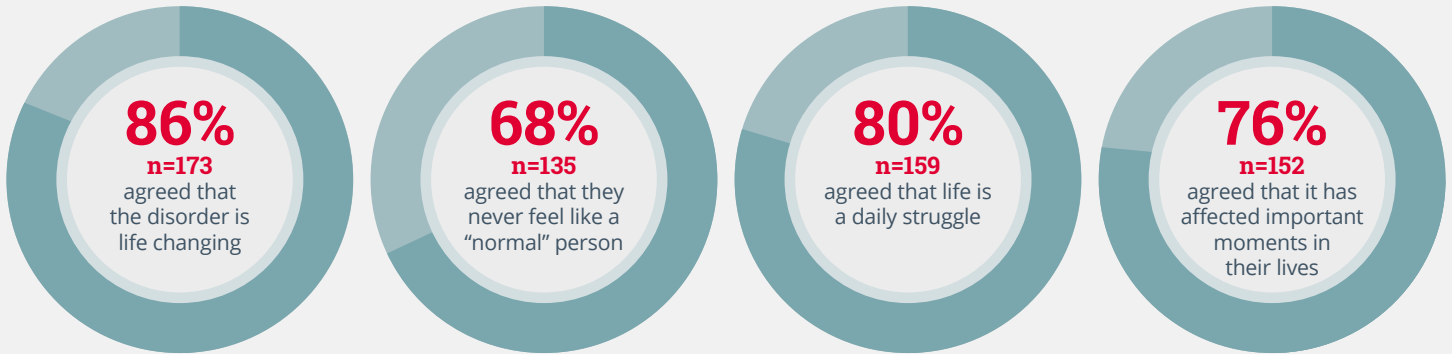


# KNOW NARCOLEPSY<sup>®</sup> SURVEY

The information shown below is based on a three-part survey of 1654 US adults including those with narcolepsy (n=200), the general public (n=1203), and physicians (n=251) currently in clinical practice who have treated patients with narcolepsy in the last two years. Surveys of people with narcolepsy and the general public were conducted online in March and April 2018, and physicians were surveyed in August 2018. Not every person surveyed answered every question. Versta Research conducted the survey on behalf of Harmony Biosciences. The Narcolepsy Network collaborated on the patient survey.

## Narcolepsy can negatively affect a person's daily functioning and social well-being, but others may not always recognize the impact.

Of people living with narcolepsy surveyed:



Yet, **78% (n=940)** of the general public surveyed agreed that they have no idea what it must be like to live with narcolepsy, which impacts approximately 165,000 Americans.

## The survey highlighted the complexity of narcolepsy and challenges in symptom recognition and diagnosis.

The journey to diagnosis can be long and complex. People may spend years living with symptoms prior to receiving a narcolepsy diagnosis.



**Nearly four in ten (n=77)** people living with narcolepsy surveyed reported they **initially received a misdiagnosis.**

## Even after receiving a diagnosis, many people living with narcolepsy continue to feel the impact of their symptoms.

Of people living with narcolepsy surveyed:



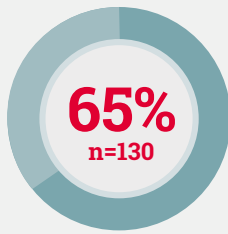
**88%**

n=175

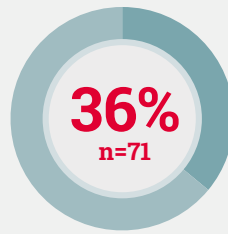
indicated that excessive daytime sleepiness (EDS) is one of their most disruptive symptoms

## People living with narcolepsy may make changes in their lives because of the disorder.

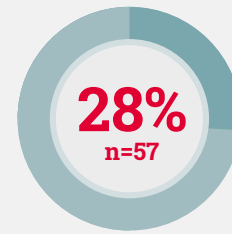
Of people living with narcolepsy surveyed:



reported social changes, like not going out as much to events, dinners, movies, and family events



reported physical changes, like changing jobs, moving, and being unable to cook or bathe when no one is around



reported emotional changes, like not showing emotions as much

## People living with narcolepsy surveyed cited the behavior and perceptions of other people as being among the biggest challenges of living with the disorder.

**72% (n=144) reported that they avoided telling people they have narcolepsy.**



When they did, **two-thirds (n=135)** agreed they believed people were skeptical.

Of people living with narcolepsy surveyed:



**68%**  
n=135

agreed they believed others thought they did not really have narcolepsy



**67%**  
n=134

agreed they believed others thought they used narcolepsy as an excuse not to work or do other things



**1 in 4**  
n=47

reported having been fired from a job or demoted because of problems related to narcolepsy



**37%**  
n=62

reported having failed a class at school or withdrawing entirely because of symptoms of narcolepsy

## Those surveyed agreed that the entertainment media portrayal of narcolepsy contributed to misperceptions about the causes, symptoms, and impact of the disorder.



**84%**  
n=210

of physicians and 74% (n=149) of people living with narcolepsy surveyed agreed that social media and the entertainment industry have a distorted view of the disorder



**Over 2/3**  
n=813

of the general public surveyed agreed that people do not take narcolepsy seriously



**29%**  
n=353

of the general public surveyed reported having seen, read, or heard somebody make light of narcolepsy or make a joke about it