

#004 Support & Guidance

Family, Friends & Colleagues



If you are a family member, friend or colleague of someone with a vestibular disorder, it is important to understand as much as you can about their condition. Everyone is affected differently so it's important to understand how your loved one is affected, what symptoms they may experience and their specific needs. By being informed, you can help them to feel supported and more confident.

What is a vestibular (inner ear) disorder?

The balance system works by coordinating information in your brain from the three senses used for balance: (i) the balance organ in your inner ear, (ii) your eyes and (iii) your internal sense of the position and movement of your body. If you feel dizzy it means your brain has not been able to coordinate the information from all the balance senses properly.

Ménière's is a long-term progressive condition affecting both the balance and hearing parts of the inner ear. Ménière's occurs when there is a build-up of pressure in the fluid in the endolymphatic sac in the inner ear. Why this happens is not fully understood. The four main symptoms are fullness in the affected ear, tinnitus, hearing loss, which is temporary in the first stage but becomes permanent as the disease progresses and most distressing of all, vertigo (severe dizziness) usually unpredictable and rotating which can last for hours. Other vestibular disorders, such as labyrinthitis or endolymphatic hydrops have similar debilitating symptoms of dizziness for those affected.

How does it affect people?

Vestibular disorders can be very debilitating. They can be frightening as the symptoms are unpredictable; an individual can experience relapses as often as remission. Symptoms can last anywhere from a few days up to a few months and then subside into remission for a similar period of time. People who have Ménière's or another vestibular condition, however, are frequently determined to lead as normal a lifestyle as possible.

When any of the information from your three balance senses changes or is incomplete, your brain has to adjust to the different information it is receiving and coordinate it to maintain balance (or as good a sense of balance as is possible). This is a gradual process and can take up to several weeks or even months for your brain to do, depending on how big the change in the information was, and how often, they formulate management plans in conjunction with their health professional to help them cope with the condition. At home most family members are involved in management and learn how to help instigate an action plan if a vertigo attack occurs. This support is beneficial as social contact can, for some people, become limited for fear of experiencing a vertigo attack in public.

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 **Ménière's & Vestibular UK**

As a friend, relative or colleague you may feel...

- *Bewildered:* One minute they look perfectly healthy and engaging in normal activities, the next they can't walk or talk. They may be confused, vomiting and distressed.
- *Disruption:* Your life is likely to be disrupted from time to time. For example, if you are just getting ready to go to a dinner party when suddenly your partner goes into a spin. You rush to find a suitable container for them to be sick into and then cancel all your plans; all dressed up and nowhere to go! Or, you are out in a large shopping complex or about to go into a meeting when they are struck down. Embarrassment is mixed with concern, not to mention the logistical problems.
- *Frustration:* You may find yourself asking questions, such as: 'Why can't I do more to help?' 'Why don't they want to go to our family gathering?' 'Why can't they go shopping on their own?'
- *Anger:* You may think, why us? Why can't they find a cure?

All these feelings are valid, but it is how you express them which can have a profound effect on the person with a vestibular disorder. Whatever you do don't say "pull yourself together it's all in the mind". They have a physical condition for which, in the case of Ménière's, there is no known cause or known cure. They may be feeling a burden on you. In worst cases, they may even have thoughts of suicide as the psychological impact can be so severe.

Listen to their fear and anxieties, they are real and understandable, no one can predict when an attack is going to occur. Don't wrap them up in cotton wool but help them to take up their normal activities when they have recovered from an attack, which may take a couple of days. It is important that those affected are seen by an experienced specialist.

What is needed most is your care, love, reassurance, understanding, patience and acceptance.



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Clear speech

Sorry, what did you say?' must be the most overused words in the vocabulary of hard of hearing people! For verbal communication to work it must be a two-way link. If one link breaks down the whole effort becomes useless. Speech for the hearing impaired must be easily understood, audible, intelligible and articulate. This will also help those who depend entirely on lipreading. We all know the frustration and embarrassment which occurs when those who try to communicate with us, fail to get their message across. They can shout, get irritable, snap isolated words and generally make things worse.

