

Narcolepsy Need-to-Know Guide

Work and Narcolepsy

Having narcolepsy does not necessarily stop someone from doing the job they want, but there are some issues which can affect work.

Narcolepsy and its symptoms

Narcolepsy is a neurological disorder, the effect of which is that the part of the brain that controls sleep and wakefulness does not function as it should. The messages about when to sleep and when to stay awake get mixed up. When you have narcolepsy, your brain moves between the stages of sleep at inappropriate times. These changes cannot be controlled and this results in a number of symptoms.

The symptoms that are most likely to have an impact on working life are:

Excessive daytime sleepiness

A continual feeling of tiredness and an irresistible urge to fall asleep during the day. This may cause someone to fall asleep at inappropriate times and in unusual places. Even if not asleep, they may be very drowsy and preoccupied with trying to resist the urge to sleep.

Cataplexy

A sudden episode of muscle weakness, usually triggered by strong emotion, mainly laughter, anxiety and anger. These episodes can last a few seconds or minutes, and may involve the muscles of the face and neck and upper or lower limbs. The head may droop and speech may become slurred. More severe episodes may cause the person to drop things or become unsteady, which may result in them falling to their knees or to the ground. It is important to note that cataplexy does not involve a loss of consciousness; the person affected is fully aware of what is happening.

Microsleeps and Automatic Behaviour

A person with narcolepsy may seem to be dreaming or is unresponsive when spoken to. This may last from a few seconds to a minute, and during this time the person is asleep. These episodes are called **microsleeps**. Microsleeps are often not obvious and are easily overlooked.

During a microsleep, the person may carry on with a task that they are involved in. This is known as **automatic behaviour**. The person will have no memory of this. They may appear confused and disorientated following these episodes.

Not everyone with narcolepsy has all of these symptoms. However, almost all suffer from excessive daytime sleepiness and many also exhibit cataplexy. The severity of the symptoms may vary considerably from one person to another.

Whether someone's narcolepsy affects their work depends on the nature and severity of their symptoms, and how well controlled those symptoms are.

Of course, it also depends on the nature of the work, and any risks that could arise as a result of, for instance, excessive sleepiness or cataplexy. Two important laws that are relevant to these issues are the Health and Safety at Work Act 1974 and the Equality Act 2010.

Health and Safety Law

The Health and Safety at Work Act 1974 makes employers responsible for ensuring that the workplace is safe for all their employees and that all employees are protected from potential dangers to their health. It is important to note that employees are also responsible for their own safety at work, as well as for the safety of their colleagues.

Equality Law

The Equality Act 2010 protects people against discrimination, including discrimination on grounds of disability.

Disability is defined in the Equality Act 2010 as “a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities”.

“Substantial” means that it is difficult or time-consuming to do activities compared to someone without a disability, and “long-term” means for a period of at least twelve months. “Day-to-day activities” include being able to get around, remembering things and being able to concentrate.

Narcolepsy is a physical, life-long condition and people with narcolepsy are therefore protected by the Equality Act 2010, even if their symptoms are well controlled, and even if they do not regard themselves as being “disabled”.

Types of Disability Discrimination

Discrimination on the grounds of disability may take numerous forms, all of which are recognised and addressed by the Equality Act 2010.

Direct discrimination

It is illegal for an employer to treat someone with a disability worse than a person without a disability, without a justifiable reason.

There are several different types of direct discrimination:

Perceived discrimination occurs when someone is treated unfairly because it is assumed that their disability affects their ability to carry out day-to-day activities. An example would be to assume without any basis that a person with narcolepsy is not able to do a job as well as someone who does not have narcolepsy.

Associative discrimination occurs when someone is treated unfairly because they are connected to someone who has a disability. An example of this type of discrimination would

be not to appoint or promote someone because they have a dependent relative with narcolepsy.

Harassment means being treated differently because of a disability, without justification and in a way that is humiliating or offensive.

Indirect discrimination

This is treating everyone the same, but in a way that places someone with a disability at a disadvantage. For instance, a rule that “everyone must use the stairs” is unfair to people who use wheelchairs. Employers must be aware that, in order to treat all employees equally, they may need to treat an employee with a disability differently from someone without a disability.

