



Narcolepsy UK

Narcolepsy UK is a registered charity

What Narcolepsy **WILL NOT DO**

- Narcolepsy will not kill you
- Narcolepsy will not make your life shorter
- Narcolepsy will not affect other areas of your brain
- Narcolepsy will not prevent you having children
- Narcolepsy will not stop you holding a driving licence once your condition is stable
- Narcolepsy will not, with help, stop you getting qualifications
- Narcolepsy will not stop you leading a relatively normal life

Benefits, Support,
Advice

Helpline:
0345
450 0394

Narcolepsy is not a communicable disease; it can't be passed on by kissing someone with narcolepsy or a blood transfusion from someone with narcolepsy.

Narcolepsy is not a psychological condition but an illness caused by an auto immune reaction. This is where the body's defence mechanisms attack parts of the body that are not sick. With narcolepsy the area attacked produces a chemical called OREXIN which regulates the sleep wake cycle and much more. Doctors can prove you have the disease by checking how quickly you go to sleep and in some cases by checking on how much orexin you have in your system.

Narcolepsy is a spectrum disorder which means each person with narcolepsy will experience it in a slightly different way. For some people it can be severe and for other quite mild. Whatever version you have Narcolepsy is not a death sentence and with help you can lead a nearly normal life and achieve much of what you want to.

Stronger Together

A charity exists to help those people with narcolepsy, their family and friends. Educational establishments, employers, etc., may all ask for guidance.

For details and other information visit our website at **www.narcolepsy.org.uk** or contact the charity by:

Telephone: 0345 450 0394
Email: info@narcolepsy.org.uk

Company Registration No: 07790071 (England)
Charity Registration No : 1144342 Scottish Charity No SC043576



Cataplexy Dreams
Automatic Behaviours EDS
Sleep Paralysis
Disturbed Nocturnal Sleep

What Narcolepsy **WILL DO**

- Having Narcolepsy will mean that you may fall asleep in unusual places or circumstances
- Having Narcolepsy can make your night time sleep more fragmented and less restful
- 90% of people with Narcolepsy develop Cataplexy at some time
- Narcolepsy can have secondary symptoms such as vivid dreams, automatic behaviour and it can make you put on weight easier
- Having Narcolepsy will probably mean you are placed on medication to reduce the symptoms
- Having Narcolepsy will mean you will not be able to drive until your condition is stable
- Having Narcolepsy is not as unusual as you might think; about 30,000 people in the UK have the condition

Cataplexy is the most common side effect of narcolepsy and is a sudden loss of muscle control. It is usually triggered by intense, often positive emotions such as laughter or surprise. For most people cataplexy is quite mild; a subtle dropping jaw or head slumping forward for a few moments is quite common; this often causes the voice to become slurred. While reduced muscle control in arms and legs is less common, some people do appear to faint from a cataplexy attack. Despite appearances during a cataplexy attack you do remain conscious and are aware, to a large extent of your surroundings.

Narcolepsy is being better controlled than ever before by a range of drugs and sleep hygiene methods but, at the moment no cure exists for the condition. Many researchers are looking at ways to replace Orexin and the advances in understanding the disease over the last five years have been huge.

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