For Employers

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.

**Employing someone with narcolepsy**

One of the key points to remember about narcolepsy is that it varies from person to person. Not all people with narcolepsy suffer from the same symptoms. Whilst most experience excessive daytime sleepiness, not all suffer from cataplexy. Those that do have that symptom experience differing degrees of cataplexy. The extent to which symptoms are controlled by medication also varies considerably from one person to another.

When employing someone with narcolepsy, it is important to consider their individual situation, and base decisions on fact. This means considering that person’s narcolepsy and the effect that it might have on their work. Talking to them about what their narcolepsy is really like, and how it might affect their work, is more helpful than making assumptions about how it affects them.
What might be useful to consider?

About their narcolepsy

• What symptoms do they have, and how well are they controlled?
• Do they suffer from excessive daytime sleepiness, and if so do they need to nap, how often and for how long?
• Do they suffer from cataplexy? If so, is there anything that increases the likelihood of a cataplexy attack?

About the job

• Does the job involve any equipment, working at heights or near water, or any other potentially risky situation?
• Does the job involve shift work, in particular night-time working?
• Do they work alone or with other people?
• Would they be responsible for other people, such as children?

Risk Assessments

Under the Health and Safety at Work Act, employers have to make sure that all their employees are safe at work.

To be able to do this, you need to know about your employees’ medical conditions, and assess any possible risks by doing a “risk assessment”.

It is important that risk assessments:

• are based on the individual's circumstances, as each situation and each workplace is different;
• are based only on factual information; and
• avoid assumptions, eg an assumption that something is going to happen simply because the person concerned has narcolepsy.

For some people with certain jobs, their narcolepsy may pose a risk to their health or safety, or to that of other people. However, Health & Safety law must never be used as a reason not to employ someone without first looking at any risks individually, and considering reasonable adjustments.

It may be necessary for you to get medical advice or ask a specialist, such as a Health & Safety expert, to help with a risk assessment. This can also help to identify reasonable adjustments.

What does equality law mean for employers?

The Equality Act 2010 covers all areas of employment from recruitment and selection to training, development and promotion.
Asking health-related questions
Under the Equality Act 2010, employers are not allowed to ask questions about an applicant’s health in any written form or in an interview, until the applicant has been offered a job, or placed in pool of successful candidates to be offered a job.

An exception to this is that you can ask applicants health-related questions in relation to the recruitment process. For example, you can ask whether applicants have any specific requirements to enable them to attend an interview.

Recruitment
The Equality Act means that you need to consider a person with a disability fairly, along with all other applicants for a job. It does not stop you employing the best person for the job and it does not mean that you have to employ someone with a disability because of their disability, if they are not the best person for the job.

Job adverts should only ask for skills and qualifications that are genuinely relevant and do not put people with disabilities at a disadvantage. For example, only ask for a driving licence if it is a genuine requirement of the job. If a skill or qualification really is needed for the job, it is not discrimination to ask for it.

Application forms should be available in a variety of formats (for example online and printed copies).

Employment contracts should be the same, in terms of leave and sick pay, for everyone applying from the job.

Interviews
When choosing applicants to interview, the key thing to consider is whether they have the qualifications, skills and experience for the job. If an applicant has told you that they have narcolepsy, it is helpful to think “are they right for the job and is their narcolepsy relevant”.

For some jobs you might need to do a risk assessment or consider what reasonable adjustments you could put in place for any employee, before you recruit. An Occupational Health team may be able to advise you about risk assessments.

When a job has been offered
Once a job has been offered, you can ask questions about a disability if that will help you put any necessary reasonable adjustments in place.

Reasonable Adjustments
Under the Equality Act 2010, employers are required to make “reasonable adjustments” so that a person with a disability is not placed at any disadvantage compared to someone without a disability.

You can ask about an employee’s health if it helps you to make reasonable adjustments.

If you ask questions that are not relevant to the job, or you use someone’s health as a reason for dismissing them, that could be discriminatory.
Not everyone with narcolepsy will need adjustments and any that are required will vary depending on the individual person's needs.

Adjustments that may be helpful to consider for someone with narcolepsy include:

- flexible hours;
- extra breaks during the working day, for naps;
- allowing them to work part-time from home;
- elimination of shift work;
- recording of meetings;
- creation of a cool, well-ventilated work environment to promote alertness.

What is “reasonable”?
What is a “reasonable” adjustment depends on the situation. Some general guidelines for working out what is reasonable include:

- how practical the adjustment is to make;
- how effective the adjustment would be in helping the employee;
- how it might affect other employees; and
- the cost of making it and your financial situation. You will need to bear the cost of reasonable adjustments that are made, though you may be able to get help with the cost through Access to Work or other schemes.

You may also need to make adjustments if someone develops narcolepsy while they are employed by you. Someone's narcolepsy may change over time, for instance if their symptoms are better controlled by medication, and so the need for reasonable adjustments may also change over time.

Time off work
If someone's narcolepsy is controlled, they are unlikely to need more time off work than anyone else.

Allowing time off work because of a disability, for instance to attend a medical appointment, could be considered to be a reasonable adjustment. It might be recorded separately from time off for other reasons.

Insurance and pension schemes
Employers' Liability Insurance covers all employees in the workplace. However, you need to have made all reasonable efforts to ensure the safety of your employees, including individual risk assessments where needed.

The Equality Act covers occupational pension schemes. All employees can join and must be treated fairly under the terms of the scheme.
More information and useful links

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.

**Health and Safety Executive (HSE)**
www.hse.gov.uk
Guidance on health and safety legislation.

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.