Tips for clear communication

DO ✓

- Ensure the light is on your face.
- Face your listener(s) all the time.
- Speak clearly.
- Give an indication of what you are discussing.
- Open your mouth and frame each syllable properly; but do not over emphasise.
- Ensure you are understood before continuing.
- Rephrase the message instead of repeating

DO NOT ✗

- Speak through clenched teeth or closed lips.
- Shout or mumble.
- Change the subject suddenly.
- Look away or down when speaking.
- Put your hand in front of your mouth or speak with anything in your mouth.
- Fidget with your hands, head or body.
- Say 'never mind, doesn't matter' if not heard.

Vertigo: Information for employers and colleagues

If someone you work with has a vestibular disorder, the most important thing you can do is be understanding. Everyone is different. Ask them how they are affected and if anything specific triggers their symptoms.

Some things to think about:

- What are the acoustics like in the office?
- Is there natural light? Are there any strong smells?
- How would someone with hearing loss know if the fire alarm sounded?
- Do you face people when you talk to them?
- Do you encourage regular breaks away from computer screens?
- Are there any work stress and worries which can be avoided?



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A-Z action plan for employers

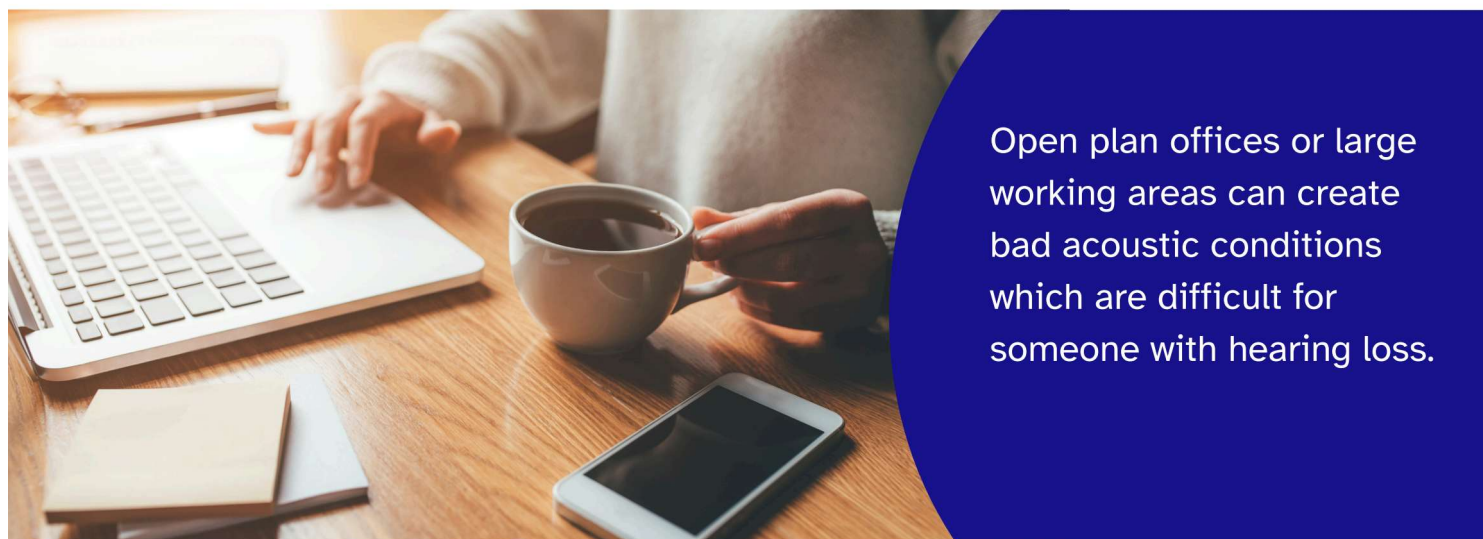
Practical steps to help you and your colleagues in the workplace

