

A large European Patient Survey on Narcolepsy and Idiopathic Hypersomnia (N/IH): 1,667 Respondents Across 15 Countries



In 2025, the European Narcolepsy Alliance for Patients (eNAP) conducted a large-scale European patient survey on Narcolepsy and Idiopathic Hypersomnia (N/IH).

Results are presented as percentages for the overall respondent group and further analysed by diagnosis, gender, age group, and country.

Below is a snapshot of the key findings, including diagnosis timelines, access to specialist care, treatment satisfaction, support needs, and quality of life.

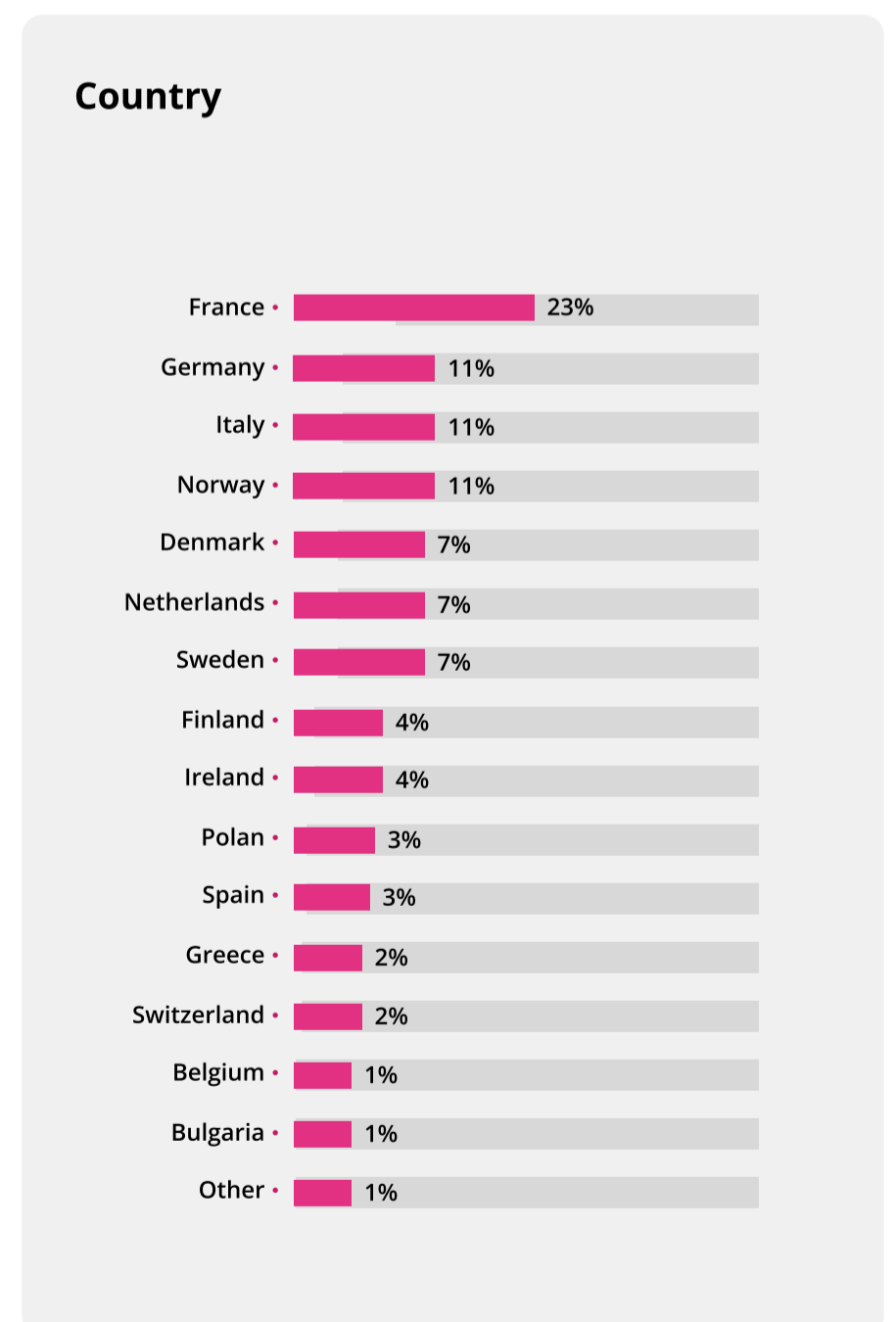
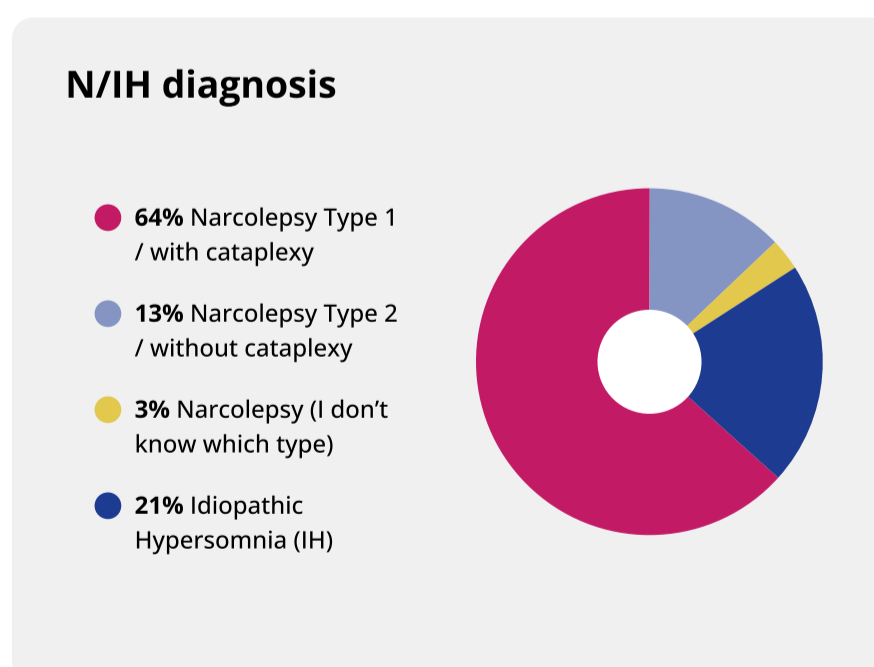
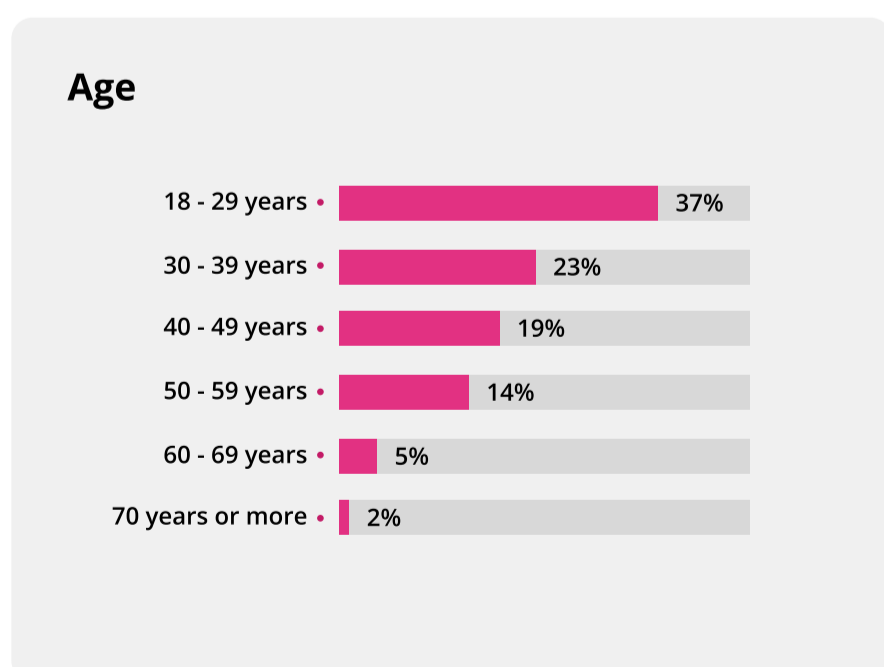
The full 180-page report is available at narcolepsy.eu.

The European Narcolepsy Alliance for Patients (eNAP) is a collaboration between patient support groups for people with Narcolepsy and Idiopathic Hypersomnia (N/IH) across Europe. The alliance is dedicated to raising awareness and improving the understanding, treatment, and quality of life for those living with these conditions.

