is attending - see more on this below.</li> <li>• Try to keep the conversations as positive as possible and speak about local or other services that may offer support.</li> <li>• Always allow the nurses or healthcare professionals present to answer questions about medication or specific treatment options. If there aren't any in attendance explain that you will ask a nurse to contact the person about their query. Please make sure you follow this up as soon as you are able.</li> </ul>
<p><b>Closing discussions/ ending the meeting</b></p>	<ul style="list-style-type: none"> <li>• This can often be difficult as the meetings are relatively short and often people haven't seen each other for a while, or met anyone else with MSA before, so have lots to talk about.</li> <li>• Be conscious of this, around 10 minutes before the end of the meeting ask for everyone's attention and explain that the meeting is coming to a close. Thank everyone for coming and say when the next meeting will be.</li> <li>• If possible also ask people to give feedback either to yourself or to the Trust Office. If possible a quote from a member, and perhaps even a photograph if they agree, is great for us to be able to promote the work of Support Groups and include in the MSA News magazine.</li> <li>• It is also a nice idea to ask members if there is anything they would particularly like to focus on at the next meeting, for example asking someone to attend from the local hospice to talk about the services they provide.</li> </ul>

<p><b>Packing away</b></p>	<ul style="list-style-type: none"> <li>• Ensure that you have arranged for someone to help you pack away at the end of the meeting so they can assist you with the tables etc.</li> <li>• Make sure you keep the register and any follow-up notes you may have made so that these can be forwarded on to the Office and kept for your reference.</li> <li>• If possible arrange future dates with the venue, and the nurse or any Trust staff member attending.</li> </ul>
<p><b>Feedback &amp; after the meeting</b></p>	<ul style="list-style-type: none"> <li>• Emma will call or email you for feedback within a few days but if you would like to contact her quicker than this because they are things to follow up, her contact details are at the end of this document.</li> <li>• As soon as possible please scan, email or post the attendance register, feedback form and the check list form (if not already complete) to the Office.</li> <li>• Ensure the Emma is aware of your next meeting dates so that invitations can be sent out in plenty of time.</li> <li>• Sometimes members may contact you to inform about things such as a change of address, notification of death or ask to no longer be contacted by the Trust. If this does happen please notify us as soon as possible so we can update our database accordingly.</li> </ul>

The next section of the guide covers a range of topics that Support Group Leaders have said that they sometimes find challenging or would like further guidance on. If there is anything additional you feel should be included, or you have something else you would like advice on, please let Emma or Andy know.

## **2. Why people attend**



Everyone is different and people attend support groups for many different reasons. Some of these reasons might be wanting to meet other people with MSA and their families; being newly diagnosed and wanting to learn more about MSA, and sometimes wanting to know what a journey with MSA may look like. People are often looking for support and the groups are a great way for people to find this.

Members may want to be able to talk about things they might be frustrated with, and to discuss local services that may be able to help, and this can be best done in a relaxed and supportive environment. Others may be attracted to attend because of a speaker, healthcare professional or one of the MSA Nurse specialists that are attending. In this way they are able to get individual advice and knowledge.

### **3. A Warm Welcome**

Having refreshments and offering people tea, coffee and biscuits allows people to feel at home so it's often good to do this before the meeting begins and half way through.

As mentioned above, at the start of the meeting, once everyone has arrived and settled down with refreshments, it is a nice idea to introduce yourself as the Support Group Leader and say a bit about your connection with MSA and why you started running the groups.

Creating a welcoming environment is key to ensuring group members feel relaxed and comfortable, which is vital for them to leave with a positive experience of the meeting. It takes a lot of courage to go to your first meeting and people may well be nervous. Try to make them feel at ease by explaining how the meeting works, what the routine will be and if possible sit them with some regular attendees or a healthcare professional. It can also be helpful to sit people together who come from a similar area, that way they can discuss local services that may benefit each other.

### **4. Setting up your venue**

Having a warm, friendly meeting space can create a positive feel to the meeting even before it begins. It's important to think about the type of venue your Support Group will be held in and to ensure that the venue, and the furniture there, is comfortable and allows people to feel at ease. Ensuring people know where to park the car, how to access the venue and arranging the chairs so people can chat to each other, are all important things to consider. If possible try to have some chairs with armrests as these are better for supporting people getting in and out of the chairs.

