Informing Decisions

Inspiring Action

Narcolepsy UK Charter Research

A presentation prepared for:

Narcolepsy UK

PP23283 v2.0 | 21st August 2018

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Business and Research Objectives

Business Objective:

To provide evidence for the Narcolepsy Charter, a document that will define the direction of Narcolepsy UK over the next five years and beyond

Research Objectives:

1. **Determine the extent to which narcolepsy impacts different areas of people's lives**
2. **Develop an infographic of the key findings to be used at the narcolepsy UK annual conference in September 2018**

Sample and Methodology

Sample = 451

People with Narcolepsy (PWN)
n= 302

Supporters of PWN
n= 149

Methodology

15-minute online survey
- consisting of multiple-choice questions and rating scales, with optional open text-box answers

3 initial pilot interviews were conducted to ensure the survey was comprehensive, understandable and easy to complete

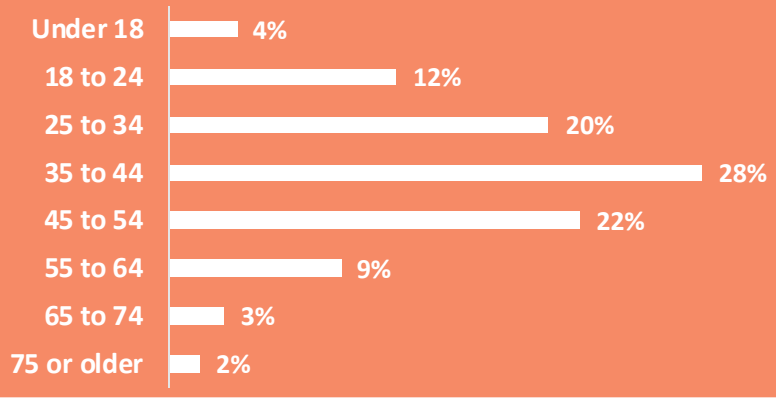
Respondents were **screened in** on the following conditions:

- ✓ **Must be a person with narcolepsy or supporter** (parent, partner or other close family or friend)
- ✓ **Must suffer at least one pre-defined symptom of narcolepsy**, including excessive daytime sleepiness and/or cataplexy
- ✓ **Must have a confirmed or suspected diagnosis** awaiting confirmation from a healthcare professional – self-diagnosis screened out
- ✓ **Must live in either England, Wales, Scotland, N. Ireland, Channel Island or Isle of Man**

Demographics of the PWN

PWN

Age



Geography

England 83%

- North East 9%
- North West 11%
- Yorkshire and Humber 8%
- East Midlands 9%
- West Midlands 9%
- East of England 12%
- London 14%
- South East 19%
- South West 9%

Scotland 11%

Wales 4%

N. Ireland 1%

Channel Islands 1%

Gender

77% **23%**

Ethnicity

93% White

4% Mixed/ multi-ethnic groups

2% Black/ African/ Caribbean/ Black British

1% Asian/ Asian British

Driving License

53% have a driving license

12% voluntarily surrendered their driving license

5% had their license **revoked**

28% never had a driving license

(2% unsure/ prefer not to say)

Employment

29% Full-time

15% Part-time

9% Self-employed

47% Do not work

(Average 31.5 hours/week)

Education

86% not in education

10% Full-time

4% Part-time

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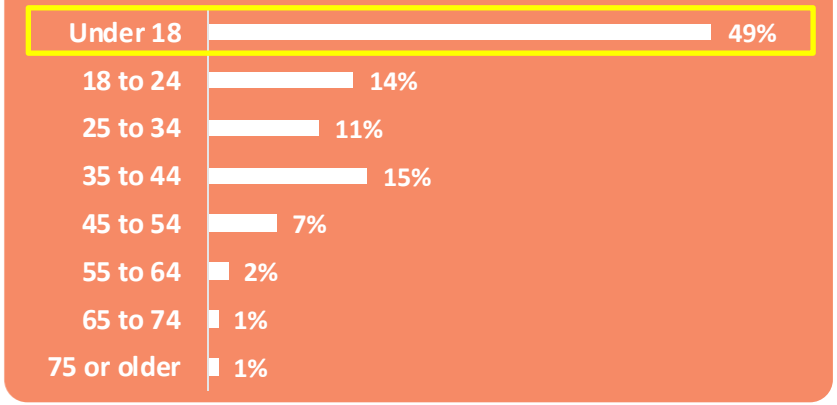
Demographics of PWN discussed by the Supporters

Supporters

Age



Geography

England 88%

- North East 8%
- North West 12%
- Yorkshire and Humber 11%
- East Midlands 5%
- West Midlands 8%
- East of England 15%
- London 9%
- South East 17%
- South West 13%

Scotland 9%

Wales 1%

N. Ireland 1%

Isle of Man 1%

Gender

56% **44%**

Ethnicity

92% White

4% Mixed/ multi-ethnic groups

1% Black/ African/ Caribbean/ Black British

1% Asian/ Asian British

2% Other/ Prefer not to say

Driving License

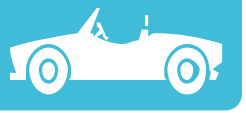
19% have a driving license

7% voluntarily surrendered their driving license

3% had their license **revoked**

66% never had a driving license

4% unsure/ prefer not to say



Employment

14% Full-time

9% Part-time

2% Self-employed

75% Do not work

(Average 30.4 hours/week)