Discrimination arising from disability

This is treating someone unfairly because of something connected with their disability. For instance, this type of discrimination would occur if someone with a visual impairment were told (without a justifiable reason) that they could not bring their guide dog to work.

Failure to consider making reasonable adjustments

Reasonable adjustments are changes that employers are expected to consider making so that a person with a disability is not placed at any disadvantage.

Victimisation

This is treating someone unfairly because they have complained about any form of discrimination, whether their complaint is in relation to themselves or on behalf of someone else.

For people with narcolepsy

As for anybody, the type of work you can do depends on your skills, qualifications, and your experience. It may also depend on how your narcolepsy affects you.

Can I do any job I want?

Not necessarily. All employers have to comply with safety and equality laws, which:

- cover you when you apply for a job, throughout your work (including promotion and training) to when you leave it; and
- apply whether you have a disability when you apply for a job or if your disability starts once you are employed.

Employers cannot legally refuse to give you a job just because you have narcolepsy. However, they do have to consider your narcolepsy, and what the job entails, to ensure your safety and that of other employees.

Safety at work

Risks to safety will depend on what your narcolepsy is like and what the job involves.

Some jobs may be a risk if you have excessive sleepiness or cataplexy attacks. Examples include working around unguarded machinery, and working at heights or around open water.

Each situation is different, and so your employer will need to carry out a risk assessment to examine how your narcolepsy could affect the safety of yourself and others at work.

Can I do a job that involves driving?

Many people with narcolepsy are able to drive, and if DVLA is satisfied that your symptoms are well enough controlled for them to issue you with a driving licence, then you should be able to do a job that involves driving. Some employers may take your ability to drive into account when conducting a risk assessment. For instance, if DVLA is satisfied that you can drive safely, your employer may decide you can work with machinery.

Other health and safety regulations

Many professions have a governing body that sets Health & Safety regulations. They will usually look at your individual situation to see whether you can do the job safely.

Reasonable adjustments

An employer needs to consider making adjustments that may help you to do a job as well as any other employee. This means looking at:

- anything about the job that is difficult for you to do or could put you at risk;
- anything about the work environment that makes it difficult for you to do the job or could put you at risk; and
- whether any changes to the job or work environment would help to overcome these problems or risks.

The aim is to make sure that as a disabled person you have, as far as is reasonable, the access to everything that is involved in getting and doing a job as a non-disabled person.

Adjustments vary and will depend on how your narcolepsy affects you and your work. Your employer can make adjustments when you apply for a job, or at any time during your employment.

Adjustments for narcolepsy could include:

- flexible working hours to allow for naps;
- provision of a designated sleep room where a person with narcolepsy can take an undisturbed nap;
- allowing time off for medical appointments.

Help with finding a job

You can look for a job through your local Jobcentre Plus office, personal contacts, newspaper and website adverts or employment agencies.

Jobcentre Plus offices have Disability Employment Advisers (DEAs) who provide support to people with disabilities. They can help with assessments, referral to schemes for people with disabilities (such as Work Choice), job matching, and information on employers who are positive about employing people with disabilities.

If you are on benefits, you can ask your local Jobcentre Plus about how your benefits might be affected.

Telling people about your narcolepsy

Do I have to tell my employer?

You do not have to tell an employer about your narcolepsy, but there are several reasons why it may be advisable to do so.

Your employer can only help if they know about your narcolepsy

Some people worry that telling an employer about their narcolepsy could affect their chance of getting a job or of being treated fairly at work. Although discrimination can happen, the Equality Act 2010 aims to protect you from discrimination and to help your employer to treat you fairly and to support you at work. Knowing about your narcolepsy can help your employer to do this.

Employers have responsibilities under the Health and Safety at Work Act

For employers to be able to meet health and safety regulations, they need to know whether their employees have any medical conditions that could affect their work. Employers can only ask you questions about your health to help keep you and others safe at work, and to help you to be able to do your job. If your employer knows about your narcolepsy they may make changes to your job or environment to make it safer for you. If you do not tell your employer, you cannot hold them responsible for not doing safety assessments for you.

Employers are expected to consider making reasonable adjustments

If your employer knows about your narcolepsy, they can consider making reasonable adjustments to your work or working environment for you. If your employer does not know about your narcolepsy, they will have no reason to consider what they can do to help you, and you cannot hold them responsible for any consequences of them not making reasonable adjustments.

