

Ménière's Society

Setting up a Local Support Group

The Ménière's Society currently has around 20 local support groups in the UK; however, we have had many requests for groups to be set up in other areas. Local support groups can be incredibly beneficial to those living with a vestibular disorder. Some people may have had their confidence knocked and/or feel isolated by their condition. By attending a group where others understand how they feel can be very reassuring.

If you are interested in setting up a group but are concerned about what it would entail, here are some pointers which may help you decide whether you would like to go ahead.

Support Group

"A group of people with common experiences and concerns who provide emotional and moral support for one another"

Source: www.merriam-webster.com



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Tips and FAQs for setting up a support group

Would I be any good at running a group?

There are many different types of people who have set up and gone on to run very successful groups. The main qualities would include being organised, approachable, and supportive to others along with being happy to chat among a group of people. Some people may be nervous about attending a new group for a variety of reasons; perhaps they have lost their confidence in going out because of the fear of an attack or they feel anxious about being in social situations because of their symptoms. Therefore, you would need to be approachable and encouraging; you understand what it is like to live with a vestibular disorder and the feelings of anxiety which are so commonly associated with it. They may need support and encouragement to help them make the first step in attending their first meeting. During the meetings you don't need to be a fantastic public speaker, but it would be beneficial to be comfortable guiding the discussions. You would also need to respect confidentiality, especially if you are recording people's personal contact details. If you are not comfortable taking the lead but more suited to organising then that is not a problem; many of our groups are run by two people working as a team and using their own personal strengths.

What type of meeting would I be expected to run?

It's entirely up to you. Some groups are very informal, and meet up just for chat and a cup of tea; others however are more formal and have regular speakers presenting on related topics. Some groups encourage partners/friends to come along too. At the first meeting it would be helpful to discuss what type of group people would like.

How much commitment would I be expected to give?

The amount of time that you are willing to commit is completely up to you. Most support groups have meetings every two to three months. Meetings generally last between one to two hours depending on group attendance and how much you have to talk about. If you are running a group you may be contacted by people who are interested in attending. Similarly you would have to set some time aside to organise the date, venue, refreshments and possibly a speaker for the next meeting. Another good reason for sharing responsibility with someone else is that you can split the tasks between you both. They can also lead the group if you were unable to attend and vice versa.

I am not an expert in vestibular disorders nor do I have any medical knowledge, is that a problem?

No, not at all! The local groups are for people with vestibular disorders to share their experiences, tips and offer support to each other. The groups are not set up to offer medical advice or counselling; therefore group leaders/members should not set themselves up as an authority on medical matters unless qualified to do so. If people have specific questions relating to their condition or medication then they should contact their health professional. Alternatively, ring the Ménière's Society information line who can point them in the right direction or provide information sheets. The Ménière's Society would be happy to provide information sheets to be distributed at group meetings for a range of issues including driving, alternative therapies, treatments and copies of Spin. As previously mentioned, some groups do arrange speakers to talk to the group on various topics.

Where would I hold the group meetings?

Try and find a suitable public venue which is centrally located with good transport links. Start by contacting your local hospital, community centre, church or local business who may have a meeting room that you could use; if possible free of charge! Some people may choose to hold the meeting in a pub or café, although this may be more preferable when the meetings are more established and when people know each other, as some people may feel uncomfortable going into a pub alone initially.

What time of the day is best for group meetings?

This depends on your preference and it is beneficial to discuss it at the first meeting for future reference. Some group meetings are held during the day; however this means that those who are working are unable to attend, whereas others are held in the evening, which can be difficult for people who need to use public transport, or don't like travelling at night. Some groups alternate meetings; where one meeting is held in the day and the next meeting is held in the evening so everyone has the opportunity to attend at some point.

Will running a group cost me anything?

Obtaining free use of a meeting room is preferable, but not always possible. If you have to pay it's worth asking the people who attend the meeting if they are willing to pay a small contribution to the cost of the room and/or refreshments. You may also find a local business who would be willing to 'sponsor' your group. The Ménière's Society can provide a small, one-off sum to new groups to cover room hire,

postage and telephone costs. If you have additional costs please get in touch with us to discuss. All requests should be put in writing to the Director.

How do I let people know about my group?

