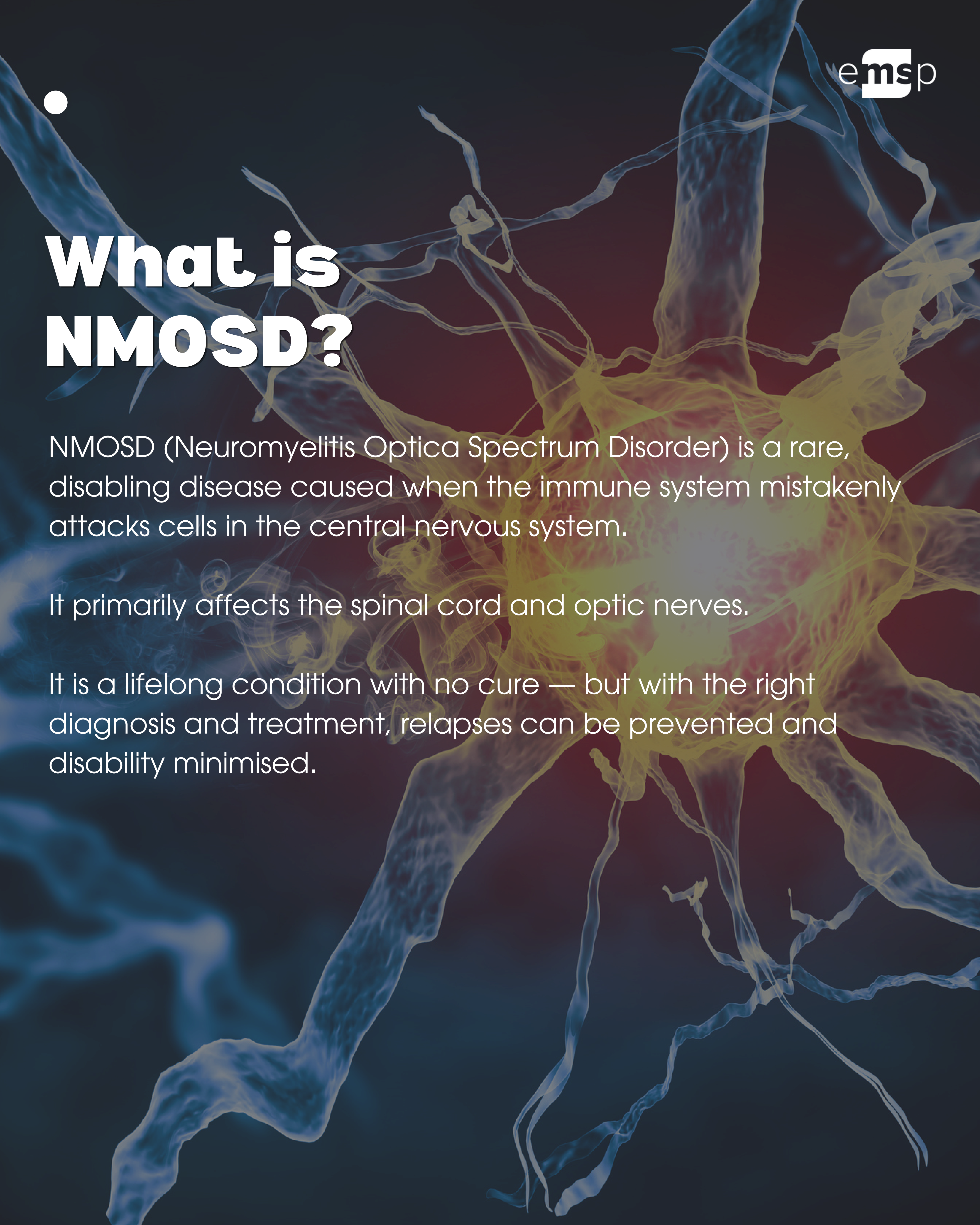
emsp

WORLD NMOSD AWARENESS DAY

27TH MARCH

Shining a Light on NMOSD



What is NMOSD?

NMOSD (Neuromyelitis Optica Spectrum Disorder) is a rare, disabling disease caused when the immune system mistakenly attacks cells in the central nervous system.

It primarily affects the spinal cord and optic nerves.