The people you work with will be more able to help you

Often people feel more comfortable with narcolepsy if they understand what it is and know what to do if you fall asleep or have a cataplexy attack. This might help them feel more confident about how to help you at work.

You have an obligation to maintain safety in the workplace

It is not only the employer that has an obligation to ensure the safety of all employees. As an employee, you too are required to ensure your own and other employees' safety. Not telling your employer about your narcolepsy could mean that you are expected to carry out duties that would not be assigned to you if your employer did know about your narcolepsy. That could place you and others at risk.

When is the best time to tell a new employer about my narcolepsy?

If you decide to tell your new employer about your narcolepsy:

- You could mention it in your application for the job, either in the application form or a covering letter. This could include details from your GP or consultant about your narcolepsy. This may help your potential employer understand your narcolepsy before you have an interview.
- You might mention it at an interview, and talk about it face to face. This gives you an opportunity to show your skills and experience, before talking about your narcolepsy.
- You might mention it at a final interview or when you are offered the job.

Once you have told your new employer about your narcolepsy, they must carry out a risk assessment and consider what reasonable adjustments they can make to help you. They may get medical advice, or ask a Health & Safety or Occupational Health expert to assist them.

Access to Work

Access to Work is a scheme that supports people with disabilities and their employers. If you have problems or particular needs at work because of your narcolepsy, Access to Work may be able to help find solutions. For example, they may be able to fund reasonable adjustments such as equipment or extra support at work, or help with the cost of getting to and from work if you are not able to drive or use public transport.

Other help with travel costs

If you do not drive because of your narcolepsy, you can apply for a railcard to get discounted rail fares. You can also apply for a free national bus pass to travel around the UK.

Could I lose my job due to my narcolepsy?

If you are already in a job and you develop narcolepsy, or if your narcolepsy changes and starts to cause problems at work, you might be worried about losing your job.

Under the Equality Act, your employer is expected to consider making reasonable adjustments so that you can carry on working.

If you develop narcolepsy, or if your symptoms are difficult to control, you may be referred to a specialist to review your narcolepsy. The review may help with making decisions about

your job. For example, it may help to identify reasonable adjustments for you. Some adjustments may be temporary, while your narcolepsy is being reviewed or treated, and some may need to change over time.

Who can I talk to?

You may want to talk to your line manager, or someone in your Personnel or Human Resources department if you have one, about how you are feeling. Talking about any problems or concerns you have might help them to support you or look for reasonable adjustments that would help you.

More information and useful links

Help with work, skills and training

Jobcentre Plus

See your local phone book or www.gov.uk/browse/working
Information on training and employment

Disability Employment Advisers

(At local Jobcentre Plus offices) can provide support for people with disabilities. They may know what schemes are available locally to help you get back into work.

Remploy

Jobseekers: 0300 456 8110
Employers: 0300 456 8113
www.remploy.co.uk
Supports people with disabilities into work.

Disability Rights UK

www.disabilityrightsuk.org
Information to support people with disabilities in education and training.

Guidance on Employment Law and discrimination

ACAS (Advisory, Conciliation and Arbitration Service)

Helpline 0300 123 1110
www.acas.org.uk
Advice for employers and employees.

Citizens Advice Bureau (CAB)

See your local phone book or www.citizensadvice.org.uk
Local CABs offer free, confidential and independent advice.

Disability Law Service

Advice line 0207 791 9800

www.dls.org.uk

A charity offering free legal advice to individuals about employment.

Health and Safety Executive (HSE)

www.hse.gov.uk

Guidance on health and safety legislation.

Trade Unions

Via personnel or HR teams. Most trade unions have positive policies on the employment of people with disabilities and can help in cases of discrimination.

Specific help for people with narcolepsy

Narcolepsy UK

www.narcolepsy.org.uk

info@narcolepsy.org.uk

Helpline: 0345 450 0394

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IMPORTANT NOTE: Whilst every effort has been made to ensure that the information in this Guide is accurate, it is for general guidance only. Specific advice on your individual circumstances should always be sought. Narcolepsy UK cannot accept any responsibility or liability for actions taken in reliance on the information contained in this Guide.