

Understanding vertigo for family, friends and employers

An important part of the management of vestibular disorders is the ability of relatives and friends to understand what their loved one is experiencing and providing appropriate care. At the same time trying to overcome the bewilderment of the situation which is not characterised by the usual visible symptoms and medicinal cures of more common complaints. It is important that you understand as much as you can about their vestibular condition. Being informed will assist you to be a good friend or employer which, in turn, will help the individual affected by a vestibular condition to regain their confidence.



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 that your brain has not been able to coordinate the information from all the balance senses properly. This could be due to a problem in the brain, or with any of the three senses. In Ménière's and other balance disorders, the balance organ in the inner ear is affected. The inner ear is comprised of the balance organ (semicircular canals) and hearing organ (cochlea).

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. Often they formulate management plans in conjunction with their health professional to help them cope with the disease. At home most family members are involved in management and learn how to instigate an action plan if a vertigo attack occurs. This support is extremely beneficial as social contact often becomes limited for fear of experiencing an attack in public places.



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As a close friend or relative you may feel...

- **Bewildered:** One minute your friend or loved one is looking 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 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 of 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 will be feeling a terrible 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 because 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 as soon as they have recovered from an attack, which may take a couple of days. It is important that the person affected is seen by an experienced specialist. What is needed most is your care, love, reassurance, understanding, patience and acceptance.

Clear Speech

'*Sorry, what did you say?*' must be the most overworked words in the vocabulary of hard of hearing people! For verbal communication to be enjoyed 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.

Some Do's And Don'ts For Clear Communication

DO

- Ensure the light is on your face.
- Face your listener(s) all the time.
- Speak clearly and reasonably slowly.
- Give an indication of what you are talking about.
- Open your mouth and frame each syllable properly but do not over emphasise.
- Ensure you are understood before continuing.
- Try to rephrase your message.

DO NOT

- Speak through clenched teeth or closed lips.
- Shout or mumble.
- Change the subject suddenly.
- Turn your head away or look down while 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, it doesn't matter" if not heard.



Vertigo: Information for Employers

If someone you employ is experiencing vertigo from Ménière's or a similar vestibular disorder the most important thing you can do is to try to understand what the person is experiencing. The person has no control over their symptoms and your support could prove invaluable. Listed below are several practical steps which can be taken to help you and the employee in the workplace:

A-Z Action Plan for Employers

- **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 www.businessdisabilityforum.org.uk
- **Acoustics:** Open plan offices or large working areas can create bad acoustic conditions. High ceilings, hard floors and surfaces all add to the reverberation of sound around the room. The main problem with these surroundings comes from the accompanying hearing loss with Ménière's disease. 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 Tactics:** 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 Ménière's 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 the mouse scroll wheel. Regular breaks away from the computer screen can be beneficial.
- **Confidence building:** Your employee may be embarrassed by their condition; they need your help to build confidence to ensure a normal lifestyle. A quip or comment regarding hearing may dismantle months of confidence building. Your employee needs the confidence in you to discuss any issues. 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.
- **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 the 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 you are 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 as 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 improve this, is to request feedback from your employee at one-to-one sessions.
- **Other employees:** Colleagues may also benefit from this information. Please contact the Ménière's Society for additional copies of this factsheet.
- **Relaxation:** By implementing relaxation the fear of the symptoms can be reduced. Most people with Ménière's understand that panic negatively affects the way they handle an attack of vertigo. 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 Meniere's disease 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.

Useful contacts

ACAS

www.acas.org.uk

ATLA (Association of Teachers of Lipreading to Adults)

www.atlalipreading.org.uk

Citizen's Advice

www.citizensadvice.org.uk

Equality and Human Rights Commission

www.equalityhumanrights.com

GOV.UK

www.gov.uk

Contact the Ménière's Society for further information:

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Disclaimer: The Ménière's Society recommends that you always consult your GP, consultant or therapist for professional guidance before you begin, change, temporarily suspend or discontinue any treatment, medication, exercise or diet. The Society cannot advise on individual cases nor accept any liability resulting from the use of any treatments referred to in this information sheet. Information correct at time of publication.

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