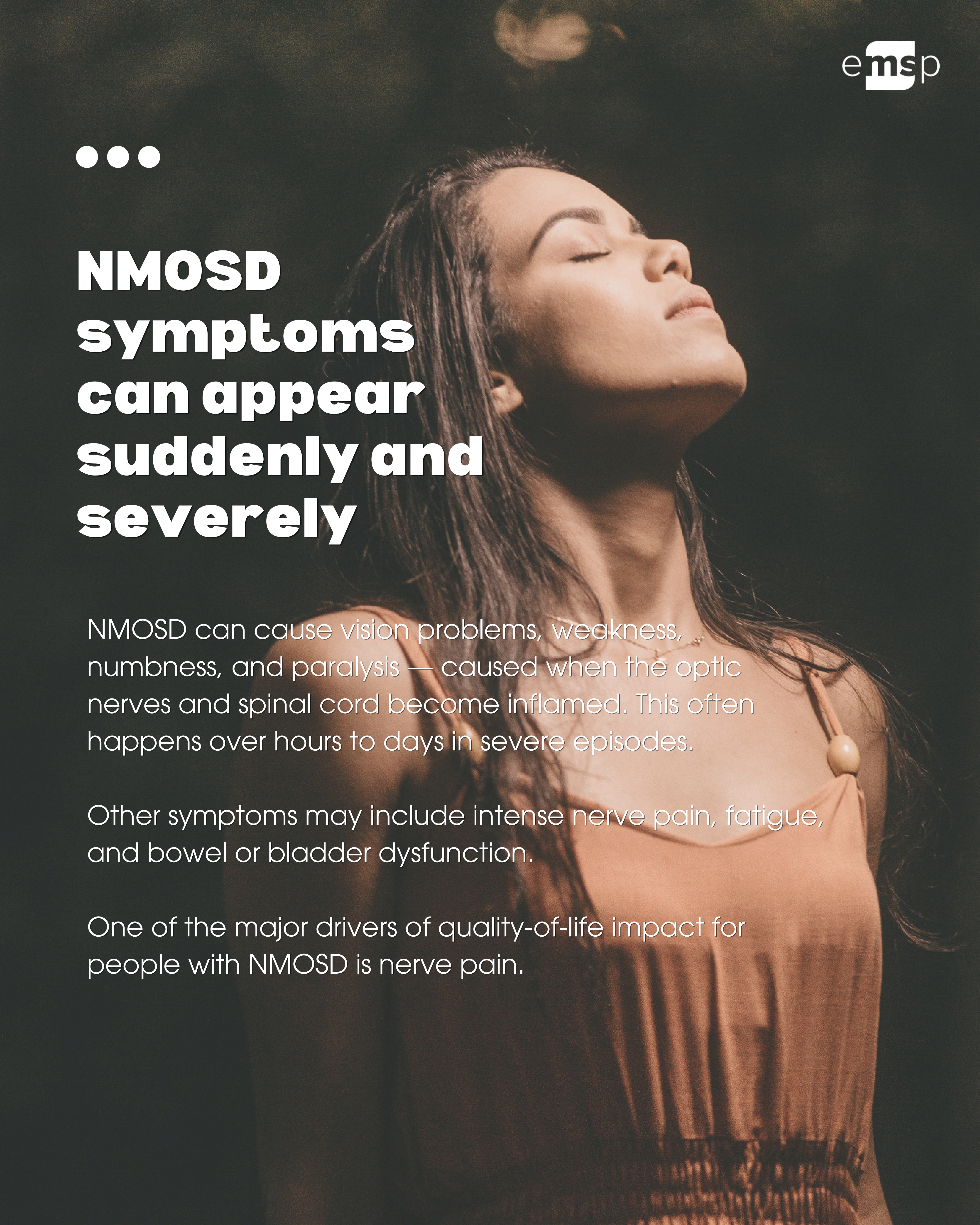
It is a lifelong condition with no cure — but with the right diagnosis and treatment, relapses can be prevented and disability minimised.

Who does it affect?

Between **0.7 and 10** people in every 100,000 have NMOSD.

It occurs more commonly in Black and East Asian populations, and is 5–9 times more common in women than in men.

