



Narcolepsy Charter

#nukcharter

The Narcolepsy UK Charter is a statement of the respect, care and support that people living with narcolepsy and their carers deserve and should expect.



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By working together... We will achieve our goal

We believe that everyone with a connection to narcolepsy (personal or professional) should recognise and respect the rights of people with narcolepsy as set out in the Charter.

By working collectively towards the Charter's vision, we will achieve our goal of providing the respect, care and support that people living with narcolepsy and their carers deserve and should expect.

People with narcolepsy have the same rights to a full and rounded life as any other person without having to fight to make this happen.

This Charter promotes accessibility to early diagnosis, quality treatments and emotional and practical support for people with narcolepsy and their carers. The findings are from an online survey of 302 people with narcolepsy and 149 supporters undertaken by Adelphi Research. The survey was made possible with support from Adelphi Research, Lincoln Medical Ltd, The National Lottery Community Fund and UCB Pharma.



ADELPHI RESEARCH



For more information, please contact us - www.narcolepsy.org.uk/contact-us
For direct support, use our helpline - www.narcolepsy.org.uk/helpline
We are a registered charity in England & Wales (No. 1144342) and in Scotland (No. SC043576)

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Supported by UCB through an educational grant. UCB has no editorial control on the contents.



Summary

1 **People with narcolepsy have the right to live in a society that understands and recognises the impact of narcolepsy on themselves and their families and carers.**

- Ability to talk about narcolepsy without fear of judgement or discrimination
- Sensitive and accurate media coverage
- Research about the causes and impact of narcolepsy

2 **People with narcolepsy have the right to an early diagnosis and information.**

- To be taken seriously when we present to General Practitioners
- A timely and appropriate referral to a specialist sleep clinic
- An accurate and early diagnosis
- Access to information at diagnosis

3 **People with narcolepsy have the right to high quality care and treatments.**

- Regular access to a named sleep specialist, neurologist and GP
- Recognition and treatment of the wider mental health and physical consequences of narcolepsy
- Timely access to approved treatments based on clinical judgement over cost
- Improved information about potential side effects of narcolepsy medication

4 **People with narcolepsy have the right to education.**

- Ability to describe how narcolepsy affects our learning experience and ask for support with confidence and without fear of discrimination
- A tailored support programme that maximises learning whilst maintaining a positive social life
- To return to education or retrain if narcolepsy affects our current career

5 **People with narcolepsy have the right to employment and career progression.**

- To be able to describe how narcolepsy affects us at work and ask for support with confidence and without fear of discrimination
- Reasonable adjustments in the workplace that are reviewed regularly
- Information about legal rights and access to in-work support

6 **People with narcolepsy and their carers have the right to maximise their quality of life.**

- A fulfilling social and family life
- A personal care plan specifying the care and support we need
- Early and regular access to quality support for family members and supporters
- Timely and appropriate access to disability benefits and carer entitlements
- Access to travel subsidies and medical driving licences



About narcolepsy

Narcolepsy is a chronic neurological disorder that affects the regulation of sleep-wake cycles.

As people with narcolepsy, we suffer from a range of symptoms such as excessive daytime sleepiness (EDS), cataplexy¹, disrupted nocturnal sleep, sleep paralysis and hallucinations.

Narcolepsy is associated with significant physical and mental health comorbidities. Without substantial support, this disability affects our ability to obtain qualifications, perform to the standards required in the workplace and maintain positive social and family lives. For many of us, this results in a need to access state benefits and financial assistance, without which additional strain is placed on our carers and relationships.

There is no cure for narcolepsy. The main treatment is pharmacological; however, no single treatment is fully effective in combating the excessive daytime sleepiness (EDS) and cataplexy. At the time of writing (March 2019) the UK lags significantly behind the majority of European countries and the USA in providing access to effective medication including sodium oxybate which was approved by the European Medicines Agency in 2005.

¹ Cataplexy is the term given to sudden muscular weakness triggered by strong emotions such as laughter, anger and surprise. The loss of muscle tone that occurs may range from a just-perceptible weakening of the facial muscles through weakness at the knees, to total collapse on the floor. Speech may be slurred, and eyesight impaired (double vision, inability to focus) but hearing and awareness remain undisturbed.



1 People with narcolepsy have the right to live in a society that understands and recognises the impact of narcolepsy on themselves and their families and carers.

- Ability to talk about narcolepsy without fear of judgement or discrimination
- Sensitive and accurate media coverage
- Research about the causes and impact of narcolepsy

As people with narcolepsy, we have the right to be able to talk about our disability without fear of judgement or discrimination. To improve access to the rights described in this document, we're calling for research and sensitive media coverage that accurately describes the causes and impact of narcolepsy.

