



## **Employment and Neurofibromatosis**

Having a diagnosis of Neurofibromatosis does not necessarily mean that you will have problems finding and keeping a job. Many people with NF have successful and fulfilling careers employed in an occupation that they enjoy.

People with NF have a lot to offer an employer: they are often hard-working, conscientious and reliable. They have also learnt how to be resourceful, skilled at working out strategies to overcome potential problems.

However a proportion of people do run into difficulties because of their diagnosis either because they have specific health factors that impact on their employment, or they may have learning difficulties that need additional resources and understanding.

The Equality Act (2010) ensures people with disabilities are protected from discrimination, including in the workplace.

### **Am I disabled? Does this affect me?**

The act defines disability in this context as a person who has a "physical or mental impairment" that has a "substantial and long term (ie more than a year) impact" on their ability to perform day to day activities.

Having a diagnosis of Neurofibromatosis does not mean that you are automatically a "disabled" person. NF is variable: some people have few if any health problems. Others will have significant health factors that affect their daily life and consequently may restrict what work they can do.

As NF is so variable each person is affected differently and so it will be up to each individual to explain about how NF affects their health.

### **What shall I tell my employer when I have NF?**

When applying for a job, some employers ask applicants to complete a health questionnaire. This is usually given at the point when a job offer is made. If you have health factors arising from the diagnosis of NF that will impact on your work these should be declared. This is so that "reasonable adjustments" can be made to support those difficulties. For example if you have hearing loss and will need additional resources to support effective communication in your workplace.

If you consider that the offer of a job has been withdrawn because of the information disclosed on the health questionnaire this is unlawful and should be challenged.

Some people worry that by disclosing a diagnosis of NF they put themselves at a disadvantage. The Equality Act specifically addresses this by stating that you have a right to fairness, equal treatment, respect and understanding at work and legal redress if an employer is failing to meet this requirement.

It is important to be realistic when applying for a job. Clearly there are some occupations that are incompatible with particular health needs: so someone who has a scoliosis, back pain or spinal tumours could be unable to perform a job involving heavy lifting no matter what adjustments an employer was able to make.

If you are employed but can no longer perform your job, consider what transferable skills you have and whether these could enable you to retrain within the company. Flexibility is valued by employers and they may prefer to keep a trusted employee rather than lose you.

### **Help to find work when you are disabled**

There are a number of organisations that can help you find work, stay in work or retrain to offer new skills to prospective employers. These include Jobcentres, careers services and some voluntary organisations.

If you have health factors that affect your ability to work you may be referred to a Disability Employment Adviser (DEA). The role of the DEA is designed to support people with disabilities and to help them into work.

The DEA can undertake an employment assessment to identify the type of work or training most suited to you. They can highlight jobs that match your skills and experience and they can refer you to the Work Programme to help prepare you for work. They can also refer people to special programmes such as Work Choice or Residential training. A DEA can also refer you to a Work Psychologist who will undertake a full assessment to help you prepare to find work and stay in work.

### **Two Ticks**

Some employers have a particular commitment to employing and supporting disabled people. These employers can be identified by this symbol:



Employers with the two ticks symbol will interview all applicants with a disability who meet the minimum criteria for the job, providing they clearly demonstrate this in their application.

### **Can't find a job...what else can I do?**

Offering your service as a **volunteer** can also be a good way to prepare for work as it helps you gain new skills, increases your contacts and builds confidence.

Sometimes the Jobcentre can link you to volunteering schemes through the programme called Work Together. If you are thinking of volunteering then talk this over with the Jobcentre, and make sure you know if the scheme will affect any benefits you receive.

It might be worth considering retraining or returning to an education setting for a change of career or to increase your skills. Your nearest **college** is a good place to start. Colleges will have a department to offer support and advice to students with disabilities.

If you are aged between 16 and 25 the **Prince's Trust** can help you. They run different courses to help young people gain experience, new skills and motivate you to get your life working. For young people who have found school difficult or whose life has taken a wrong turn the confidence building course run by the Prince's Trust can be particularly helpful. The trust also makes grants to help people aged 18-30 set up their own business. For more information look at [www.princes-trust.org.uk](http://www.princes-trust.org.uk)

There are other organisations such as **Shaw Trust** whose aim is specifically to help people with disabilities find work and then offer support to help them remain successfully in the job. More information can be found on their site [www.shaw-trust.org.uk](http://www.shaw-trust.org.uk).

Not all areas of the country are covered. It will depend on where you live. If you cannot easily access a computer remember your local library can help and will have computers available for you to use there.

Different parts of the UK may have their own schemes to help you with work. Find out what is available in your area through the DEA.

Finally there is a very helpful website [www.directgov.uk/disability](http://www.directgov.uk/disability) that gives detailed information about disability and work related matters.

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**Please seek further information from [www.nervetumours.org.uk](http://www.nervetumours.org.uk), or contact our helpline on the details above.**

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