- **Access to work:** The Access to Work programme is run by the Employment Service. It provides financial assistance towards the extra costs of employing someone with a disability. For further information visit gov.uk/access-to-work
- **Acoustics:** Open plan offices or large working areas can create bad acoustic conditions which are difficult for someone with hearing loss. High ceilings, hard floors and surfaces all add to the reverberation of sound around the room. Desks next to windows, against a wall or acoustic screens all aid in cutting down the noise 'bouncing' around the room. As an effect of this concentration levels improve through less distraction.
- **Communication:** Most of these tactics your employee may already be implementing, but they are still worth knowing from your perspective. To improve communication the distance between you and the person with hearing loss should only be four to six feet. This enables lipreading to occur alongside observations on body language and facial expressions. The lighting needs to be good so as not to throw a shadow across the speaker's face.
- **Computers:** Most computers have LCD screens which do not flicker and have much less glare. Setting the environment properly with the correct seating height, screen angle and brightness setting can also help. Some people have also found that experimenting with screen tints/colours is helpful. If movement is a problem the employee may find it helpful to use keyboard shortcuts rather than the mouse scroll wheel. It is important to take regular breaks away from the computer screen.
- **Confidence building:** Your employee may be embarrassed by their condition. A quip or comment regarding hearing loss may dismantle months of confidence building. Ensure time at one-to-one sessions to review the fact sheet and ensure you are both getting the best results.
- **Environment:** If possible, try to provide a work environment free of patterned carpets and walls as these can affect people suffering from vertigo. In addition, try to provide an alternative to fluorescent lighting as they produce a flicker which can have an adverse effect on sufferers.
- **Equality Act:** The Equality Act 2010 prohibits, amongst other things, discrimination of disabled people in employment and requires the employer to make 'reasonable adjustments' for a disabled person or employee if they are at a substantial disadvantage in relation to a non-disabled person.



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- **Fire alarms:** Your employee may not be able to hear the fire alarms in the building. As part of the action plan, ensure they know when test days are and at what time to avoid concern. If possible, equip their working area with visual indicators as well as audio alarms. If in any doubt consult your local Fire Department who should be able to advise further on your employees' safety.
- **Flexible Working:** Where possible, implement flexible working for the employee, such as modified or part-time hours, a flexible leave schedule or working from home.
- **Lifts:** Access to lifts or ground floor desk space can help your employee; walking up and down stairs may bring on dizzy spells for some individuals.
- **Lipreading:** Your employee will pick up around 30% of the words you speak via lipreading. To make this easier for your employee, they need to see your lips. Covering your mouth with your hand, smoking, eating, drinking or even facial hair makes this difficult. The best way to improve this, is to request feedback from your employee at one-to-one sessions.
- **Masks:** If you need to wear a mask, please try to use a clear face mask or visor when communicating with employees with hearing loss as they rely on being able to see your mouth. If this is not possible and/or you are unable to remove your mask for health and safety reasons, please ask how you can assist them in this situation, such as using alternative visual cues (e.g. written instructions).
- **Other employees:** Colleagues may also benefit from this information. Please contact Ménière's & Vestibular UK for additional copies of this factsheet.
- **Relaxation:** Implementing relaxation can reduce the fear of symptoms. Most people with Ménière's understand that panic negatively affects the way they handle a vertigo attack. Techniques such as simple breathing exercises or muscle relaxation reduce extra symptoms. In the workplace, many employers now offer their staff on-site relaxation classes, such as massage and reflexology.
- **Staff facilities:** The nearer the better and, preferably, on the same floor as there may be times when a person with a vestibular disorder such as Ménière's needs to use toilet facilities urgently. Access to fresh water dispensers are excellent for all staff and are more convenient for someone with Ménière's disease; particularly if they have to take their medication.
- **Telephones:** Amplified phones can be a great asset for someone with a hearing loss. They aid by giving amplification and some improvement on clarity. Another key element lies in the fact that most amplified phones accept appliances such as headsets and extra earpieces.



Open plan offices or large working areas can create bad acoustic conditions which are difficult for someone with hearing loss.



In summary

- Vertigo can come without any warning; people have no control over their vestibular symptoms.
- Symptoms are unpredictable and can fluctuate - they might be 'ok' one day, but not the next!
- People's symptoms can vary and how they deal with them can vary too – ask them what helps them.
- Listen to them! Your support is invaluable. What symptoms are they experiencing? Do they have hearing loss, tinnitus, headache or fullness as well as dizziness? Does one symptom affect them more than another.
- Vertigo (severe dizziness) can sometimes make people nauseous/sick.
- Are there plans in place for coping with a vertigo attack in the office, when away from home or on their own? Can they get home from work safely?

Employer awareness

Contact us for more information about our employer awareness sessions. Introduce your team to balance disorders and help them support you in the workplace.

Disclaimer

You should always consult your GP, consultant or therapist for professional guidance before you begin, change, temporarily suspend or discontinue any treatment, medication, exercise or diet. Ménière's & Vestibular UK cannot advise on individual cases nor accept any liability resulting from the use of any treatments or information referred to in this resource. To the best of our knowledge, information correct at time of publication.

Further factsheets

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