



Supporting an employee who has Neurofibromatosis Type 2 (NF2).



What is NF2?

You will want to give any employee who has a medical condition the appropriate support. This can be difficult when faced with a relatively obscure condition such as Neurofibromatosis Type 2, so this leaflet provides some basic information and directions to resources for further support.

Neurofibromatosis Type 2 (NF2) a rare genetic condition caused by a “misspelling” on chromosome 22. NF2 occurs in 1 in 30,000 of the population.

NF2 patients will need operations or other treatments for brain or spinal cord tumours. Also, people will develop tumours typically in the brain and spine. The hallmark of NF2 is the development of benign tumours called vestibular schwannomas which grow on both hearing nerves. These tumours can cause hearing loss, deafness, and mobility problems due to the pressure exerted on key nerves. Benign tumours may also develop on the nerve roots as they leave the spine and on the coverings of the brain. Some people with NF2 have a few benign tumours on the skin nerves.

Who can I talk to?

Nerve Tumours UK Specialist Support

Nerve Tumours UK helps fund a team of Support Specialist in a number of regions across the United Kingdom. These specialists work to improve the lives of those affected by Neurofibromatosis and provide crucial support to patients and families.

National Helpline

Another service we work to maintain is our national helpline. **Open Mondays and Wednesdays 9am–5pm**, if you need someone to talk to or some help getting to the right place. **Call 07939 046 030 or email helpline@nervetumours.org.uk**

Nerve Tumours UK Website

Head over to our website site to find out more information on Neurofibromatosis Type 2 (NF2) and where you can find more help. **www.nervetumours.org.uk**

A guide to typical challenges where support is needed.

Identifying strengths and weaknesses is a starting point. Your employee has lived with Neurofibromatosis all their life and will know what they can do... and what they find difficult.

It is likely that your employee will have some problems with their hearing. They may have become deaf and have no hearing at all, relying on lip reading skills. It is important to take account of this especially when speaking.

Hearing

- Shouting will not help! **Speak clearly** and ensure your face can be seen by the person who is hearing impaired.
- Try not to turn your head away or cover your mouth. This will help the person to lip read and improve communication.
- Ensure seating is appropriate and ask for advice from your employee about what position helps them most. Remind attendees at meetings to face the person with hearing difficulty, and not to talk at the same time.
- A round table may be most helpful. In meetings ask people to speak one at a time. Ask the Chair to repeat questions as they are asked to help focus the meeting and to clarify the subject under discussion.
- Ask for deaf awareness training for all staff. There will be contacts locally.
- Delegate some tasks to other hearing members of the team. Use a colleague to support the hearing impaired employee if needed.

Balance

- If your employee has balance difficulties ensure lighting is good and minimise trip hazards.
- Ensure safety at all times especially if announcements are used to alert staff.

Practical advice about hearing loss support in the workplace please look at:

www.actiononhearingloss.org.uk

www.hearinglink.org



Do you have nerve tumours? We're here to help.

nervetumours.org.uk
info@nervetumours.org.uk
020 8439 1234

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Our Nerve Tumours UK Specialists are available to offer support to anyone living with nerve tumours.

Call our helpline on 07939 046 030
Monday and Wednesday 9am-5pm

Nerve Tumours UK
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Never Tumours UK is the trading name of the Neurofibromatosis Association.
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