Education

42% not in education

54% Full-time

4% Part-time

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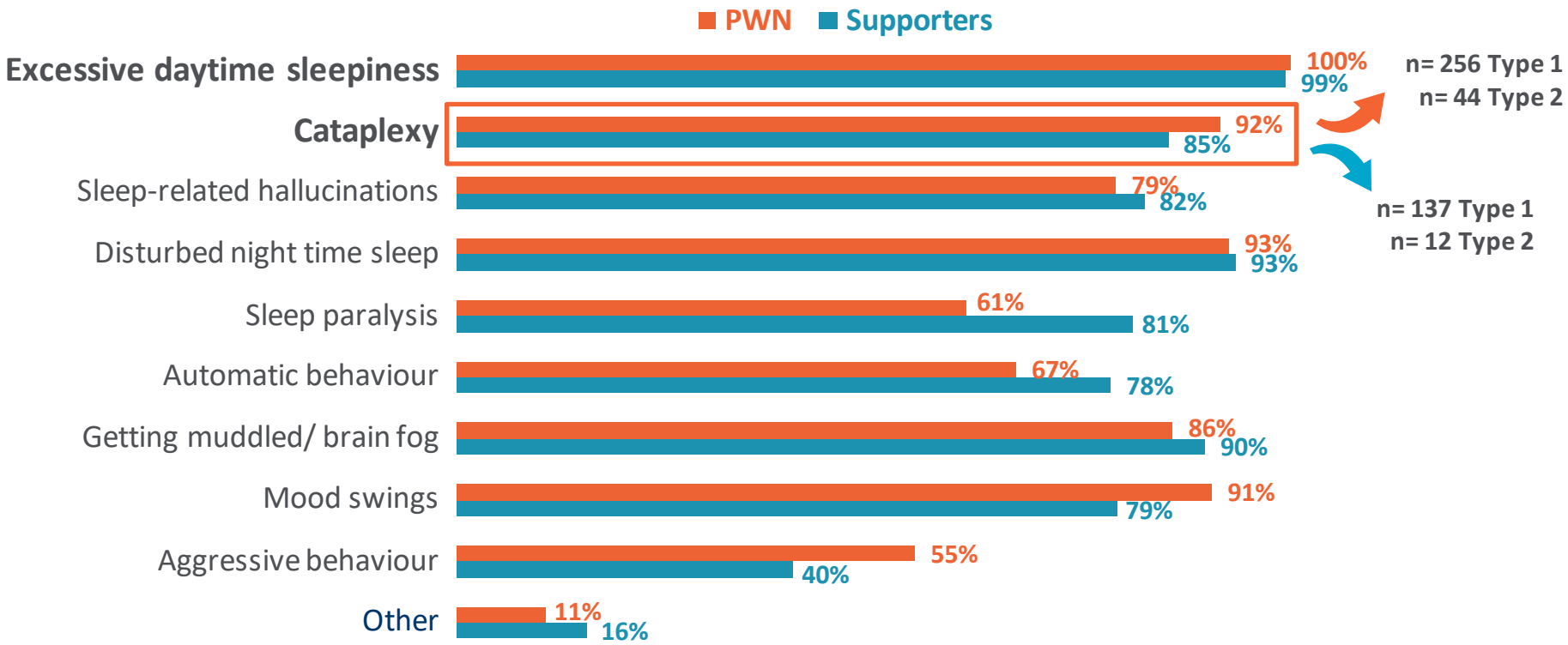
Whilst most PWN suffer a number of different symptoms, excessive daytime sleepiness and disturbed night time sleep were experienced by almost all



Depression 25%
Anxiety 19%
Memory loss 17%
Hunger/ excessive need to eat 13%
Micro-naps 10%
Difficulty regulating body temperature 10%
Weight gain 10%

Also mentioned:
Sleep eating, insomnia, headaches/ migraines, fibromyalgia/ chronic pain, daytime hallucinations, nightmares, short attention span, lethargy/ fatigue, sleep attacks, sleep walking, false memories, muscle weakness, aphasia, restless leg syndrome

Overall, people with Type 2 narcolepsy seem to be less impacted by their condition

Throughout the research, we consistently found that those with Type 1 were more negative about the impact narcolepsy has had on their lives, compared to those with Type 2

Type 1 – narcolepsy with cataplexy n=393 (88%)

Type 2 – narcolepsy without cataplexy n=56 (12%)

People with Type 2 narcolepsy are:

- Likely to have less symptoms overall
- Slightly more likely to have suspected narcolepsy waiting for referral from GP rather than confirmed (88% vs 97%)
- Less likely to be young – (24 or younger 20% vs 33%)
- More likely to
  - Be in full time employment (46% vs 21%)
  - Have a driving license (64% vs 39%)
  - To feel their life is less impacted by their condition

The majority of respondents had a confirmed diagnosis of narcolepsy, but on average this took 8 years

95% respondents had a **confirmed diagnosis from a sleep specialist**

5% had a suspected diagnosis and were awaiting confirmation from a sleep specialist/ referral for treatment

On average, it took **8 years** for a confirmed diagnosis from initial symptoms
(Ranged massively, from 1 – 50 years) (Median 4.4 years)

Shorter time to diagnosis for **Type 1** than Type 2 (7.9 vs 9.0 years) –

Longest time to diagnosis seen in **Wales** (14.1 years), **South West** (10.9 years), **North West** (9.7 years)

Self employed take **longer** to be diagnosed (15.4 years)

Longer for **PWN** than Supporters (9.8 years vs 4.2)

Females slightly **longer** than males (7.2 vs 8.2 years)

Time to diagnosis increases with age

In their own words, narcolepsy affects all aspects of people's lives

PWN
Supporters

Social life
- Inability to plan ahead and missing events
- Not leaving the house from fear of falling asleep
- Struggling to travel
- Managing emotions to prevent cataplexy

Employment
- Unable to find a job / financial problems
- Struggling to progress
- Forced early retirement
- Lack of support from employers / health and safety at work

Lack of independence
- Reliance on others for daily tasks
- Endangering themselves with everyday tasks
- Feeling like a burden / frustrated
- Losing out on opportunities

Lack of understanding
- Accusations of being drunk / laziness
- Loss of friends
- Little support (medical staff, schools)
- Misunderstandings
- Being bullied

Weight / diet
- Too tired to exercise
- Overeating during waking hours

Mental health
- Low mood
- Lack of self confidence
- Low self esteem
- Anger and aggression

Cognitive function
- Slurred speech
- Bad balance
- Lack of coordination/spatial awareness
- Poor short term memory
- Lack of concentration
- Change in personality

Limited energy / lack of enthusiasm

Relationships
- Lack of attention towards partner
- Reliance puts strain on relationships

Family life
- Struggling looking after children
- Struggling to explain their condition to them

Education
- Struggling to stay awake in lessons/lectures/exams
- Struggling to study away from school
- Fewer career choices due to lack of qualifications
- Lack of support from school

Narcolepsy has a significant impact on supporters lives too

Supporters

Constant tension / stress
- Dealing with mood swings
- Managing side effects of disease and medication
- Managing patient safety

Constant worry
- About patient vulnerability
- About PWN mental health
- About siblings
- About side effects of medication
- About the future
- About lack of support from schools
- About how PWN will function in social situations

Planning life around PWN
- Difficult to plan events suitable for everyone
- Schedule / activities dictated by PWN moods / sleep

Impact on siblings
- Unable to share attention fairly
- Sibling anger
- Activities focused on PWN

Employment
- Limited work options / unable to work as needed for support

Mental Health
- Depression from dealing with condition
- Frustration at on going reliance
- Feelings of grief and sadness at the lives PWN have to lead

Need to provide constant support
- Manage medication / meal times
- Provide transport
- Unable to have own social life
- Unable to leave PWN alone

Dealing with abuse
- PWN thrashing out with frustration

Disrupted sleep
- Need to medicate late at night / early morning
- Woken through night terrors / hallucinations