About the survey

The patient survey collected responses from 1,667 people across 15 European countries living with Narcolepsy or Idiopathic Hypersomnia. Respondents represented different diagnostic groups, including Narcolepsy Type 1 with cataplexy (64%), Narcolepsy Type 2 without cataplexy (13%), and Idiopathic Hypersomnia (21%), as well as a small group who were unsure of their specific N/IH diagnosis (3%).

The majority of respondents were female (76%), while 24% were male. Most were aged 18-39 years (60%).



The report is available at the website of eNAP: narcolepsy.eu. Check the website for more information about eNAP and its member organisations or contact us at enap@narcolepsy.eu.

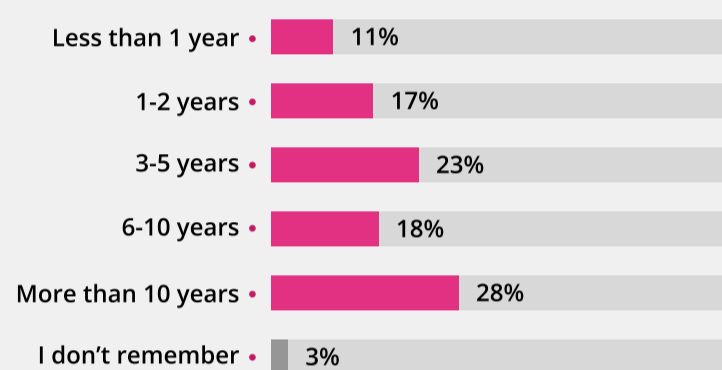
Diagnosis journey

The time from first symptoms to diagnosis is often strikingly long and complex. Only 28% of survey respondents received an N/IH diagnosis within two years, while 28% waited 10 years or more. Before receiving their diagnosis, many respondents had already consulted several healthcare professionals: 49% saw 1-3, 38% saw 4-10, and 6% saw more than 10.

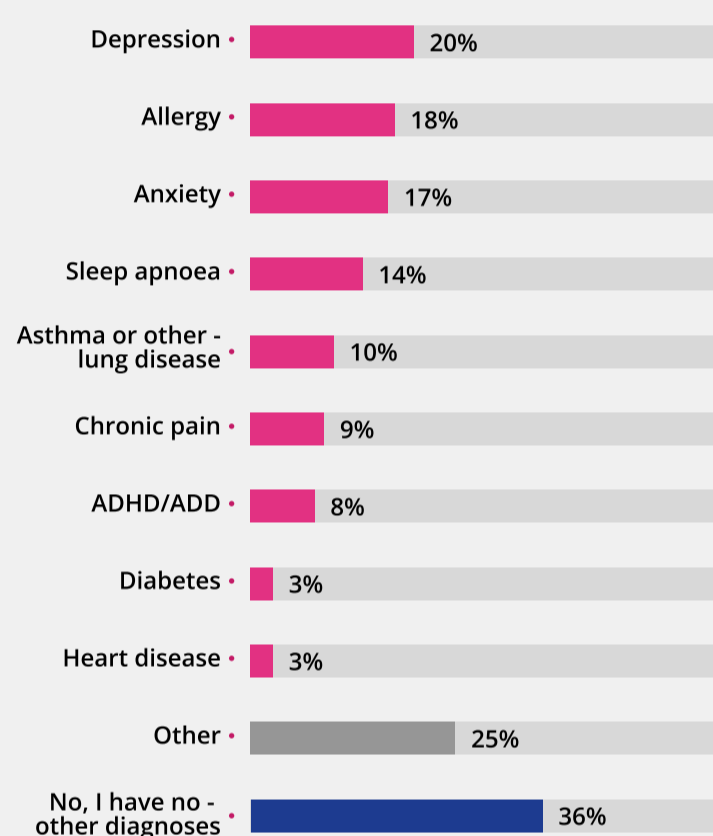
The majority of respondents reported having at least one additional diagnosis, with 20% reporting depression, 17% anxiety, and 14% sleep apnoea. Despite these challenges, most respondents were (very) satisfied with the emotional support from family, friends, healthcare professionals, and patient organisations – less so from work and educational settings.



