

## Challenges in different life stages for people with narcolepsy at eNAP's patient session in Leiden 2023

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The 14th European Narcolepsy Days (END) conference took place in November 2023 in Leiden, the Netherlands, with a wide range of participants: researchers; neurologists and other health care professionals; representatives from the pharmaceutical industry; patients with narcolepsy and idiopathic hypersomnia (IH); their relatives and parents of children with narcolepsy.

During a patient session organised by eNAP (European Narcolepsy Alliance for Patients), the participants discussed the challenges faced by people with narcolepsy/IH at different stages of life. In addition to the participants from the conference, several Dutch narcolepsy patients and parents of children with the disease also contributed. They were divided into 10 groups, with two groups in each of the five subjects: newly diagnosed; parents of children; teenagers; young adults and adults.

Organised as a structured conversation, the sessions were guided by a set of questions (Fig. 1) asking about challenges, positive experiences and requesting suggestions for solutions to improve the lives of those living with narcolepsy/IH.


 <p><b>Challenges in different stages of life</b> Patient session Saturday 11<sup>th</sup> of November at END in Leiden 14.30 – 15.30</p>	<p><i>Focus on the 2 chosen topics in the next three questions...</i></p> <table border="1"> <tr> <th colspan="2">Question no. 3: What is already working/helping?</th> </tr> <tr> <td></td> <td>Discuss what may already be working/helping with topic 1 and 2</td> </tr> <tr> <td></td> <td>Topic 1</td> </tr> <tr> <td></td> <td>Topic 2</td> </tr> </table> <table border="1"> <tr> <th colspan="2">Question no. 4: What could be helpful?</th> </tr> <tr> <td></td> <td>Discuss what things could be helpful to contribute to these topics.</td> </tr> <tr> <td></td> <td>Topic 1</td> </tr> <tr> <td></td> <td>Topic 2</td> </tr> </table> <table border="1"> <tr> <th colspan="2">Question no. 5: Who or what can contribute?</th> </tr> <tr> <td></td> <td>Give examples of who and/or what can contribute to helping these topics.</td> </tr> <tr> <td></td> <td>Topic 1</td> </tr> <tr> <td></td> <td>Topic 2</td> </tr> </table>	Question no. 3: What is already working/helping?			Discuss what may already be working/helping with topic 1 and 2		Topic 1		Topic 2	Question no. 4: What could be helpful?			Discuss what things could be helpful to contribute to these topics.		Topic 1		Topic 2	Question no. 5: Who or what can contribute?			Give examples of who and/or what can contribute to helping these topics.		Topic 1		Topic 2
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Fig. 1: Discussion questions used to guide the group conversations

Given the complex nature of living with a rare disease, the conversational approach was determined to be the most productive way to delve deeper into the subject matter. The initial question (Q1) allowed for a broad examination of the challenges, with the participants writing down all the challenges that they experienced with narcolepsy/IH on an A1-sized sheet of paper, which was posted afterwards in the atrium for all to see.

## Results

The “Q1: What is the biggest challenge?” question raised a wide range of themes among the groups including many of the practical matters associated with living with the disorders. As summarised in Fig. 2, acceptance, in its many forms, resonated strongly for all stages of life.