Financial support
- Providing financial security as PWN cannot work

Impact on education

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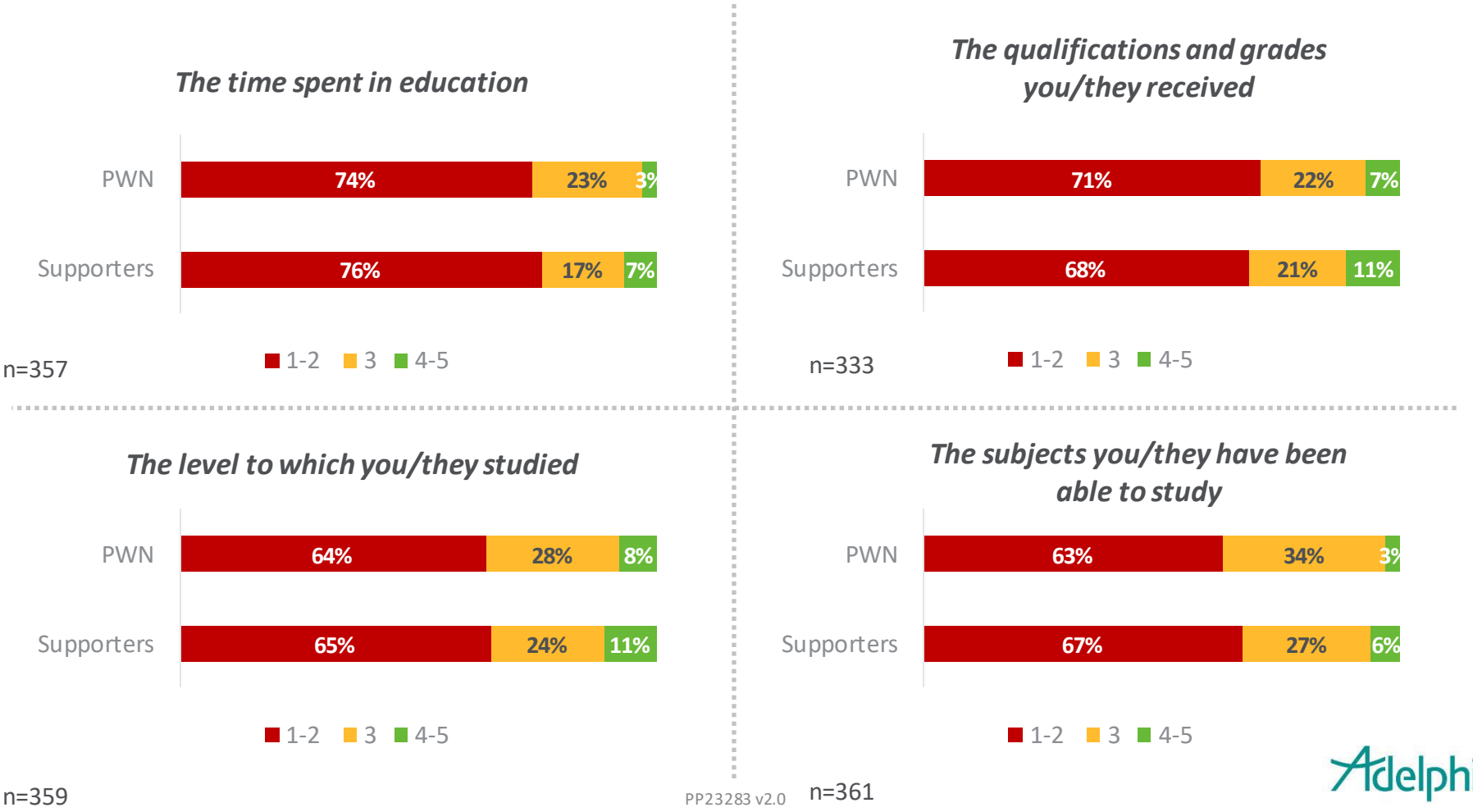
Overview of impact narcolepsy has on education

Education

*To what extent has narcolepsy impacted the following aspects of **education**?'*

1 Very negatively | 2 Negatively | 3 Not at all | 4 Positively | 5 Very positively



Q48 To what extent has narcolepsy impacted the following aspects of your education

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Narcolepsy has a huge negative impact on time spent in school and the qualifications and grades PWN are able to achieve

Education

75%

Said narcolepsy **negatively*** impacts the **time they are able to spend in education** (days off sick)

n=357

- **Greater impact in people aged 18-24** (86%)
- **Lower impact** in the **East of England** (56%)
- **Higher in unemployment** (80%) vs full-time employment (59%)

Absent from sleeping and hospital appointments

"I have also had many days off due to narcolepsy and I have also missed days off school due to the number of hospital appointments I have to attend"

Falling asleep in lessons

"She slept in most lessons for the first 3 ½ years of high school."
"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"

Ineffective medication

"In December she was started on fluroxatine this changed her body clock which resulted in 4 months of missed school"

Reaction of others can be negative, making them less likely to want to go to school

"Constant bullying she faces because the school and pupils not educated in narcolepsy. You tell them they don't want to know""

70%

Said narcolepsy **negatively*** impacts the **qualifications and grades they received**

n=333

- **Greater impact in people aged 18-24** (85%)

Difficulty concentrating for long periods of time / staying awake

"I fell asleep through most of my GCSE exams but luckily I managed to complete enough before and after nodding off to still get desirable grades." (PWN)

Stress of exam conditions triggering attacks

"She found exam conditions extremely difficult due to the silence and nervousness exasperating attacks"

Lack of understanding / support from educators

"I remember my history teacher telling me to go for a walk around college and get a coffee this happened a few times and I was mortified."

Turning from 'top' pupil to low performing pupil and negative impact on mental health

"I know at least one exam passed completely in auto behaviour as I remembered nothing and my answers were apparently so bad as to negate all the A standard work I'd done all year."

Q48 To what extent has narcolepsy impacted the following aspects of your education? *negative = score 1 or 2
A - The time spent in education (I.e. days off sick)
D - The qualifications and grades you received

Narcolepsy often results in PWN making education choices that they may not want but can manage

Education

65%

Said narcolepsy **negatively*** impacts the **level to which they studied**

Lower in **full-time employment** (51%)

n=359

Did not get the grades required to continue

"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 education level his intelligence should have and therefore corresponding jobs."

Prevented from / choose not to study further

"I would love to have gone on to study for a master's & PhD."

"Narcolepsy has prevented me from doing any further study because I can't follow things because I fall asleep and or cannot focus."

"I have never attempted any further education as I find reading almost impossible."

Takes longer to complete studies

"I've just finished my MA in design management. I had to submit my thesis about 4 times before it passed."