The layout of your meeting room will depend on the type of meeting you have organised (see next section). You can test out a few different combinations and see which you think works the best for your group but it is normally not a good idea to move people around after the meeting has begun.

## 5. Different Meeting Formats



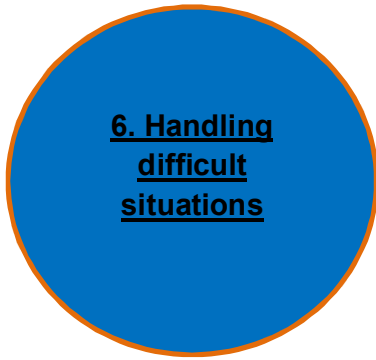
We have found that what seems to work well is to have either a healthcare professional, MSA Nurse or other speaker to do a presentation towards the start of the meeting. It's great if you can secure a health or care professional to come and do a talk about a particular topic such as physiotherapy, hospice care or benefits. However, you might also like to have an independent speaker come to do an activity that's not actually connected to MSA such as wildlife or baking. This enables people to benefit from time doing a social activity together and gives the Support Group a sense of community.

Alternatively a group discussion for the first hour of the meeting can also work well and it's always useful to have some starting discussion points ready. If you need any support with some discussion points for instance, recent research or Trust development or a new piece of equipment someone has tried, please contact us in the Office and we will help with some suggestions. Often people come with specific issues they would like to discuss and will ask these as the discussion progresses. Some group members who are withdrawn may just take a little longer to warm to the group situation and open up. The group needs to have an encouraging, positive approach; however nobody should be pressured to participate.

One approach that has been successfully used, and is helpful in making people feel at ease, is to go round the group asking them to think of something good that has happened to them in the last couple of weeks. Also gently asking group members if they have had any experience with a particular topic may draw them in to the conversation. Try to keep the discussion positive about how people can get support, and promote local services that can help. Often people will have very handy tips from their own experiences. The final hour of the meeting can then be designated to private and individual chats with nurses or healthcare professionals and a chance for everyone to have some social time together.

If there is no health or care professional at the meeting it can be helpful if you try to get round to talk to everybody so that whether they have contributed or not they still feel part of the meeting.

**Make sure you ask a few weeks in advance if your speaker will require any ICT equipment, so you can prepare this and set it up. It is also a good plan to have some pre-prepared questions for after the presentation in case people are anxious about speaking first.**



## **6. Handling difficult situations**

**Occasionally, but inevitably, some difficult situations may arise during your Support Group meetings. It's important to remember to keep calm if this happens and be confident that you have the ability to solve or help with the issue. We have looked at some of the more common scenarios below:**

In some circumstances a discussion can turn negative because either someone with very negative views dominates the discussion, or somebody has had a bad experience with a service or a particularly distressing situation. If it is upsetting others, or distracting from the point of the presentation or topic, it might be appropriate to rephrase the point in milder terms and acknowledge that they feel strongly about the issue and invite the group for their comments. Lengthy and often unproductive, whole group discussions can sometimes be avoided by offering to discuss the issues with the individual on a one to one basis after the meeting. This can sometimes defuse the heat and enable the discussion to move on. Do remember to pick up the issue individually afterwards though. This may be difficult or awkward at the time but will be much better in the long term.

People that have come alone without any support may become upset during the meeting so keep an eye on this and support where possible. Active listening is a key technique when facilitating Support Group meetings. Often people just want someone to talk to and be understanding of the situation they are in. They don't expect you to have all the answers to the problems but need to know someone is there to listen to them. Be sympathetic and reassure them but don't promise them anything that is untrue or you can't deal with.

If someone is becoming distressed try to remove them from the situation and take them to one side to speak individually, if a MSA Nurse or Trust member of staff is present this may be something you ask them to help with.

