How To:

Set Up a Local Support Group

Local support groups are incredibly beneficial for those living with a vestibular condition. Meeting with others who know exactly what you are going through can be supportive and reassuring; especially if the condition has made you feel isolated.

There are currently around 30 local support groups in the UK for people with Ménière's and related vestibular conditions. If you are interested in setting up a support group and you aren't sure where to begin, here's some useful information to help you get started…

> *A support group is a group of people with common experiences and concerns who provide emotional and moral support for one another.*[i]

Where do I start?

You already have! By reading this leaflet you're already thinking about it and taking the first step towards setting up a support group. Many different people have set up and run very successful groups. The key thing is to want to do it. It helps too if you are organised, approachable and supportive to others, and happy to chat among a group of people. Some people may be nervous about attending a new group, so it's important you are approachable and encouraging. You understand what it is like to live with a vestibular disorder and the feelings of anxiety commonly associated with it. During meetings you don't need to be a fantastic public speaker, but able to start and guide discussions. You also need to respect the confidentiality of people sharing their stories in the room and as well if you are recording people's contact details. If you are not comfortable taking the lead, but more suited to organising, don't worry, many of the groups are run by two (or more!) people working as a team.

What type of meeting would I be expected to run?

It's entirely up to you. Some groups are very informal and meet up for a chat and a cup of tea. Others 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 is helpful to discuss what sort of group people would like, and what level of commitment/resources you have to run the group. Consideration needs to be given on who your group is to be aimed at. Whilst only inviting those with a diagnosis of Ménière's is acceptable, it may limit your attendance numbers. You may want to consider opening it up to all those who suffer from a vestibular disorder as many of the symptoms overlap. The choice, however, remains as yours.

How much commitment would I be expected to give?

This is completely up to you. Most groups meet every two or three months. Meetings generally last between one to two hours depending on group attendance and how much you have to talk about.

Outside of meetings, 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. They can also lead the group if you were unable to attend and vice versa.

I'm not a medical expert, is that a problem?

No, not at all! The groups are not set up to offer medical advice or counselling and group leaders/ members should not set themselves up as an authority on medical matters unless qualified to do so. The local groups are purely for people with vestibular disorders to share their experiences, tips and offer support to each other. If people have specific questions relating to their condition or medication then they should contact their health professional. Alternatively, contact the Ménière's Society who can provide further information.

Where and when should I hold the 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 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. The time of the meeting depends on your preference and it is beneficial to discuss this at the first meeting. Some groups meet 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. We can also provide posters, completed with your groups' details, for you to advertise your next meeting i.e. in GP surgeries, community centres and hospitals. You may also want to publicise your group in the local media and contact members in your local area to ensure that they are aware of the new group. Previously, some groups have contacted their healthcare professional for them to mail shot those in their local are who are affected with vestibular disorders. The Ménière's Society suggests that you set up a generic email address for your group that people can use to contact you, rather than using your personal email address; however the choice is of course yours. The Ménière's Society group co-ordinator can advise on this if you need further information.

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. A newsletter dedicated to the support groups is sent out four times a year to inform you of what the Society is doing, fundraising opportunities and ideas from other groups on what they find works well.

The Ménière's Society Groups Co-ordinator is happy to answer any questions you may have, not only at the point of setting up your group, but also going forward. We want to make it as easy as possible for you to run your group and therefore provide support to those who suffer with vestibular disorders – so we are happy to help where possible.

> *I really feel supported in this by the Society. No longer out on a limb.*[ii]

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 (held yearly in September), 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.

Inspire your community to join the fight against vestibular disorders

As a local group you can engage, motivate and encourage the people in your area in a way that we can't. As our champions of the cause in your community you have got a real opportunity to raise vital funds as well as raise awareness of vestibular disorders and the work of the society. We can't continue our work without fundraising. You're a vital part of our fight for a world where vestibular disorders can do no harm.

Fundraising is a chance to be creative and enjoy yourself. We can help you organise a fundraiser, your way, to inspire your community to join the fight against vestibular disorders. We have fundraising materials available including: t-shirts, collection boxes, posters, sponsor forms and information booklets.

Please see the links below for more information, or contact us for a copy:

- A-Z Fundraising ideas
- Fundraising Pack

If you have any questions on fundraising, please contact: fundraising@menieres.org.uk

Next steps

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

- Contact the Ménière's Society so we can advertise your new group and collate interest. 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.
- Complete the group details form provided by the Ménière's Society.
- 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 placed adverts in their local newspaper or parish magazine.
- Once you have some interest, decide and confirm a time, date and venue for your meeting.
- 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 dates, time and venue of the meeting. Try to make them as accessible as possible.**
- **Advertise your group. Put up notices in your local area and let the Ménière's Society know the details of so it can be included in Spin and posted on the social media platforms.**
- **Communicate with the Ménière's Society. We are here to support you and your group too.**
- **Keep meetings friendly and cheerful. Be 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 most need the support.**
- **Make sure you know how to contact people if you need to cancel or rearrange a meeting.**
- **Don't be disheartened if there is low attendance. Persevere and keep up with advertising your group. It can take time for groups to become established. Bear in mind that not everyone will come to every meeting – some people will only come to meetings when they feel they need the support.**
- **Encourage group members to join the Ménière's Society so they can benefit from receiving Spin and the support offered.**

Safeguarding

Safeguarding is everybody's responsibility. We all have a role in keeping children and adults at risk safe. For further details on safeguarding roles and responsibilities for support group please contact our safeguarding lead at info@menieres.org.uk

Accountability

Please note the local support groups are:

- completely autonomous from the Ménière's Society
- responsible for their own finances
- not accountable to the Ménière's Society.

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. The Ménière's Society logo may only be used with the Ménière's Society's permission. Members of local support groups must not make statements purporting to come from the Ménière's Society without the prior approval of the Director or Trustees.

Contact us: Laura Fulco - Groups Liaison Officer
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Ménière's Society
for dizziness and balance disorders

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[i] Source: www.merriam-webster.com Last accessed 01.02.17
[ii] Source: Comments from a current group leader in 2018