Scared to tell people of condition, so do not get suitable / relevant support

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

64%

Said narcolepsy **negatively*** impacts the **subjects they were able to study**

Lower in **full-time employment** (51%)

Higher in people diagnosed between 6-10 year ago (76%)

n=361

Unable to handle workload

"She studied Law but found it incredibly difficult to do the course. She later registered to do PGCE. That was a real struggle even though she completed it and passed."

"I was studying to be a chartered certified accountant (ACCA) but I couldn't put in the hours needed for the final level and continue to work a full time job. I have to give up and remain part qualified"

"I couldn't finish my accounting qualification as I get too many sleep attacks and the exam was online and time bound."

Can't do overnight trips, impacting subject choices

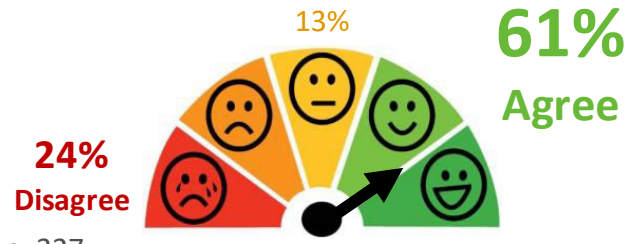
Unable to take part in extracurricular activities/ after-school clubs as too tired

Q48 To what extent has narcolepsy impacted the following aspects of your education? *negative = score 1 or 2
C - The qualifications and grades you received
D - The subjects you were able to study

Despite two-thirds of PWN being happy to discuss their condition with educators they still do not get the support they need

Education

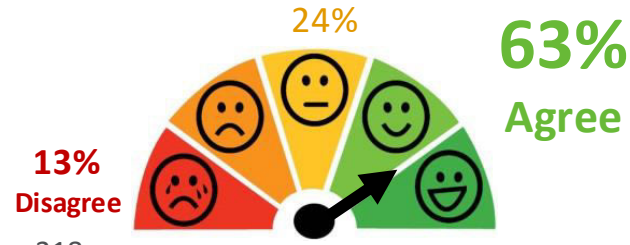
*I am **happy to tell educators about my condition** to receive the level of support I need from them*



n=327

SO

*I would like **more support / guidance on how to describe my condition** to educators to get the support I need*



n=318

The majority of PWN are happy to tell educators about their condition to improve support, but the response they receive varies widely

"I was happy to tell educators but they weren't happy to support me sadly."

Educators have a lack of exposure to and therefore awareness of narcolepsy

"They haven't received much support because the staff have never come across anyone with narcolepsy before"

"Teachers don't know much about narcolepsy and it was me who had to ensure that they had a copy of the Narcolepsy UK guide for teachers. There is definitely a lot of work needed in this area"

The level of support provided varies by institution / teacher

Support received is very much down to individual schools, however standard allowances (I.e. exam time, naps etc) should be given by all.

People would like more guidance in how to get the support they need

Resources from other services have been invaluable…

- Narcolepsy UK (info sheet)
- Narcolepsy nurse
- Sheffield Children's Hospital Sleep Team

…but generally PWN have had to share them with educators

Clearer guidance / awareness on the support available

- EHCP
- SENCO support
- Disabled student allowance
- Disability allowance

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A greater awareness and understanding of the condition and flexible learning is what will improve education experience

How things can be improved?

Education

- ✓ **Quicker diagnosis** and **treatment initiation**
- ✓ Being **flexible** offering a **working pattern that works** for them
  - ✓ With teaching schedule
  - ✓ Allowing PWN to drop subjects to **make schedule more manageable**
  - ✓ **Extra time** added to the exam times
  - ✓ Given space / **time to nap**
  - ✓ **Extra tuition**
- ✓ Understanding the benefits of subjects I.e., **encouraging physical activity** helping them stay awake
- ✓ **School awareness course/ seminar –** more consistent approach across schools

"Actually dancing I was great, but as I was up doing something and my mind was active it worked for me."

"Degree studying was easier as you can get extensions easier and manage sleep around the timetable."

"My second degree was nursing, this was different for me as I had started on modafinil and uni were aware. I managed to do this degree and working long shifts worked for me rather than short days as my I was on my feet and very busy. I was never off sick due to my narcolepsy."

"I took outdoor recreation and leisure for 6th form, I suspect as I can stay awake whilst doing lots of sports."

"Not all courses can allow the flexible approach to attendance with modules available on line when required – but this Is a necessity for my daughter to access uni."

"Since she's been diagnosed and taking medication she's been much better and only fallen asleep in lessons/exams maybe 20 times in the last 12 months"

"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 when she needed, adjusted her timetable, gave her a timeout card to be used in classes and quietly ignored her when she fell asleep. She was provided with a private room and an invigilator for her final exams with extra time and a 'stop the clock' option. This in very large state school. She approached the exams with confidence and feels the school fully supported her."

"Early diagnosis and counselling – particularly in career choice – could make a big difference.

Impact on employment

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Narcolepsy has an extremely negative impact on the type of work PWN can do and the level to which people can progress

Employment

82%

Said narcolepsy **negatively*** impacts the **type of job they can do**

- **Lower impact in** full-time employment (64%)
- **Lower** in **East of England** (67%)

n=369

76%

Said narcolepsy **negatively*** impacts their **ability to progress within a job**

- **Lower impact** in full-time employment (55%)
- **Lower impact** in people with a driving license (67%)
- **Greater impact** in **Scotland** (88%). Lower impact in East of England (57%)
- **Lower for people aged <24** (62%)

n=344

Perceived as being lazy

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

Unable to progress / take on key roles

Difficult to maintain full-time roles

Chosen / enforced early retirement

"Retired after 35 years service in the NHS. I was making too many errors."

Can get fired

Numerous sick days and sleeping during work

"due to my illness being unpredictable many employers couldn't accept the sickness days I would possibly take."

Do not want promotion due to lack of confidence

"My confidence in myself means I won't put myself up for promotion, I would feel uncomfortable pulling colleagues up if they weren't hitting performance targets."

"I had numerous suggestions to put forward but because of the excitement surrounding perhaps heated discussions I might have a cataleptic attach and fall to the floor and lose all my dignity."

Additional hours needed to remain on the same level as everyone else

Inability to drive impacts prospects

"I cannot progress due to not having a driving licence. Although I am capable, not being able to drive has severely limited the work I can do."