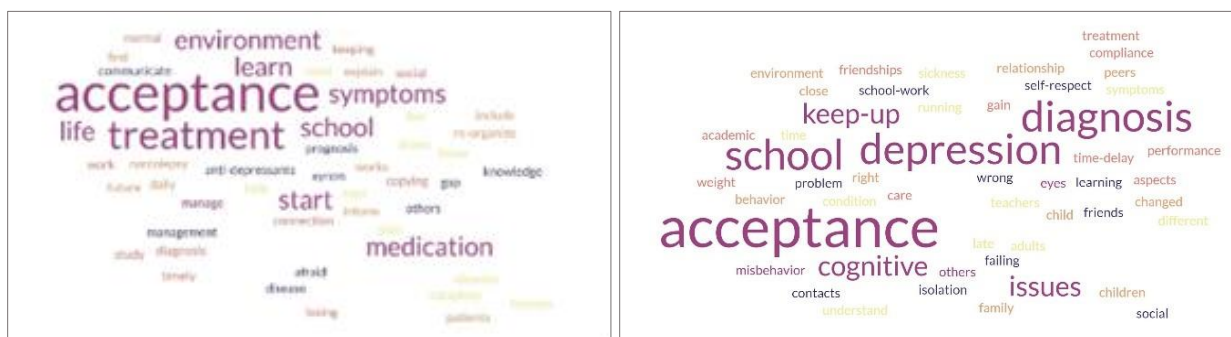


Fig. 2: Word clouds of the responses from the newly diagnosed and young children’s groups on the question of challenges that they face

The second stage involved focusing on the top two topics (Table 1).

Group no. and name	Topic 1	Topic 2
A1: Newly Diagnosed	Acceptance	Disease management
A2: Newly Diagnosed	Lifestyle changes	Creating a supporting environment
B1+B2: Young children	Acceptance of disease including social aspects/school aspects	Struggle to get and accept diagnosis, for parents and child
C1: Adolescent	Social relationships	School/studying
C2: Adolescent	School incl. managing school and getting sufficient help	College incl. having good routines and time for exams
D1: Early adulthood	Balance between professional/ social life	Family planning incl. effects of non-medication during pregnancy
D2: Early adulthood	Daily life	Social life
E1: Adult	Financial situation	Gender influences + other health aspects
E2: Adult	Balance (work-life-social)	Health care support system

Table 1: Answers to Q2: Choose the 2 biggest challenges (topics) to continue focusing on in the next questions.

The remaining questions (Q3, Q4 and Q5) explored what has already helped and what/who could help. Here the responses varied across the individuals, age groups and nationalities and included support associations, lifestyle changes, work and social conditions, amongst others.

Under these headings, many different challenges emerged, beneficial experiences to meet the challenges and suggestions for even better solutions. That being said, overall, the participants had a lot of the same themes in common.

## Issues Affecting the Quality of life for people with narcolepsy/IH

From this broad approach, the discussions did reveal issues, challenges, existing and potentially better solutions to improve the quality of life for people living with narcolepsy/IH in Europe (Table 2).

• Family, relationships/dating and friends (the "close" social)
• Connections in the community that offer support to life with narcolepsy (other social)
• School; flexibility, having a mentor, both at the primary school and university levels
• Work, ambitions, changing career dreams, not being able to work full time and flexibility
• Lifestyle, sport and diet
• Treatment and diagnosis, health systems, medicine
• Psychological aspect; guilt and shame, embarrassment – own influence of normality, stigma, etc.
• Government, political, state bodies/the public system
• Larger community connections (other than the above family/friends/community), including patient networks/support groups and associations, that offer better information about the disease.
• Holistic approach, complex issues, self-respect and acceptance, coping strategies, overcoming perceptions of what is normal, dilemmas that narcolepsy creates, maintaining a positive/optimistic attitude
• Economic conditions
• Children and pregnancy
• Daily structure, time, planning, importance of have a routine
• Lack of understanding/misunderstanding, negative perception of the narcolepsy patient's behaviour, stigma

*Table 2: Issues Affecting the Quality of life for people with narcolepsy/IH*

## Discussion

### Acceptance and coping with a chronic sleeping disorder

For a large proportion of the participants, there was a consensus on the importance of acceptance, which is both a challenge and a solution to achieving a better quality of life. This sentiment was expressed in different ways, including as a challenge for children to accept the need for several naps during the day – an important tool for dealing with the disease.

However, it turned out during the sessions that acceptance was quite a broad theme in all groups (Fig. 2) - beyond challenges, positive experiences and proposed solutions. The discussions noted that people also struggled to accept that they have a chronic illness that limits the patients' lives.

As one of the groups of young adults expressed it, this is everyday life, social life and working life, including the balance between what you want to and can do.

Here they described that part of the acceptance of having a chronic illness is recognising it and being open to their bodies' needs. In their surroundings at any given time, is there a possibility

of taking a nap; can that possibility be created? This self-advocacy is an important element of self-acceptance.