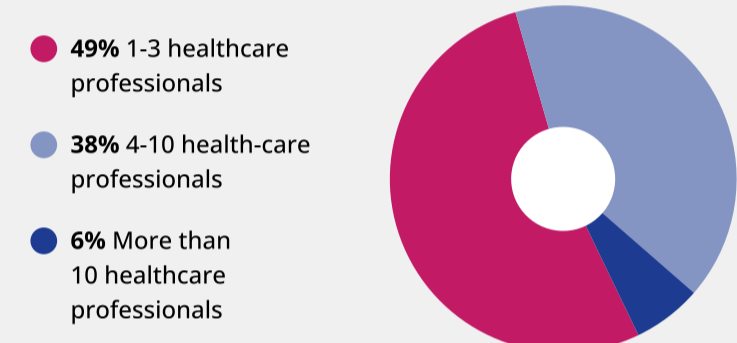
Time before diagnosis



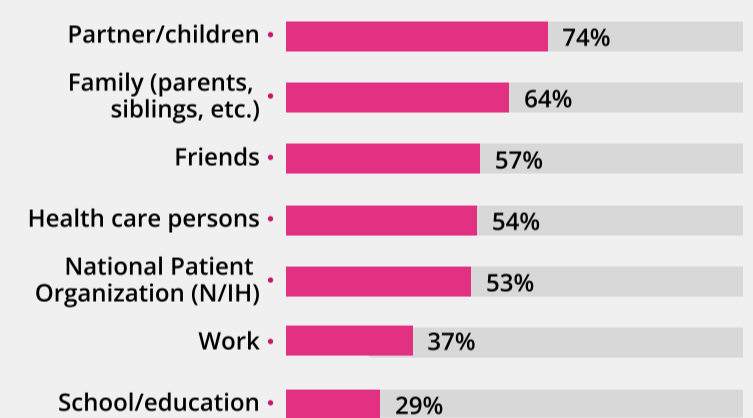
Other diagnoses



Number of HCP's seen before diagnosis



(Very) satisfied with emotional support from...



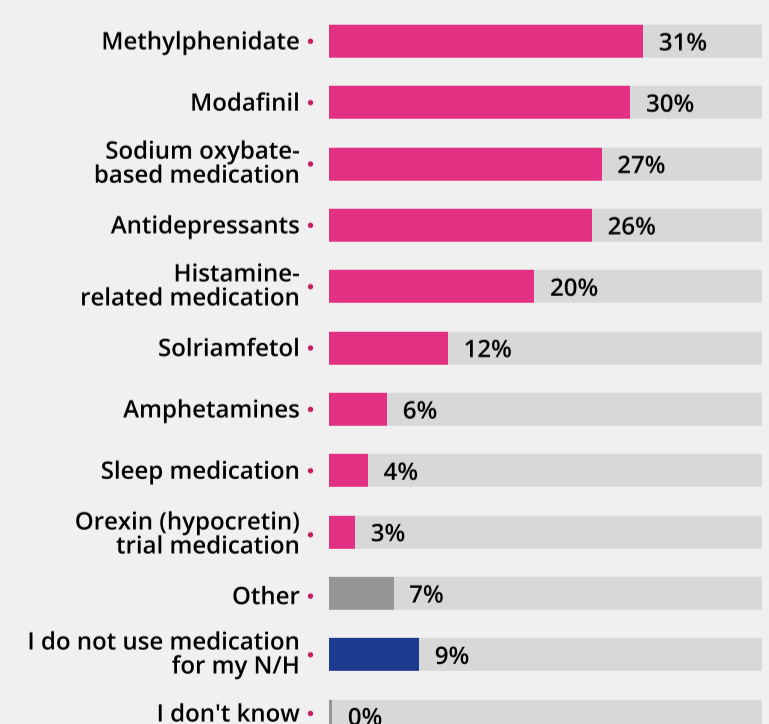
Treatment

Treatment for N/IH typically involves specialist care and regular follow-ups. Encouragingly, 84% of respondents were treated by a neurologist or a sleep specialist. However, follow-up patterns varied; 6% had no follow-up appointments, 53% had up to one yearly appointment, and 41% had at least two appointments per year. Medication plays a central role in treatment. The vast majority (91%) used medication, most commonly stimulants

such as methylphenidate (31%) and modafinil (30%), followed by sodium oxybate (27%) and antidepressants (26%). Overall, 57% of respondents were satisfied with their treatment.