Q50 To what extent has narcolepsy impacted the following aspects of your employment? *negative = score 1 or 2
C – The type of job they can
B- The ability to progress within a job

Narcolepsy also significantly restricts the ability to find and keep a job

Employment

65%

Said narcolepsy **negatively*** impacts their **ability to find a job**

n=347

- **Greater impact in people aged 18-24** (70%)
- **Lower impact** in full time employment (34%) and **greater in non employed** (84%)
- **Lower impact in those with a driving license** (48%)

64%

Said narcolepsy **negatively*** impacts their **ability to keep a job**

n=340

- **Lower impact** in full-time employment (28%) and **higher in non employed** (87%)
- **Lower impact in those with a driving license** (50%)

Difficult to find a job that caters to needs

"I am also limited to the type of job as I have to be on my feet because I fall asleep/become less coherent if I'm sat down for long periods of time."

"I cannot focus sufficiently to keep to a work schedule or perform work tasks reliably. I suffer from long periods of mental fog and am frequently unable to recall what I am doing or have been doing"

Disclosing disability often leads to not being hired / having offers revoked

Falling to sleep at work/ showing symptoms

"I had to do a lot of nightshifts 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."

Too many sick days/ days absent

"Due to my illness being unpredictable many employers couldn't accept the sickness days I would possibly take."

Necessary to take early retirement

"Narcolepsy was the primary reason for my taking medical retirement from my career as a college lecturer"

Number of hours required I.e., 9-5 often difficult to maintain

Q50 To what extent has narcolepsy impacted the following aspects of your employment? *negative = score 1 or 2
A – The ability to find a job
D- the type of job they can do

PWN are reticent to tell employers about their condition and would like more guidance on how to do this successfully

Employment

I am happy to tell employers about my condition to receive the level of support I need from them

n=314

Yet for many…

I would like more support / guidance on how to describe my condition to employers to get the support I need

n=312

Half of patients are uncertain about disclosing narcolepsy to employer

"It's unfortunate but as soon as Narcolepsy is mentioned, in my experience, employers lose interest!"

- **PWN do not want employers and colleagues defining them by their condition**
- **Senior management perceived as being much more negative towards the condition**
- **PWN fear they will be discriminated against if narcolepsy is declared**

I was happy to tell my employer everything. He tried to use it against me, and made me feel inadequate."

- **Employer might think the patient is lazy/ lying due to lack of knowledge about condition**

They would like help in how to explain the condition and ways in which employers can help

"I would like to know how to describe it .. for instance is it an illness or a neurological condition?

"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."

"I've told my employer but do not feel they offer any targeted support. Id like it to come from them rather than from me.."

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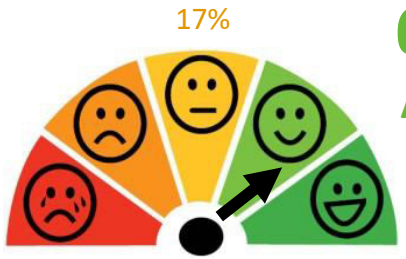
Getting financial support is an ongoing struggle that PWN are frustrated with

Employment

I am happy to tell benefits advisors about my condition to receive the level of support I need from them



n=309

I would like more support / guidance on how to describe my condition to benefits advisors to get the support I need

n=313

Almost two thirds are happy to share their condition with benefits advisors, but most feel they are not listened to

- **Felt that narcolepsy not recognised as a disability to be eligible for support**

  "Getting support with benefits advisors is essential, most have never heard of the condition and don't understand it! I often feel that if I attend a meeting and don't have an attack that they question my diagnosis! "

  "They don't seem to accept narcolepsy as a disability and force you to beg for support"

- **Assessment is based on general criteria not applicable to narcolepsy (e.g. distance you can walk, need to do web searches)**

- **Getting support that is needed is getting harder**

Benefits advisors need more education in what narcolepsy is and why it deserves support

"I have been refused benefits and so have no income"

"The system isn't helpful for narcoleptics. The questions mean nothing and judgements are made by none specialists."

"I have to fight at every ESA assessment to get the correct results. I had no difficulty getting DLA but am dreading the migration to PIP because I hear so many stories of people being refused and since I lost my job I need those benefits."

"It would be of great benefit to get someone from narcolepsy uk or someone who understands what narcolepsy is to help the benefit agency understand exactly how having narcolepsy effects people like myself and how to deal with us fairly."

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Raising awareness of the condition among employers and all staff will help people understand the support that is needed

How things can be improved?

- ✓ **Employer focused awareness programme to be shared internally with all staff**
  - To ensure there is no misconception of the condition I.e., perceived as lazy etc.
  - Customised **management approach** for line managers
- ✓ Tailored **career progression**
- ✓ Accommodate for **sporadic sleepiness/naps/ breaks at work**, esp. full-time
- ✓ Help with **travel to work benefits** for public transport
- ✓ Specialist contacting work directly to **inform employer of diagnosis/ what to watch out for** whilst at work
- ✓ **Clarity on special condition** outlined to employers in discrimination seminar
- ✓ Workplace **open to discussion around the condition** regardless of control

"Current employer has been accommodating and helpful with managing the sleep condition while working a full time job." (PWN)

"My daughter has had a lot of support from her Neurologist in informing her employers of her need for support at work.." (PWN)

"They sent her to occupational health to assess the support she would need at work" (Supporter)

"I think it should be clearly establish whether narcolepsy is a disability, a special condition, a sleep disorder etc and then establish exactly what the person with narcolepsy is entitled to depending on which stage of his life he is in. I think that would make things clearer and easier for everyone" (PWN)

Impact on social life

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Narcolepsy has a major impact on the activities PWN can take part in and their ability to spend time with friends

Social life

88%

Said narcolepsy **negatively*** impacts the **activities they can take part in**

Higher in **West midlands** (100%)

n=451

- **Specific activities can result in cataplexy attack I.e., large groups**

  "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 become jumbled and I end up suffering a cataplexy attack.."

- **Incapable of travelling to certain events/ activities**

  "Can't always go out as too tired. Can't go on days out they arrange as can't travel that far."

- **Unable to participate in full-day/ long events**

- **Some events embarrassing due to falling to sleep; cinemas, musicals, restaurants etc.**

  "Visits to cinemas, plays and musical events were an embarrassment because once the lights went out, so did I"

86%

Said narcolepsy **negatively*** impacts their **ability to spend time with friends**

Higher in **West midlands** (100%)

n=451

- **Lack of energy and focus – rarely arrange or participate in activities**

  "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.)"

- **Inability to join in with full day events / certain activities I.e.,**

  "I have to say no to some events as I'm that tired. Other times I have to leave my friends downstairs in my house while ill go to bed"

- **Forgetful of events that friends have arranged**

  "My friends know that any social event has to be planned in advance with them giving me regular reminders as I forget."