One of the adult groups detailed the challenge of balancing work and social life, with respect to diet and nutrition. Both were found to have been important and beneficial for disease management but sticking to that regime can also have consequences affecting one's social life. This arises when one has to decide between keeping to a structured diet (lifestyle) and their social life.

In the young adult group, structure and planning proved to be important, in particular creating a good everyday structure in relation to naps and medication. Despite what is currently available (country dependent), there is a demand for better medications to alleviate the symptoms of narcolepsy/IH.

One of the teenager groups echoed this sentiment and went further highlighting the need for help with better planning of when and which medication should be taken. To this end, proposals for an interdisciplinary team were suggested, or a specialized team to be able to support and help narcolepsy patients in the best possible way.

#### Interdisciplinary teams:

##### Better communication and involvement of several caregivers/supporters

Several groups suggested the need to bring together different types of caregivers/supporters. For example, one group of adults wanted communication between teachers, doctors, family and friends. It was their experience that their current support networks are often lacking and that the illness is not taken seriously by those around them. This experience is also shared by one of the adolescent groups.

A young adults' group wanted to create better communication between healthcare providers, psychologists, social workers and patient organizations in order to achieve a better balance between their work and social life. Here, a psychologist could contribute to creating this, with a focus on accepting the disease and what that involves for the individual patient.

When the disease starts early in life, the parents-with-children-with-narcolepsy groups noted that acceptance is a big challenge, for both the children and the parents themselves. Their concerns were aimed primarily at the child's school and social life.

The goal of the interdisciplinary teams is that they need to cooperate together (communicating with each other) in a holistic approach to support the patient. It was also suggested that communication tools, such as publicly available videos, need to be maximised to increase awareness of the disease in the general population, and educate people to recognise the symptoms of disease. On top of this, better awareness among general practitioner/primary care doctors is essential.

The newly diagnosed patients suggested a similar proposal. They suggested making information online easily accessible to everyone and preparing an information flyer for friends, family and the workplace, in order to create a supportive and understanding circle of friends.

At the same time, one of the adults' groups wanted better communication between the health system, patients, relatives, teachers and patient organisations.

The participating doctors expressed that they experience good communication with the patient in relation to creating an individual medication plan. However, they proposed that better research and more financial resources within sleep disorders could contribute to better medication and a better situation for narcolepsy patients.

## **Conclusions**

eNAP's main mission is to raise awareness about narcolepsy/IH. To this end, this year's eNAP patient session was a positive step forward in achieving that goal. It allowed for direct discussions on the challenges and hopes from the relevant players (patients and professionals).

As expected, conversations proved to be a very good way to get around complex diseases like narcolepsy/IH.

We saw this complexity unfold in all the challenges, experiences and proposed solutions that were offered at the patient session.

It is hoped that the dissemination of this report on the patient session at the END 2023 conference can create fertile ground for more conversations about challenges, experiences and proposed solutions. The goal is to create a better quality of life for people with narcolepsy/IH, to let them know that they are not alone and that there are both communities, hope and opportunities for those living with the diseases.

## **Methodical progress**

The preparation of the article is based on a relatively open colour coding of answers to questions for all documents at the patient session as the primary methodological progress. Colour coding is a division of a text into central themes, which aim to form an overview of the text's content.

In this case, the themes of the colour coding are determined based on the content of the participants' answers to the questions; Namely, which elements of the answers are repeated? These are subsequently divided into themes (Table 2).

That is to say, the focus is on what the participants primarily talk about in the questions, rather than how the participants answer the questions, in order to see which central themes (colour coding) can be established and thereby form the starting point for the article. From this, the content of the article is created.

The article is based on one of eNAP's activities; about communication and collaboration with its members (15 national narcolepsy organisations in 13 European countries) to create positive changes and ensure that the organisation's activities create value for people with narcolepsy/IH. Communication of the patient session's results aims to have a beneficial effect for people with narcolepsy/IH – and other relevant stakeholders – as the patient session participants themselves define what a better quality of life looks like for people with narcolepsy/IH and how it can be created.