



Neurofibromatosis type 1 and employment...some useful information that an employer needs to know.

Recruiting and retaining reliable staff can be a problem. Employers who actively seek applicants with a disability tap into a wider choice of potential employees. These employees bring a range of skills and a positive and enthusiastic attitude to the workplace. Research has demonstrated that people with disabilities have better attendance records and remain loyal to their employer for longer compared to non-disabled people.

By targeting this group an employer enhances their public reputation and incidentally fosters good relations with existing staff.

Employers also have the advantage of accessible support from Job Centre Plus if needed and guidance from a Disability Employment Adviser.

Neurofibromatosis in brief

Neurofibromatosis (NF) is a variable and unpredictable genetic condition.

There are 2 separate conditions: NF1 and NF2. They are different and can cause different health problems.

NF1 is comparatively common. It causes lumps and bumps (tumours) to grow on nerves. The lumps are called neurofibromas and can be seen on the skin. These are not infectious; they cannot be passed on to anyone by touch (not contagious). However they are distressing for the person concerned and a source of embarrassment for some.

The most common problem in NF1 is mild difficulties with learning. People tend to have a normal IQ but their way of learning benefits from a modified approach.

Some people with NF1 have more difficult health problems to manage.

NF2 is a separate and different condition. It is rare. People will have lumps growing in their brain and spine. They will have hearing loss. They may have balance difficulties.

For more detailed information about NF1 and NF2 please look at the appropriate fact sheets on our website. The likely needs of people with NF1 and NF2 are different. It is important to understand these so you can maximise your employee's contribution to the workplace

THIS INFORMATION IS ABOUT NF1

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 this 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.

Consider redeployment rather than lose a skilled member of staff.

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 of the problems listed below. So it is important to identify what your employee's particular difficulties are by asking them to describe these.

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

<p>Concentration difficulties Ensure you have the employee's attention Use simple plain English Break instructions into manageable bits 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 Allow a brief break before going on to the next task</p>	<p>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 people have difficulty expressing themselves...but know what they want to say Pause between instructions Check understanding...yours and theirs!</p>
<p>Memory difficulties (especially short term/working memory) Simplify information Give short sentence instruction Reinforce point by point or offer a visual prompt Repeat information Check to ensure understanding</p>	<p>Organisation difficulties Help employee to know the starting point Demonstrate the task and offer prompts and reminders Provide visual reminders of each step Break larger tasks down into smaller steps Use different coloured folders/paper for different tasks Offer calendars, diaries, organisers etc.</p>
<p>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 Often resourceful, conscientious and hard working Everyone thrives on praise when a task is done well</p>	<p>Social skill difficulties Prefer routine and can be upset by change... so prepare for this in advance by explaining what the changes will be Can be shy, "a loner", awkward with others and may appear rude inadvertently Explain rules clearly and simply Explain unwritten social rules (e.g. dress code, if employees use a specific chair or mug) Explain "custom and practice" Offer mentoring/support by more experienced employee if needed</p>

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