The Ménière's Society will publicise your group's contact details and activities in Spin and on the Society's website and social media. The Ménière's Society could also help with publicising your group in the local media and contact members in your local area to ensure that they are aware of the new group.

What other support will the Ménière's Society provide?

Leaflets and information can be provided to pass onto those who attend the group and assist with ideas for speakers. The Society can also put you in touch with other group leaders to share ideas and resources. We can also arrange for one of the Ménière's Society staff members or a trustee to attend one of your group's meetings.

How can my group support the Ménière's Society

As a group leader, we ask you to encourage people to join the Ménière's Society. Membership subscriptions help us raise funds, enabling us to continue to develop the Society for the benefit of those with balance disorders, their families and carers. We also hope you will take part in Balance Awareness Week, as well as promoting the Society at every opportunity. Group leaders will be sent updates when activities are taking place throughout the year and we hope you and your group will participate.

Next steps

Once you have decided you want to set up a local group there are several steps you need to take:

- Decide and confirm a time, date and venue for your meeting.
- Contact the Ménière's Society with details of your group – complete the group details form (page 6).
- Advertise your group in the local area: put up posters/notices in the ENT department of your local hospital, GP surgery, library, community centre, newsagent or supermarket. Don't forget to ask permission first if necessary. Some people have also chosen to advertise in their local newspaper.
- The Ménière's Society can also contact members in the local area to let them know you are setting up a group. This is done from our office as we are unable to pass on personal details.
- If you intend to have a speaker at your meeting arrange this as soon as possible.

Top Tips for Running a Successful Support Group

Talk to leaders of existing groups.

Find out what has worked for them - and what hasn't!

Consider the dates, time and venue of the meeting.

Try to make meetings accessible as possible.

Advertise your group.

Put up notices in your local GP surgery, hospital, library, community centre, etc and let the Ménière's Society know the details of your group so it can be included in Spin too.

Communicate with the Ménière's Society.

We are here to provide information and support for you and your group too.

Keep meetings friendly and cheerful.

Remember you are there for mutual support, not to burden each other.

Don't let your condition put you off!

There will be days when people don't turn up for meetings – and sometimes that person could be you! Keep the group going as these are the times when you need the mutual support most.

Keep a contact list.

Make sure you know how to get in touch with people if you need to cancel or rearrange a meeting.

Don't worry if there is low attendance.

It can take time for groups to become established. Don't be disheartened, persevere and keep up with advertising your group.

Encourage group members to join the Ménière's Society

So they too can benefit from receiving Spin and the support offered.

Ménière's Society - Local Groups Contact Information Form

Thank you for giving your time to run a local support group for people affected by vestibular disorders. Please complete the form below with your group's contact details and publication preferences. Return your completed form by post to: Ménière's Society, The Rookery, Surrey Hills Business Park, Wotton, Surrey RH5 6QT.

Group Details		Publication Preferences <i>delete as applicable</i>		
		Spin Magazine	Ménière's Society Website	Ménière's Society Social Networks
Group Name ⁱ :		<i>Compulsory Listing</i>		
Group Leader Name:		Yes/No	Yes/No	Yes/No
Contact Name for Group: (if different from group leader)		Yes/No	Yes/No	Yes/No
Local Group Mailing Address:		Yes/No	Yes/No	Yes/No
Telephone Number:		Yes/No	Yes/No	Yes/No
Email Address:		Yes/No	Yes ⁱⁱ /No	Yes/No
Website (if applicable):		Yes/No	Yes/No	Yes/No
Meetings held at (address):		Yes/No	Yes/No	Yes/No
Forthcoming meeting dates and/or frequency of meetings:		Yes/No	Yes/No	Yes/No

Signature _____ Print Name: _____ Date: _____

Please keep us up to date with any changes to your group's details in the future. Many thanks.

ⁱ No Group shall be entitled to use the expression "Ménière's Society" in its title. Nor are they entitled to use the Ménière's Society's Registered Charity Number. Members of local support groups must not make statements purporting to come from the Ménière's Society without the prior approval of the Trustees.

ⁱⁱ If you choose to share your email address on our website, users will be able to email you direct from a link on the groups page of our website <http://www.menieres.org.uk/information-and-support/find-support-near-you>