

Narcolepsy UK Charter Research

We conducted a market research project with Adelphi Research to **understand the extent to which narcolepsy impacts different people's lives**, with the aim to provide evidence for the Narcolepsy Charter - a document that will define the direction of Narcolepsy UK over the next five years and beyond

To do this, we spoke to...



302 People with Narcolepsy (PWN)



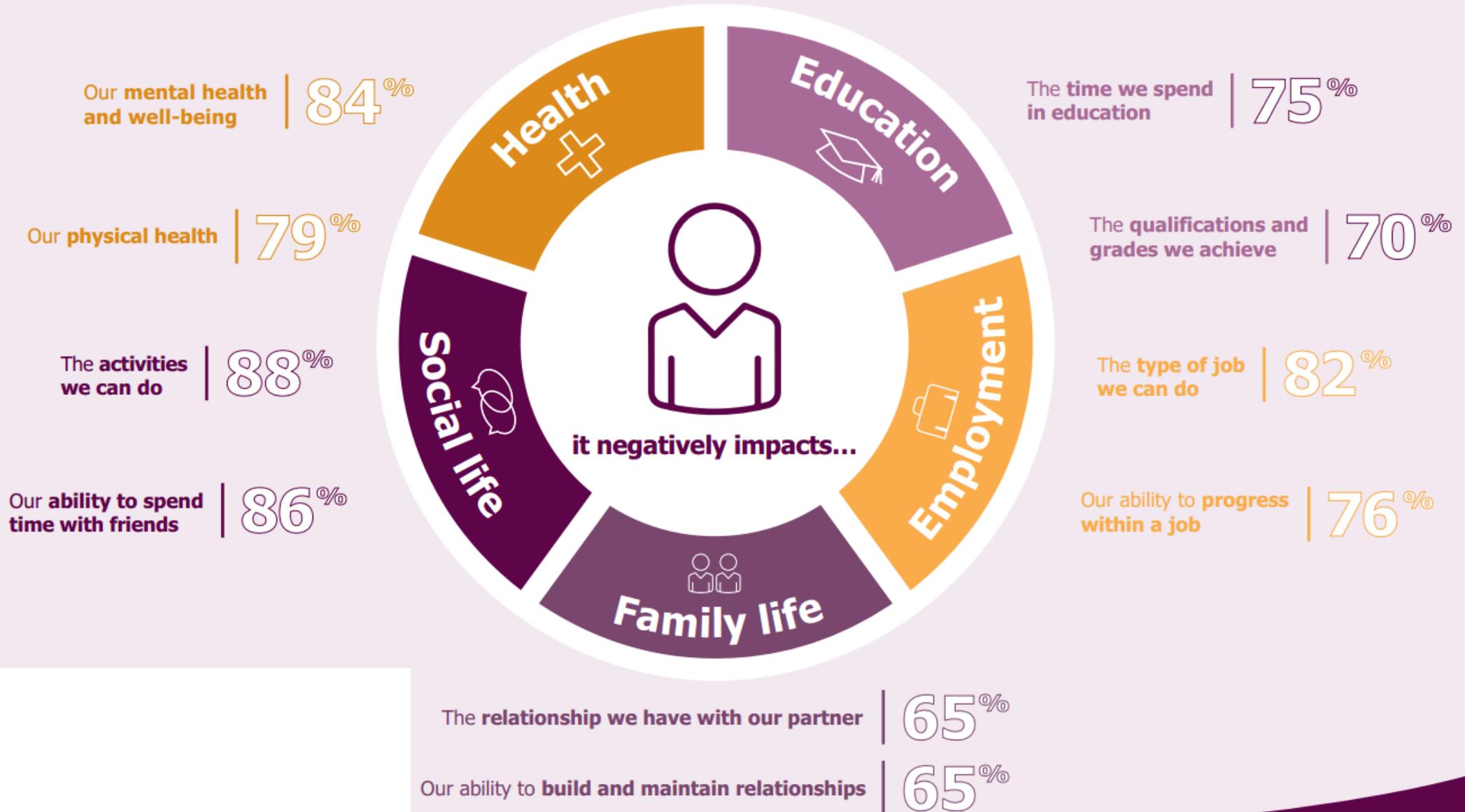
149 Supporters of PWN
(parents, partners or other close family and friends)

...using an online approach

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



Narcolepsy affects every area of our lives



Health

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

“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.”

Social life

“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 enjoy (for example I don't drink and can't do dark pubs/clubs or stay up too late.)”

“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..”

Education

“As I have always been a hard working, bright student, this impact on my education has had an extremely negative impact on my view of myself.”

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

Employment

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

“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.”

Family life

“My partner gets annoyed when I forget my meds and I get too drowsy. He thinks I am ignoring him but I can't physically focus on things all the time. A lot of my energy goes on work.”

We have to fight for appropriate medical care

The **relationship we have with our partner**

65%

Our ability to **build and maintain relationships**

65%



31%

were **taken seriously when they first presented with symptoms**



33%

feel they were **diagnosed within a reasonable time frame**

58%

feel they **currently have access to the best medications** to treat their condition – this **often takes years to perfect**, and **NHS budgets can limit access to the preferred drugs**



57%

feel they have had **adequate support from a specialist** in the last year – getting to the right specialist is a **long and frustrating road**



17%

feel their **GPs have sufficient knowledge of narcolepsy**



On average, to receive a confirmed diagnosis it takes people aged over 18 **6** years and people under 18 **1.7** years



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

“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.”

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

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

“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 from the sleep consultant at the hospital just because the GP was worried about price thinking there must be a cheaper alternative!”

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

Despite this we battle on



14%

aged over 18 are
in education



53%

are in employment



99%

aged under 18
are in education

Many of us have
active family lives,
parents, partners,
children... and our
condition affects
them too

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

“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 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.”

“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.”

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

But we need help with describing our condition to get the support we need

People with narcolepsy want more support...

to describe the condition
to **educators**

40%

aged over 18

64%

aged under 18

to describe the
condition to **employers**

54%

aged over 18

11%

aged under 18

to describe the condition to
benefit advisors

57%

aged over 18

24%

aged under 18

on how to help them **deal with the impact of narcolepsy
on themselves and the rest of their family**

59%

aged over 18

58%

aged under 18

The adult men among us and ethnic minorities may find it harder to seek support



ADELPHI RESEARCH

Based on a survey of 302 people with narcolepsy and 149 supporters

“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”

“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 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 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.”