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

Of people living with narcolepsy surveyed:

- **86%** \(n=173\) agreed that the disorder is life changing
- **68%** \(n=135\) agreed that they never feel like a “normal” person
- **80%** \(n=159\) agreed that life is a daily struggle
- **76%** \(n=152\) agreed that it has affected important moments in their lives

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 up to 200,000 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.

In fact, for people living with narcolepsy surveyed, it took **6+ years** on average to receive a diagnosis following the onset of their symptoms.

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:

- **Only 1 in 8** \(n=24\) agreed that their narcolepsy symptoms are completely or mostly under control
- **88%** \(n=175\) indicated that excessive daytime sleepiness (EDS) is one of their most disruptive symptoms
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.

Of people living with narcolepsy surveyed:

- 65% (n=130) reported social changes, like not going out as much to events, dinners, movies, and family events.
- 36% (n=71) reported physical changes, like changing jobs, moving, and being unable to cook or bathe when no one is around.
- 28% (n=57) 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.

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.

Know Narcolepsy is a registered trademark of Harmony Biosciences, LLC. Harmony Biosciences name and logo are registered trademarks. © 2018, 2019, 2020 Harmony Biosciences, LLC. All rights reserved. US-NAR-2000079/Aug 2020