- **Lack of self-confidence restricts patients from interaction**

Q52 To what extent has narcolepsy impacted the following aspects of your social life?
*negative = score 1 or 2
A- The activities you/they can take part in
B - Your/their ability to spend time with friends

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PWN also struggle to maintain and make new friends

Employment

66%

Said narcolepsy **negatively*** impacts their **ability to maintain friendships**

n=451

- **Greatest negative impact** in **West midlands** (91%)
- **Higher impact** for those non employed (72%)

Lost friends due to being too tired to go out/ keep up with them

"I lost many friends through being too tired to go out or too tired to visit friends, and despite trying to explain, they would not understand"

Excessive mood swings pushes friendships apart I.e., aggressive

"I can't always go out to see my friends and so some friendships have deteriorated. My low moods can make if difficult to make new friends."

Lack of understanding about patients condition

Lost contact with friends due to them constantly feeling on edge regarding possibility of attack

Reliance on social media for contact and interaction

"Without the media of Facebook I would probably have not survived the last 8 years"

65%

Said narcolepsy **negatively*** impacts their **ability make friends**

n=451

- **Higher in supporters** (72%)
- **Greater impact** for those **under 18yrs** (74%)
- **Greater impact** for non employed (71%)
- **Lower impact** for **people with driving license** (53%)

Patients do not interact with people enough to make new friendships

"I don't like to make new friends because I find it hard to socialise as much as I did"

Maintaining conversations difficult with new people due to 'brain fog'

"I now find it difficult to maintain friendships and virtually impossible to make new friends due to the effects of the brain fog that tends to occur when I try to maintain conversations."

Developing new friendships makes patient vulnerable

"To make new friends and form new relationships is too scary"

Patients apprehensive around building new friendships due to previous friendships ending

Reliance on internet / social media to make new friends

Q50 To what extent has narcolepsy impacted the following aspects of your social life?
*negative = score 1 or 2
D- Your/their ability to maintain friendships
C- Your/their ability to make friends

Raising awareness so that people are more aware of the seriousness of the condition and how they can support PWN is key

How things can be improved?

Social life

- ✓ **Campaigns like 'end the awkward' overcoming the myths of narcolepsy by explaining what the condition is and what the symptoms are**
  - ✓ Reason why people need to sleep
  - ✓ Impact of different activities on the condition
  - ✓ Reasons why people always cancel / forget engagements
  - ✓ Understanding the need to plan ahead
- ✓ **Providing PWN help in how to explain condition to friends without scaring them**
  - ✓ What causes cataplexy attacks
  - ✓ How people can help in these situations
- ✓ **Guidance on how people can support and help**
  - ✓ What causes cataplexy attacks
  - ✓ How people can help in these situations

"I choose not to socialise because my friends make me laugh a lot which causes me bad cataplexy attacks."

"I am embarrassed by my diagnosis and do not look therefore to make friends outside of the narcolepsy circle. I find that these are the only people that understand how I feel."

"Generally speaking it's easier to maintain friendships with friends who also have disabilities and understand how difficult it is to predict how you will feel on any given day."

"Most people don't understand what this is or how people can support"

"I can never be spontaneous as I need to prepare for a social event by getting as much sleep as I can during the week before an event."

"Important is to be open and ensure friends are aware of me having narcolepsy, explaining to them the signs and symptoms."

Impact on family life

Adelphi

ADELPHI RESEARCH

Narcolepsy has a significant impact on peoples relationships partners and being able to build and maintain them

Family life

65%

Said narcolepsy **negatively*** impacts the **relationship with their partner**

n=316

- **Partner needs to support and manage patient as well as their own life**
- **Negative impact of aggressiveness of mood swings**
- **Brain fog makes it difficult to build relationships – gets too drowsy to sustain conversation**

"My partner gets annoyed when I forget my meds and I get too drowsy. He thinks I am ignoring him but I cant physically focus on things all the time. A lot of my energy goes on work."

- **Unable to be independent and is draining partner**
- **Partners have got 'bored' with patients due to them having no energy**

65%

Said narcolepsy **negatively*** impacts the **ability to build and maintain relationships**

Higher in supporters (73%)

n=407

- **Perceived to 'make no effort' / lazy**
- **Restricts relationship progression**
- **Frightening to children when patient has an attack / suffers from symptoms**
- **Children and partner fed up with forgetfulness**
- **Strain on family – relied on to do every day tasks that the patient would normally do**

Q54 To what extent has narcolepsy impacted the following aspects of your family life? *negative = score 1 or 2
A- The relationship with your/their partner
B- The ability to build and maintain relationships

Narcolepsy also negatively impacts the relationship with other family members and children

Family life

62%

Said narcolepsy **negatively*** impacts the **relationship with other family members**

Lower in London (46%)
Lower with people diagnosed over 11 years ago (54%)

n=446

Limited interaction with extended family
due to; them being judgemental / not having energy / inability to drive / lack of understanding

"Unable to spend time going out with family as I constantly feel tired, I haven't seen my grandparents for 2 years as its a long drive and I hate falling asleep as passenger on the way down."

"Extended family do not understand as they cannot see it and I have the sense they do not believe me."

"My family are very supportive. Extended family lack of understanding."

"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."

"Most close family understand, even the kids, but extended not so."

57%

Said narcolepsy **negatively*** impacts the **relationship with their children**

n=216

Fear of an cataplexy attack when looking after children alone

"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 whilst I work to help look after the children."

Criticised for being a bad parent due to the inability to look after them

Unable to play with children due to exhaustion and need for napping

Inability to have days out with 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"

Q54 To what extent has narcolepsy impacted the following aspects of your family life? *negative = score 1 or 2
D - The relationship with other family members
C - The relationship with your/their children

ADELPHI RESEARCH

Whilst PWN are generally others to tell people about their condition to get support, they feel like it does not result in what they need

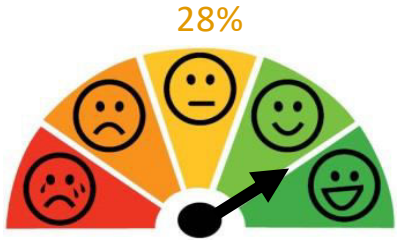
Family life

I am happy to tell others about my condition to receive the level of support I need from friends and family

n=446

However…

I would like more support / guidance on how to help me deal with the impact of narcolepsy on myself and the rest of my family



n=442

Majority are happy to tell others of their condition, but most feel this doesn't lead to the support they need

- **Easier to tell (close family) than friends**
- **People feel ill equipped to adequately describe the impact the condition has**
  - And unsure what support they need
- **An invisible condition so people don't believe / forget you're ill**
- **Lack of information and support available**
  - Limited medical support (NHS)
  - Limited information online
  - No emotional support (counselling) offered
  - Many rely on Narcolepsy UK support
- **Families need clearer guidance on the severity of the disease and its symptoms**
  - To be able to provide practical and emotional support

"One thing that stands out but I'm sure is difficult for lots of people - the invisibility of the condition"

"I feel I need more guidance than I am currently able to get from the internet and my GP in terms of possible new medication and help towards the costs associated with the condition. ."

