



Supporting an employee who has Neurofibromatosis Type 1 (NF1).



What is NF1?

You will want to give any employee who has a medical condition the appropriate support. It can be difficult when faced with a relatively obscure condition such as Neurofibromatosis Type 1, so this leaflet provides some basic information and directions to resources for further support.

NF1 is a common genetic condition that causes nerve tumours to grow where they shouldn't. The "spelling mistake" in the gene is found on chromosome 17 and occurs in 1 in 2,500 of the population. There are approximately 25,000 people in the UK diagnosed with NF1.

NF1 varies widely in how it affects those who have the condition. Many people with the disorder will be affected very mildly and may have nothing more than skin changes. A minority of people (around a third) who have NF1 will have medical problems related to the disorder at some time in their life. Some of these problems will be mild and easily treatable and others will be more severe.

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 1 (NF1) and where you can find more help. **www.nervetumours.org.uk**

A guide to typical challenges where support is needed.

If your employee has NF1

A range of mild learning difficulties is quite common in NF1. Not everyone with NF1 has these difficulties. When someone has NF1 and problems with learning, it is unlikely they will have all the problems listed below. It is important to identify what your employee's particular challenges are by asking them to describe these.

Talk to your employee about what they find difficult

Identifying strengths and weaknesses is a starting point. Your employee has lived with NF1 all their life and will know what they can do... and what they find difficult. Their difficulties may arise directly from health factors or because they have mild learning difficulties.

Sometimes there can be apparent inconsistencies in some of the difficulties someone has with NF1. For example, you may notice that a skill you assumed had been mastered may need to be "re-learned" if you move an employee to a different setting or environment. This is not a major problem...it just needs a little thought and planning.

Under the Equality Act reasonable adjustments must be made in the workplace to support employees with disability. These do not necessarily involve major costs and can often be achieved by relaxing arbitrary rules, or by listening to your employees' concerns.

In the instance of an underperformance that is a direct result of their NF1, the employer should consider redeployment rather than lose a skilled member of staff.

Here are some examples of the sorts of learning problems that can occur and suggestions about how to help:

Concentration Difficulties

- Ensure you have the employee's attention and use simple plain English.
- Break instructions into manageable bits and check for understanding.
- Reduce distraction (noise, movement).

- Move employee to a quieter (but not isolated) area.
- Consider a mentor until your employee has mastered the task.
- Practice it until confident and allow a brief break before going on to the next task.

Language Difficulties

- Give short sentence instructions.
- Use plain English.
- Avoid figures of speech (e.g. don't say "We are all in the same boat" but do say "We all feel the same about...")
- Some people with NF have unclear speech. Some may have difficulty expressing themselves, but know what they want to say.
- Pause between instructions, check understanding, yours and theirs.

Memory difficulties

- Simplify information.
- Give short sentence instruction.
- Reinforce point by point or offer a visual prompt.
- Repeat information.
- Check to ensure understanding.

Organisational Difficulties

- Help employee to know the starting point.
- Demonstrate the task and offer prompts and reminders.
- Provide visual reminders of each step.
- Break large tasks down into smaller steps.
- Use different coloured folders/paper for different tasks.
- Offer calendars, diaries, organisers etc.

Lack of Confidence

Adults with NF1 may have had significant problems in school. That experience can lead them to seem unwilling to try new tasks. But with encouragement and the right approach they will do well.

- Play to their strengths.
- Everyone thrives on praise when a task is done well.



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
First Floor, 44 Coombe Lane, London SW20 0LA

Never Tumours UK is the trading name of the Neurofibromatosis Association.
Registered Charity Number: 1078790 and SC045051