It is not unusual for people to consider the symptoms of narcolepsy amusing.

A large proportion of the general public have never heard of narcolepsy and understanding of the condition is poor². This lack of awareness with narcolepsy contrasts with widespread familiarity with low level tiredness and strong societal assumptions that tired people are lazy or have chaotic lifestyles. Furthermore, it is not unusual for people to consider the symptoms of narcolepsy amusing rather than serious and disabling.

As a result of this, only 64% of respondents to our survey were happy to tell others about their condition so they may receive the level of support they need from friends and family.

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Willingness to talk to employers and educators was even lower (54% and 61% respectively). The majority of people with narcolepsy would like support with describing their condition.

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I don't see members of my extended family very often but when I do, they try their best to understand, but because there is nothing physically wrong with me, they struggle.



There's so little honest and well-known information out there, people who haven't been affected (one way or another) by narcolepsy don't know anything accurate or correct about it and could make snap decisions.



It was undiagnosed. I thought I was crazy so told no-one, everyone called me lazy and teachers refused to help with catch up.

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2

People with narcolepsy have the right to an early diagnosis and information.

- To be taken seriously when we present to General Practitioners
- A timely and appropriate referral to a specialist sleep clinic
- An accurate and early diagnosis
- Access to information at diagnosis

Timely treatment following an accurate and early diagnosis substantially reduces the impact of narcolepsy on our lives.

Participants in our survey were diagnosed an average of four to five years after the appearance of initial symptoms.

Only one third of participants in our survey agreed that medical professionals took them seriously when they first reported with symptoms and that they were diagnosed within a reasonable time frame. Participants diagnosed over the last five years experienced an average delay of four to five years after the appearance of initial symptoms.

When narcolepsy is suspected, patients are often referred to general neurologists who have limited knowledge of sleep disorders and can get lost in the system following multiple referrals. When people are eventually referred to a sleep centre, they often experience delays in accessing overnight tests and getting the results.

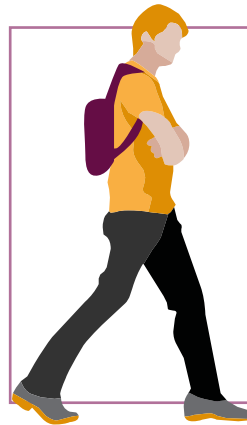
When people are eventually referred to a sleep centre, they often experience delays in accessing overnight tests and getting the results.

At diagnosis we should be offered access to appropriate information and be informed about Narcolepsy UK.

“



One GP even voiced how incredible it was to her that I had an appointment just for being tired.



A quick diagnosis enabled me to complete my A Levels which I wouldn't have passed otherwise.



It was only when I started having cataplexy attacks that narcolepsy was suggested.

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3

People with narcolepsy have the right to high quality care and treatments.

- Regular access to a named sleep specialist, neurologist and GP
- Recognition and treatment of the wider mental health and physical consequences of narcolepsy
- Timely access to approved treatments based on clinical judgement over cost
- Improved information about potential side effects of narcolepsy medication

Narcolepsy cannot be cured but the impact on our physical and mental health can be reduced by timely and effective intervention and treatment from a specialist sleep centre and a knowledgeable General Practitioner. As the symptoms and impact of narcolepsy vary between patients and evolve with patients' lifestyles, continuity of medical treatment is important.

Only 57% of participants in our survey felt they had adequate support from a specialist in the last year. Waiting lists are often long, appointment time is minimal and we struggle to see the same specialist consistently. Patients are often referred back to their GP once their medication is stable and then left without follow-up.

Only 57% of participants felt they had adequate support from a specialist in the last year.

Only 13% of participants in the survey agree that their GP has enough knowledge of narcolepsy to understand how it affects their general health and care needs. Although some GPs make a personal effort to improve their knowledge, general awareness and training are lacking, and we find it hard to consistently get appointments with the same GP.

Although effective medication has transformed lives, only 58% of participants in our survey feel that they currently have access to the best medications to treat their condition. Getting to the right treatment can take years of experimentation and fine-tuning and NHS budgets often limit access to sodium oxybate and pitolisant. Side effects can be severe, and we should be made aware of these.

Underlying the problems described above is a lack of recognition of the impact of the symptoms of narcolepsy on our mental and physical health by the NHS as a whole, and a shortage of training and investment in this area.

“



It's very rare to come across medical staff who know anything about the condition!



Getting put on Xyrem* enabled me to return to work. My GP argued about the shared care agreement because of the cost of Xyrem which led to a delay in it being prescribed.



I am very lucky I have a GP at my local surgery who has an interest and knowledge of narcolepsy and cataplexy due to knowing someone who also suffers with the condition.