The approximate age of onset is between **33 and 46 years** — striking people at the height of their working and family lives

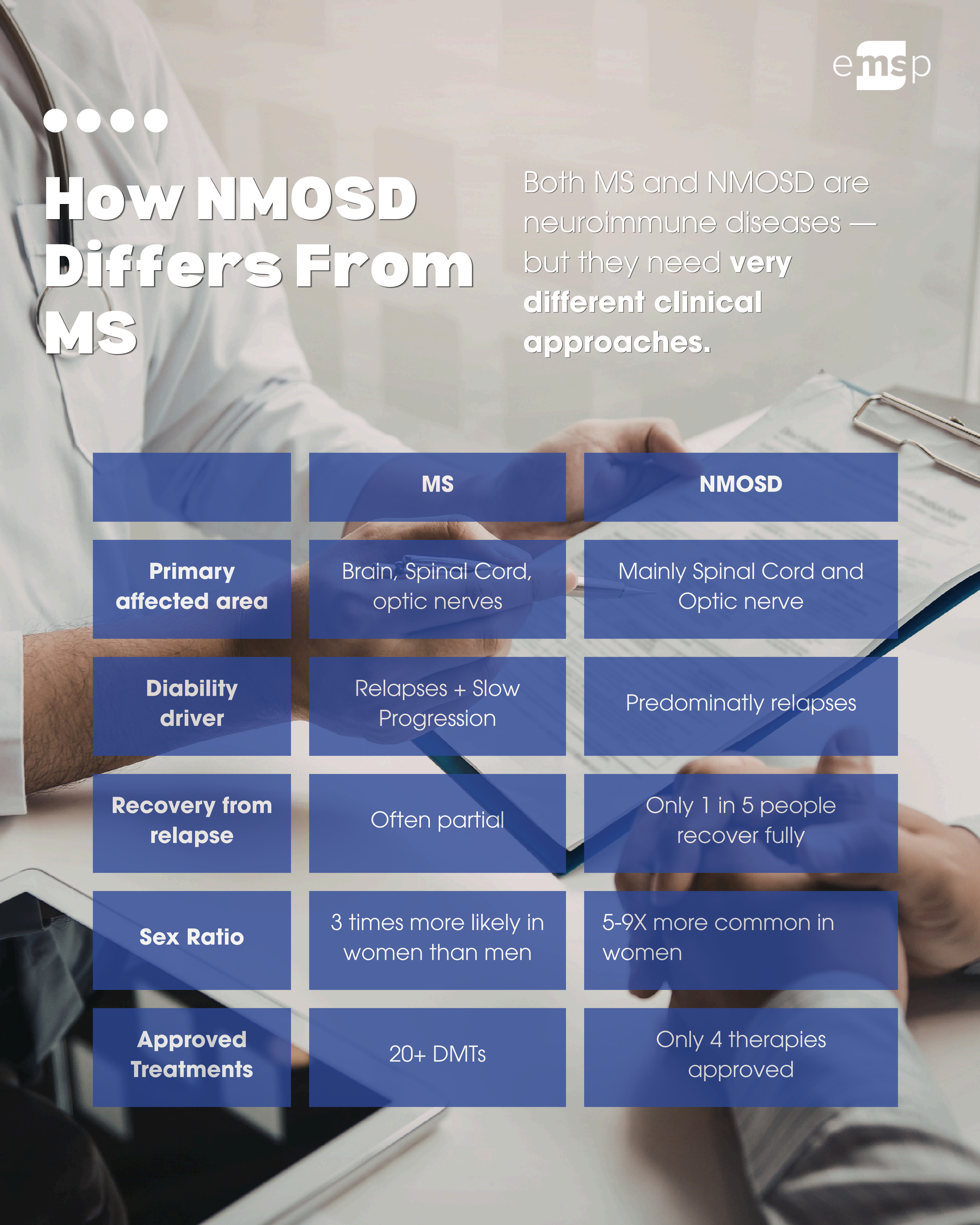


NMOSD symptoms can appear suddenly and severely

NMOSD can cause vision problems, weakness, numbness, and paralysis — caused when the optic nerves and spinal cord become inflamed. This often happens over hours to days in severe episodes.

Other symptoms may include intense nerve pain, fatigue, and bowel or bladder dysfunction.

One of the major drivers of quality-of-life impact for people with NMOSD is nerve pain.



How NMOSD Differs From MS

Both MS and NMOSD are neuroimmune diseases — but they need **very different clinical approaches.**

	MS	**NMOSD**
Primary affected area	Brain, Spinal Cord, optic nerves	Mainly Spinal Cord and Optic nerve
Diability driver	Relapses + Slow Progression	Predominatly relapses
Recovery from relapse	Often partial	Only 1 in 5 people recover fully
Sex Ratio	3 times more likely in women than men	5-9X more common in women
Approved Treatments	20+ DMTs	Only 4 therapies approved

The Misdiagnosis Crisis

Only **11%** of people with NMOSD had it correctly diagnosed following their first contact with the healthcare system.