"I do not feel I have received any support for myself and my family. It has been something we have adapted to the best we can as the symptoms gradually got worse. I feel there is things that I could greatly benefit from due to the condition but struggle to get help as I am not understood and people see me as an able bodied person as they can not see the condition."

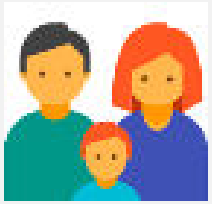
"I would have loved to have received help post diagnosis in mentally dealing with the pre diagnosis challenges and grief of life lost so far and it's lifelong prognosis. Help working through questions of value, contribution to family and society, guilt, confidence.... also very practical help in terms of how to keep safe, how to run your home in a simple way, support available for families, how to minimise stress, or control emotions related to triggers, healthy sleep routines, helpful mindset around food, exercise, routines, work opportunities or advice, help right from beginning in accessing any help or support socially available/benefits."

"I don't think there is anywhere near enough support given to patients with narcolepsy. I have spent hours online searching for information/advice on how to live with narcolepsy but there is next to nothing available"

ADELPHI RESEARCH

Offering counselling and support for families to give them an understanding of what to expect and how to cope will be useful

How things can be improved?



Family life

- ✓ **Provided better and earlier access and awareness to support networks for family members**
  - ✓ Information sheets, videos real life experiences of what its like to live with narcolepsy
  - ✓ Helping family know the triggers and spot the signs, and giving advice on what to do in these instances
  - ✓ Activities and groups (in person and online) bringing families together to share experiences and coping mechanisms
- ✓ **Offer support**
  - ✓ Counselling services
  - ✓ Childcare options to give people chance to sleep
  - ✓ Support for children who become proxy carers
  - ✓ Daily chore support (supporter worker / cleaner)
- ✓ **Use PWN as advocates – real life experience teachers**
  - ✓ Childcare options to give people chance to sleep
  - ✓ Support for children who become proxy carers

"Support could also come from meeting with other people with narcolepsy. I attended such event before with Narcolepsy UK and I found it very helpful."

"I am happy to talk to others about my condition and not only family members to try and educate others about the condition.."

"In a long term relationship now and Narcolepsy as minimal impact on this relationships because symptoms now generally well managed and we have a greater understanding of this condition and put coping strategies in place."

"I use my condition as a tool for my nieces and nephews, to educate them about it – they think its cool, like sleeping beauty"

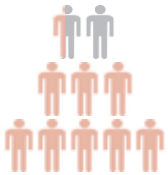
"I think there is a clear lack of support and knowledge of narcolepsy given to family members whereas this could help them and myself too. I think hearing the severity and description of the symptoms by the consultant will help the family understand for example that my dreams are not just simple dreams and that it is normal if it is difficult for me to deal with them."

Impact on health and views of available medical support

Adelphi

ADELPHI RESEARCH

The negative impact narcolepsy has on mental and well being is overwhelming for some



84%

n=444

Said narcolepsy **negatively*** impacts their **mental health / wellbeing**

Lower in East of England (70%)

- **Impact on self confidence**
- **Increases anxiety**
- **Causes depression / suicidal thoughts / self harm**
  - Narcolepsy can often be misdiagnosed as depression
  - Medications lead to increased depression
- **Suffer extreme mood swings / intense anger**
- **Feeling lonely and isolated**

"I think I'm still going through a grieving process, grieving my lost health and all the things I could be doing if only I didn't have these illnesses. This hits me all at once sometimes and I end up having a mental health crisis and feeling suicidal as I have tried all treatments unsuccessfully and therefore feel hopeless and like my life is going to be like this (low quality) forever"

"It's mentally and physically draining to be tired all the time and that takes it toll emotionally"

"Since diagnoses I have bouts of depression and self harm as I sometimes find narcolepsy so overwhelming"

"I'm am very unwell, my mobility is getting worse and my anxiety is in decline. Everyday is a struggle"

"It has made me become depressed because of the limitations it has caused me. It has also heightened my anxiety because of fear of attacks what people might think."

Q56A – My/their mental health- To what extent has narcolepsy impacted the following aspects of your health?
*negative = score 1 or 2

The conditions itself, its symptoms (cataplexy) and the medications all play a role in negatively impacting physical health

79%

n=446

Said narcolepsy **negatively*** impacts their **physical health**

- **Higher in PWN** (82%)
- **Lower in East of England** (66%)

- **Impact on weight**
  - Bad eating habits lead to weight gain / weight loss
  - Condition makes it hard to do exercise
- **Impacts /causes other conditions**
  - Fibromyalgia
  - Headaches
  - Other autoimmune diseases
  - Other conditions from being sedentary
  - Can't take high level pain killers
- **Cataplexy causes bruising / injury / muscle wastage**
- **Leads to people being run down and more susceptible to catching bugs**
- **Medications have own side effects**

"My physical health, and general well being has suffered as a result of the diagnosis and the subsequent drugs I have been put on to get me back on track."

"There was a time that I also was borderline anorexic"

"Doesn't always have the energy to exercise even though exercise helps to increase energy. Has put on weight as will eat convenience foods because it takes up less time '

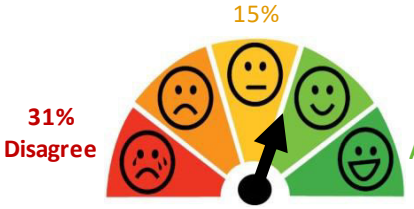
" Side effects of stimulants also left me with dystonia of my right side. A condition dare I say is worse than narcolepsy"

"I struggled with my diet before I was diagnosed as I was constantly diving for all the wrong foods looking for a sugar hit to keep me awake or to try and stay more alert. Although I now know that wont help me I am left overweight and struggling to shift it. Exercising is hard as it knocks the energy straight out of me"

Q56B – My/their physical health- To what extent has narcolepsy impacted the following aspects of your health?
*negative = score 1 or 2

There are high levels of dissatisfaction with medical support around initial symptoms, GP interaction and diagnosis, with PWN happier with current management

I feel confident in describing my condition to receive the level of support I need for medical care



n=444

First symptoms

n=449

Medical professionals took me seriously when I first reported the symptoms of narcolepsy

GP interaction

My GP has sufficient knowledge of narcolepsy to understand how it affects my general health and care needs

n=444

Diagnosis

n=446

I was diagnosed within a reasonable timeframe

Specialist interaction

Over the last year, I have received adequate support from a specialist who has a good understanding of narcolepsy

n=441

Current management

n=439

Currently, I have access to the medications that I need to best treat my narcolepsy

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The initial stages of diagnosis are painful, discouraging and long winded

First symptoms

- Symptoms often dismissed
- Often questioned about reality / severity of symptoms – not believed
- Often laughed at for seeking help for being tired
- Especially difficult for 'typical lethargic teenagers'

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

"I felt like no one believed or was listening to me. It took me asking to be sectioned by my GP as if they could find nothing physical then there must be something mentally wrong with me, it was only then that I was referred for a sleep study - 20 years after first showing symptoms"

GP interaction

- Often have little or no knowledge or dismiss chances of condition due to it being too rare
- Difficult to maintain continuity with same physician

"These days I never see the same person twice."