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6. High quality care and treatments

*The respondent quotes in this section refer to Xyrem. Xyrem is a brand name for sodium oxybate.

4

People with narcolepsy have the right to education.

- Ability to describe how narcolepsy affects our learning experience and ask for support with confidence and without fear of discrimination
- A tailored support programme that maximises learning whilst maintaining a positive social life
- To return to education or retrain if narcolepsy affects our current career

The symptoms of narcolepsy often start to appear when people with narcolepsy are at school or in higher education. Our survey found that this had a negative impact for the majority of people affected in the following ways: time spent in education (75%), the qualifications and grades received (70%), the level to which they studied (65%) and the subjects they are able to study (64%).

Parents of children with narcolepsy and older students also need to be made aware of, and able to access, support services for children and students with special educational needs.

This can be greatly improved with understanding, encouragement, and tailored support from the school, higher education or university community. Parents of children with narcolepsy and older students also need to be made aware of, and able to access, support services for children and students with special educational needs.



My notes used to start neat and as I fell asleep it would be like a spider had drawn on the page and I couldn't read them back.



One of my exams happened whilst I was in auto mode. I couldn't remember taking the exam and my answers were apparently so bad that I'd negated all the 'A' standard work I'd done all year.

My daughter was greatly supported at school once we were told she may have narcolepsy. Despite having no knowledge or experience of the condition they listened to us and provided her with a medical room to nap in, adjusted her timetable and gave her a timeout card to be used in classes.



He did not take up his university place as during A Levels he was constantly falling asleep instead of studying, so this was a struggle and embarrassing. Therefore, he does not have the educational achievement to reflect his intelligence.



5 People with narcolepsy have the right to employment and career progression.

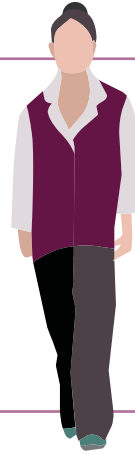
- To be able to describe how narcolepsy affects us at work and ask for support with confidence and without fear of discrimination
- Reasonable adjustments in the workplace that are reviewed regularly
- Information about legal rights and access to in-work support

The majority of people in our survey have found that narcolepsy negatively affects the type of work they can do (82%) and their ability to find (65%), progress within (76%) and keep a job (64%).

We need to be able to describe how narcolepsy affects us at work to co-workers at all levels, human resources and occupational health, with confidence and without fear of discrimination.

Despite this, 59% of those aged 18-64 do work and these challenges could be reduced through access to reasonable adjustments in the workplace and regular review. For this to be effective, we need to be able to describe how narcolepsy affects us at work to co-workers at all levels, human resources and occupational health, with confidence and without fear of discrimination (see point 1). Often, this requires an understanding of our legal rights and the availability of in-work support.

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I retired after 35 years' service in the NHS. I was making too many errors.



I had to do a lot of night shifts at my previous jobs which I liked but it messed my sleep up even more and so I fell asleep at work which resulted in me being immediately fired.

I had numerous suggestions to put forward. However because of the excitement surrounding heated discussions, I was afraid of having a cataplectic attack, falling to the floor and losing my dignity.



I found some employers were understanding and others just thought I was lazy, it's very demoralising.



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6

People with narcolepsy and their carers have the right to maximise their quality of life.

- A fulfilling social and family life
- A personal care plan specifying the care and support we need
- Early and regular access to quality support for family members and supporters
- Timely and appropriate access to disability benefits and carer entitlements
- Access to travel subsidies and medical driving licences

Living with narcolepsy means that we have to decide where to focus our energy. Often it is our relationships, social lives and family lives that suffer. We have the right to maximise our quality of life beyond our working lives and education and to minimise the impact of our disability on our family and friends.

I used to go to rock gigs, but the 3 I have been to since narcolepsy, I have slept through. I find groups of people difficult to be around as the noise becomes jumbled and I end up suffering a cataplexy attack.



I have lost a lot of friends over the years as I am unable to keep up with them energy level wise, so can't do some of the activities they enjoyed (for example I don't drink and can't do dark pubs/clubs or stay up too late).



Since he's been really bad with his narcolepsy, I have not been able to leave him on his own with our children. We have been having to get family and friends to spend time here every Saturday while I work to help look after the children.



I would love nothing more than for my kids to experience a full day out with Mum, but they are few and far between.



Our respondents said that narcolepsy affects:

- The activities we can do..... 88%
- Our ability to make friends... 65%
- Time spent with friends..... 86%
- Maintaining friendships..... 66%



- Building and maintaining relationships... 65%
- Our relationship with a partner..... 65%
- Our relationships with other family members..... 62%
- Our children..... 57%