

# Living with neuromyelitis optica spectrum disorder (NMOSD): Diagnosis, impact and hope

Neuromyelitis optica spectrum disorder (NMOSD) is a rare, lifelong and debilitating autoimmune disease of the central nervous system.<sup>1,2</sup> Awareness and understanding of the impact of NMOSD on people is key to supporting them.

We conducted a survey to hear from the NMOSD community – this is what they shared with us.

Survey completed by **98 people** with NMOSD across **13 countries**<sup>3</sup>

## Early diagnosis is key<sup>3</sup>



**40%** said their condition worsened if they had to wait for treatment following diagnosis;

with

**73%** waiting three or more years before obtaining a diagnosis.



## Mental health impact<sup>3</sup>



**92%** said NMOSD had impacted their mental health and wellbeing



*"I don't feel confident at all anymore, I've been deprived of my freedom."*  
**Female, 56 years old, Belgium**

## Effect on day-to-day life<sup>3</sup>

As a result of their NMOSD diagnosis\*:



**Over half** were forced to **stop working**

**Over half** stopped or reduced **socialising**

**Nearly three quarters** experienced difficulty or had to reduce **looking after their families**

\*Based on 24 responses

## Following their most severe relapse,

people with NMOSD experienced debilitating symptoms for more than three months that impacted their quality of life<sup>3</sup>



**85%**

experienced fatigue



**72%**

experienced numbness or abnormal sensations in arms, legs and/or body



**Nearly half**

had partial loss of sight



**Nearly half**

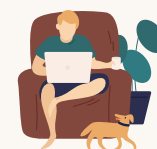
still had difficulty walking

*"Becoming blind is my biggest fear, I've already been completely paralysed, I've been on life support because my body couldn't do anything anymore."* **Female, 50 years old, Netherlands**



## Treatment autonomy<sup>3</sup>

**48%** of people with NMOSD would prefer their treatment at home



**77%**

prefer being in the comfort of their own home

**30%**

save money travelling to appointments

**51%**

save time travelling to appointments



However, **60%** of people who prefer their treatment at home either aren't given the choice or it isn't available to them

## What the future holds

*"I'm glad someone's finally listening to us and thinking along with us."* **Female, 26 years old, Netherlands**

At Roche we believe greater awareness of NMOSD will benefit all those living with the condition; we are committed to the community through our ongoing research.

To learn more about NMOSD and hear the stories of people with the condition, please [click here](#).



### Survey methodology:

People with NMOSD were invited to participate in an online survey, via platform Conconfirm. The survey was conducted in 14 languages. To be eligible for the survey, respondents had to fulfil the following criteria: diagnosed with NMOSD and aged 18 years or older. Participants were recruited via the PIPHealth patient panel and their networks.

### References:

1. Oh J, Levy M. *Neurol Res Int* 2012;2012:460825.
2. Papadopoulos MC, Bennett JL, Verkman AS. *Nat Rev Neurol* 2014;10:493-506.
3. Roche data on file – NMOSD Patient Survey.

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