**It's important to remember that we want all group members to feel safe and comfortable and we wouldn't want someone to stop attending because of the behaviour of one person.**



## 7. How to keep people attending



A sense of belonging is what will keep people coming back to Support Group meetings over a period of time. People will feel like they belong to a group when things such as shared connections, friendships, feeling involved and a sense of wellbeing are present. By attending an MSA Support Group most people already have something in common and therefore a mutual concern and connection. To encourage these connections you could include an icebreaker activity at the start of the meeting. Also try to make sure that tables and chairs are laid out so people can talk easily.

Building in time to socialise with other members is extremely important at support group meetings and can lead to lasting friendships. Having a balance between speakers, presentations or activities and time for people to sit down and have a chat is key to a successful meeting.

Individuals like to feel that they are involved in the meetings and have some control over what goes into the schedule. Therefore it's important to always finish the meeting by asking for feedback and even doing a quick evaluation. You could ask people to either speak or write down their thoughts about the meeting; what did they like? What do they think could improve the sessions? What would they like to see at future meetings? etc.

It's good practice that if you ask for feedback you try to ensure some of these changes are made at the following meeting. Otherwise people will feel that their feedback wasn't really wanted or listened to.

**It goes without saying that the welfare of those who need us is paramount. Many members are not fully aware of the full range of services and support the Trust can offer, so it's always helpful to be confident yourself that you know what we can help with. We are happy to have a discussion with you about this at any time.**

In terms of making sure people feel part of the group there are some other ways we can help people feel wanted including, collecting contact details on the attendance sheet so that you can send a follow up email or thank you message for attending. If you decide to email your group attendees please ensure that all email addresses are included under Bccq It might also be a nice idea to send a card if you hear that someone isnq well or is recently bereaved, or perhaps calling if they donq turn up for a meeting unexpectedly. This way it shows that you care and reassures people that you want them at the meetings.



The Trust is unable to give out contact details so you must collect these on the attendance sheet, and therefore have the personq permission, if you want to make individual contact. It is vital that as Support Group Leaders you are clear about your role boundaries and donq agree to something that is outside of this remit for instance, agreeing to do home visits.

This is not only for your own protection, and that of the person who would be visited, but also for legal reasons as this role would have to be subject to clearance from the Disclosure and Barring Service. If you want to discuss any activity that you feel would be beneficial for the group to be involved with, please contact Emma or Andy on the contact details below.

**Obviously this list isn't exhaustive and there are many other ideas for making your Support Group meetings a success. Every group and leader is different and therefore you need to find what's the best fit for you and your group. Don't feel despondent if the numbers of your group fluctuate as this can be for a whole range of reasons, some connected to MSA, but others related to the time of year or even the weather. If you are worried about constant low attendance then please contact us and we'll see if we can help with additional promotion of your group.**

## 8. Useful contacts



We know how important Support Groups are to people living with MSA and we know just how important your role is in making them happen.

Please do not hesitate to contact us if you need any help or information, we are here to support you. Both Emma and Andy would be your first point of contact but we have also listed people from other departments at the Trust which can help with particular queries.

Thank you so much again for dedicating your time to volunteering as a Support Group Leader and supporting people affected by MSA.

**Emma Rushton** (Support Services Officer) 0203 621 1348 . [emma.rushton@msatrust.org.uk](mailto:emma.rushton@msatrust.org.uk)

**Andy Barrick** (Head of Services) 0203 621 1347 . [andy.barrick@msatrust.org.uk](mailto:andy.barrick@msatrust.org.uk)

**Katie Rigg** (MSA Nurse Specialist) 01343 381932 . [katie.rigg@msatrust.org.uk](mailto:katie.rigg@msatrust.org.uk)

**Samantha Pavey** (MSA Nurse Specialist) 0203 371 0003 . [samantha.pavey@msatrust.org.uk](mailto:samantha.pavey@msatrust.org.uk)

**Jill Lyons** (MSA Nurse Specialist) 01934 316119 . [jill.lyons@msatrust.org.uk](mailto:jill.lyons@msatrust.org.uk)

**Karen Walker** (Chief Executive Officer) 0203 621 1344 . [karen.walker@msatrust.org.uk](mailto:karen.walker@msatrust.org.uk)

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# MSA Trust