- Some GPs make personal effort to improve knowledge, but general awareness and training is lacking
- Lack of interest in helping continued treatment

"My GP has taken vast steps to understanding my condition and has been very supportive but I feel still lacks training."

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

"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"

Diagnosis

- Long and frustrating

"In total since I first suggested a sleep disorder it has been 15years."

- Often misdiagnosed with other conditions
  - Depression
  - Sleep Apnoea
- Lots of referrals to unnecessary specialists
- Evidence of cataplexy leads to faster diagnosis

"It was only when I started having cataplexy attacks that Narcolepsy was suggested"

- Many do own independent research to prove disease
- Quicker in private setting

" A quick diagnosis enabled me to complete my a levels - I wouldn't have passed otherwise."

And when PWN reach a specialist it is often still be a frustrating experience

Specialist interaction

- **Usually referred to neurologist first**
  - Often have limited knowledge of disease

"I saw many neurologists that did not have any knowledge about narcolepsy."

- **Due to multiple referrals, patients often get 'lost' in the system**
- **Satisfaction with sleep specialists is higher, but level of competency varies and accessing them is frustrating**
  - Can take years / multiple sleep tests
  - Waiting lists very long
  - Time with them is minimal
  - Can struggle to see the same one consistently
- **Once medication is 'sorted' often referred back to GP**
  - Can be prescribed medication and then left without follow up for many years
- **Constant assessment is tiring and frustrating**

"I asked to see a specialist in Narcolepsy but was informed that I had to see the local neurologist first. She had only ever treated one person and with ritalin. At that point I thought I had a firm diagnosis. I had to try ritalin first and if that did not work then I would have a better case for sodium oxybate. I took it for three months ..it was awful. I waited a full year for a review appointment and was sent 60 miles to the wrong neurologist and hospital. She wrote to my neurologist but did not send me a copy. I never got an apology or another appointment from my neurologist but was referred eventually to Neville Hall Hospital. That took 4years."

Current management

- **Two thirds people feel its generally quite good**
  - If now handled by sleep specialist
  - but has taken a long time to get here
  - Required lots of independent research
  - Was very frustrating
- **Can be difficult to see same physician consistently, impacting treatment**
- **NHS cost restrictions limits access to some treatments**
  - Xyrem
  - Wakix
  - Modafinil
- **Some reticence toward medication due to high level of nasty side effects**

"In 1992 I was seen by hospital consultants and had various tests done but narcolepsy was never mentioned until 2017. I do not find this and adequate time frame."

"Getting put on xyrem enabled me to be able to return to work however my GP argued about the shared care agreement because of the cost of xyrem which led to a delay in it being prescribed from my local pharmacy so my mum had to get an emergency prescription frim the sleep consultant at the hospital just because the GP was worried about price thinking there must be a cheaper alternative!"

"I have transferred now to an amazing neurologist. He is very supportive and helps me to facilitate social activities rather than just basic care. It is something I didn't have from my previous doctor and it makes a huge difference in my general well being."

Earlier diagnosis and medical staff who understand the condition would play a significant role in improving the impact on mental health

How things can be improved?

- ✓ **Earlier diagnosis**
  - ✓ To give access to health care support
  - ✓ To ensure correct medications are given as quickly as possible
- ✓ **Providing counselling services**
  - ✓ For PWN and their family
- ✓ **Health care professional education programme**
  - ✓ So more are aware of the condition, its symptoms, triggers and treatments
- ✓ **Guidance and support on diet management and suitable / relevant exercises**
  - ✓ Meal planning guidance
  - ✓ Benefits of exercise on physical and mental health and wakefulness – how they can achieve this when exhausted

"He has found great benefit from physical activity in terms of his mental health and his physical well being"

"Physically – her choice of activity has made a huge difference and as a dancer is very healthy. It has a double benefit in that the choice itself helps to maintain her wakefulness when active as well as maintaining fitness and good health."

"She has had counselling to try to help her to deal with accepting her condition"

"We are awaiting counselling for us a family but more so for my daughter who has Narcolepsy."

"Now I have a diagnosis can manage much better especially with Xyrem"

How things can be improved

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Conclusions

Diagnosis

- It is a long, slow process to a confirmed diagnosis, taking 8 years on average
  - Health care professionals at the early stages are poorly educated and equipped to diagnose the disease, often dismissing it or misdiagnosing
  - Even when PWN reach specialists, which can take years, numerous referrals and constant assessment are common, causing unnecessary stress and frustration
  - Level of knowledge and expertise varies hugely amongst specialists which impacts the extent to which PWN are treating correctly

Narcolepsy has a hugely negative impact on all areas of life

Education

- PWN struggle with all aspect of education
  - It impacts their choice of subjects and length of study, but most notably their attendance and ability to achieve
- Educators' awareness and knowledge of narcolepsy is generally limited and has a huge impact on the level of support made available
  - There are pockets of good examples, where flexible learning and support to deal with symptoms is provided, but this is generally driven by enthusiastic individuals and not consistent across staff / institutions

Conclusions

Employment / benefits

- Narcolepsy hugely impacts the ability to find, progress within and maintain a job
  - 80% PWN are restricted as to what job they can do because of their condition
- Only half of PWN feel confident in telling their employers about their condition
  - Often frightened that it will have a negative impact on them
- Employers awareness and ability to support PWN is minimal
- Seeking benefits is also extremely frustrating
  - Benefits advisors are completely unprepared to assess the condition, with many dismissing it as something which needs support
  - 74% of PWN need help in how to explain their condition to assessors in order to get the support they need

Social life

- Narcolepsy causes people to feel isolated and lonely
  - 86% of PWN are hugely limited in what activities they can do, which impacts their ability to spend time with friends
- Social media plays a significant role in providing some sense of normality in social interaction

Conclusions

Family life

- Narcolepsy prevents people from building and maintaining relationships, often causing long term relationships to break down
- Extended family often find it difficult to understand the day to day struggles of the condition which leads to rifts

Health

- The condition, its symptoms and side effects of medication play a significant role in the deterioration of PWN's physical and mental health

Thank you

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