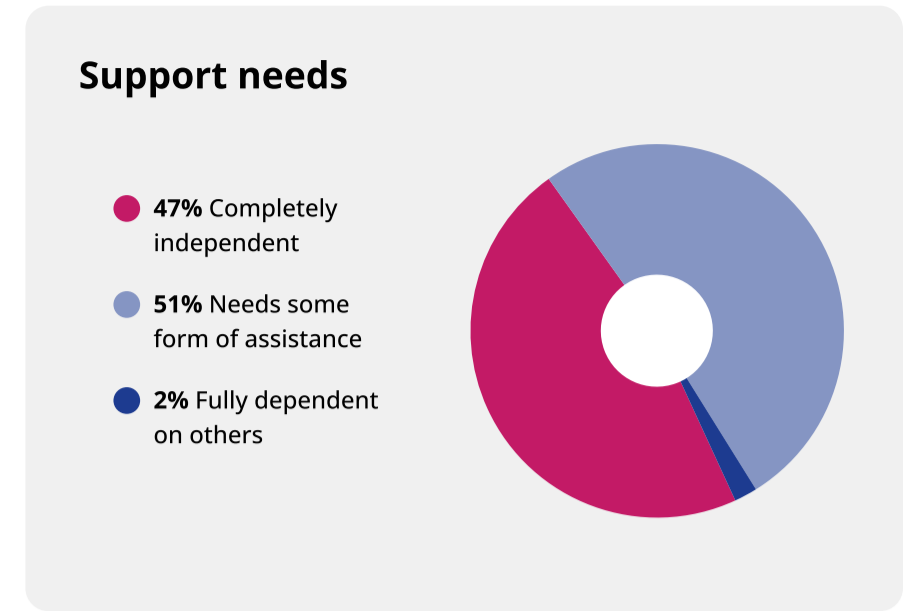


N/IH medication



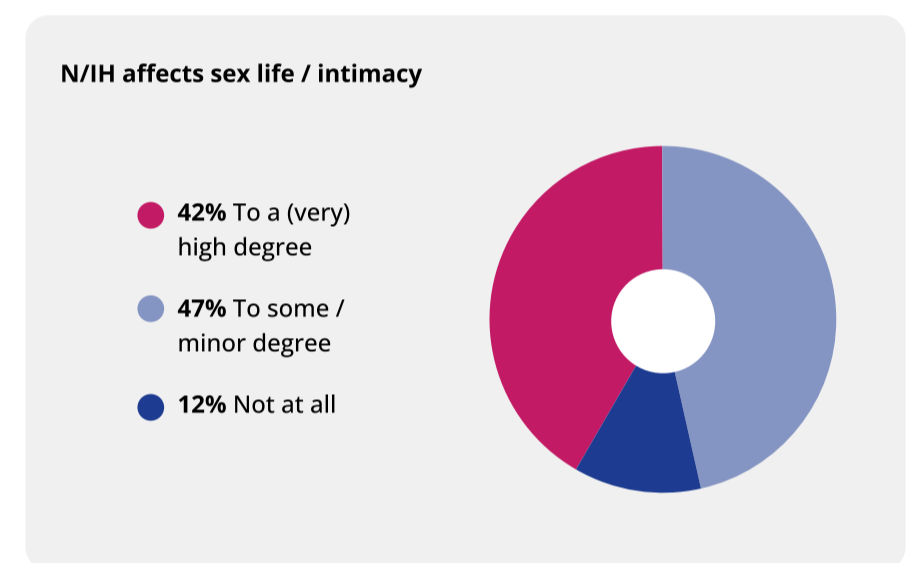
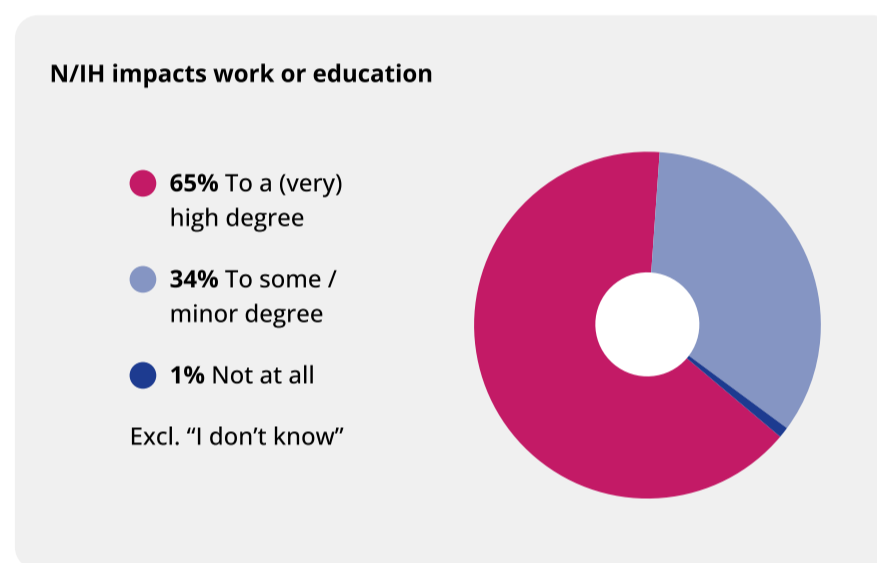
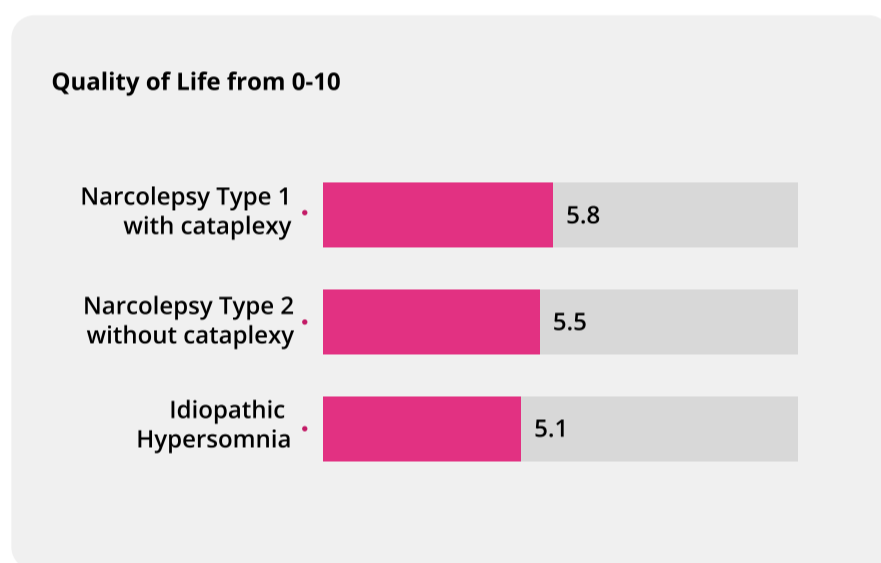
Support

Support needs vary. While 47% of respondents were completely independent in managing daily activities, 51% needed some form of assistance from others, and 2% were fully dependent on others. Mobility is also significantly affected; 72% said their condition limited or prevented them from driving a car, and almost half (49%) had a driving licence but drove less than they would like due to their condition. Patient organisations play an important role; overall, 58% were (very) satisfied with their patient organisation.



Everyday life with N/IH

Everyday life with N/IH is affected across multiple areas. Respondents rated their quality of life at 5.6 out of 10, which is 1.7 points below the EU average (7.3)¹. A majority (65%) reported that N/IH impacts their work or education to a (very) high degree, while 34% reported some or minor impact, and 1% reported no impact. Among respondents who are in a sexual/intimate relationship, 42% reported that N/IH affects their sex life and/or intimacy to a (very) high degree, 47% to some degree, and 12% not at all.



The most frequently reported challenges in daily life:

Daytime sleepiness

Not feeling refreshed in the morning

Automatic behaviour **Feelings of sadness or depression**

Concentration and attention problems

Weight gain **Lack of physical energy**

Memory problems **Bad night sleep**

Lucid/realistic dreaming

1) Source: EU quality-of-life indicators – Statistics Explained, EU-SILC survey data, 2023