Why?
The non-specific nature of the symptoms can contribute to misdiagnosis, highlighting the need for access to specialists and the option of additional opinions.

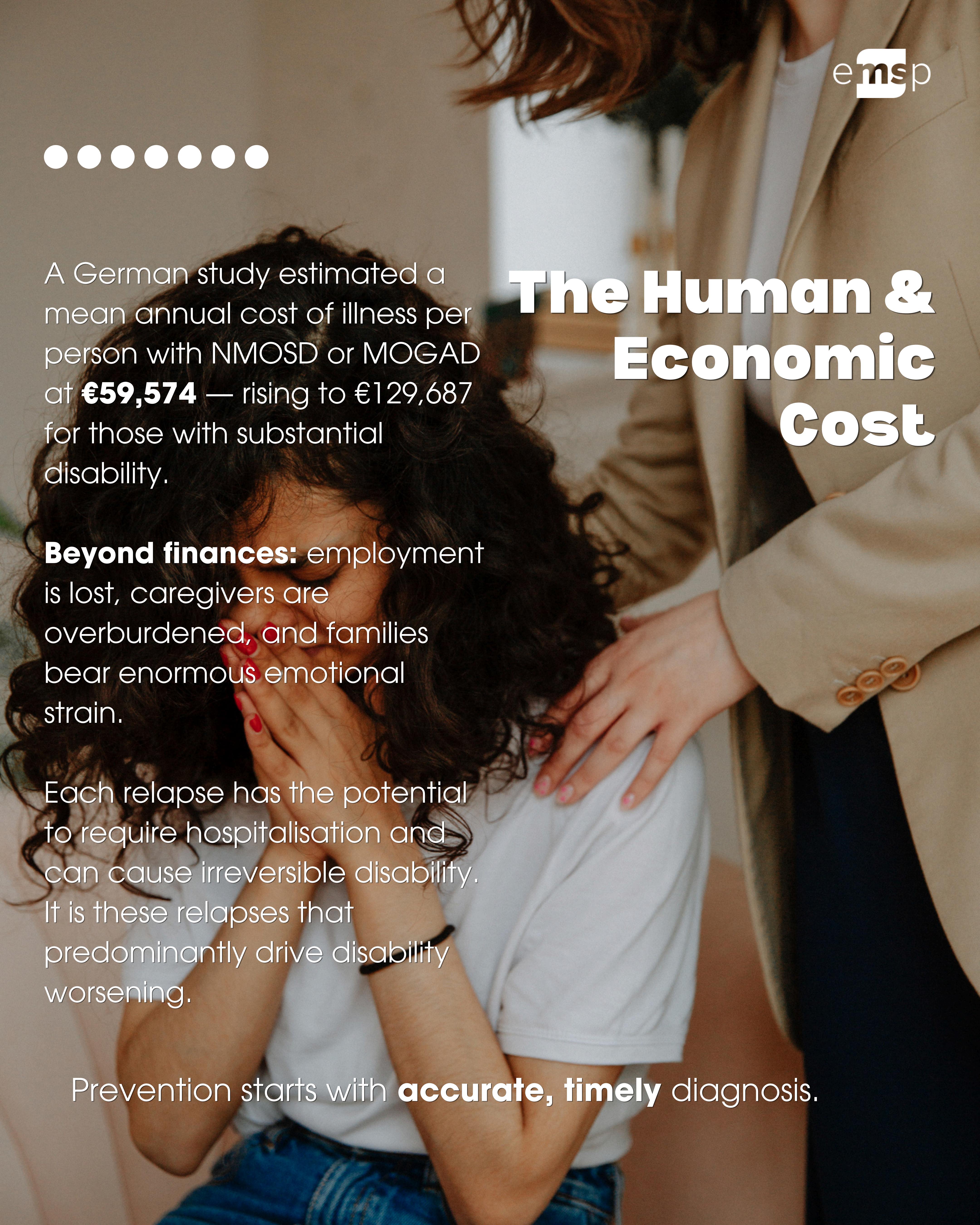
The Danger of getting it wrong

A misdiagnosis of MS can potentially multiply risk for the person because some treatments for MS have been reported to trigger severe relapses in NMOSD

Every delayed or incorrect diagnosis means:

- More relapses, more damage
- Irreversible disability accumulation
- Delayed access to the right therapies
- Incomplete recovery following relapses can lead to cumulative neurodegeneration, progressive neurological disabilities, visual impairment, blindness, paralysis, and early death.

emsp



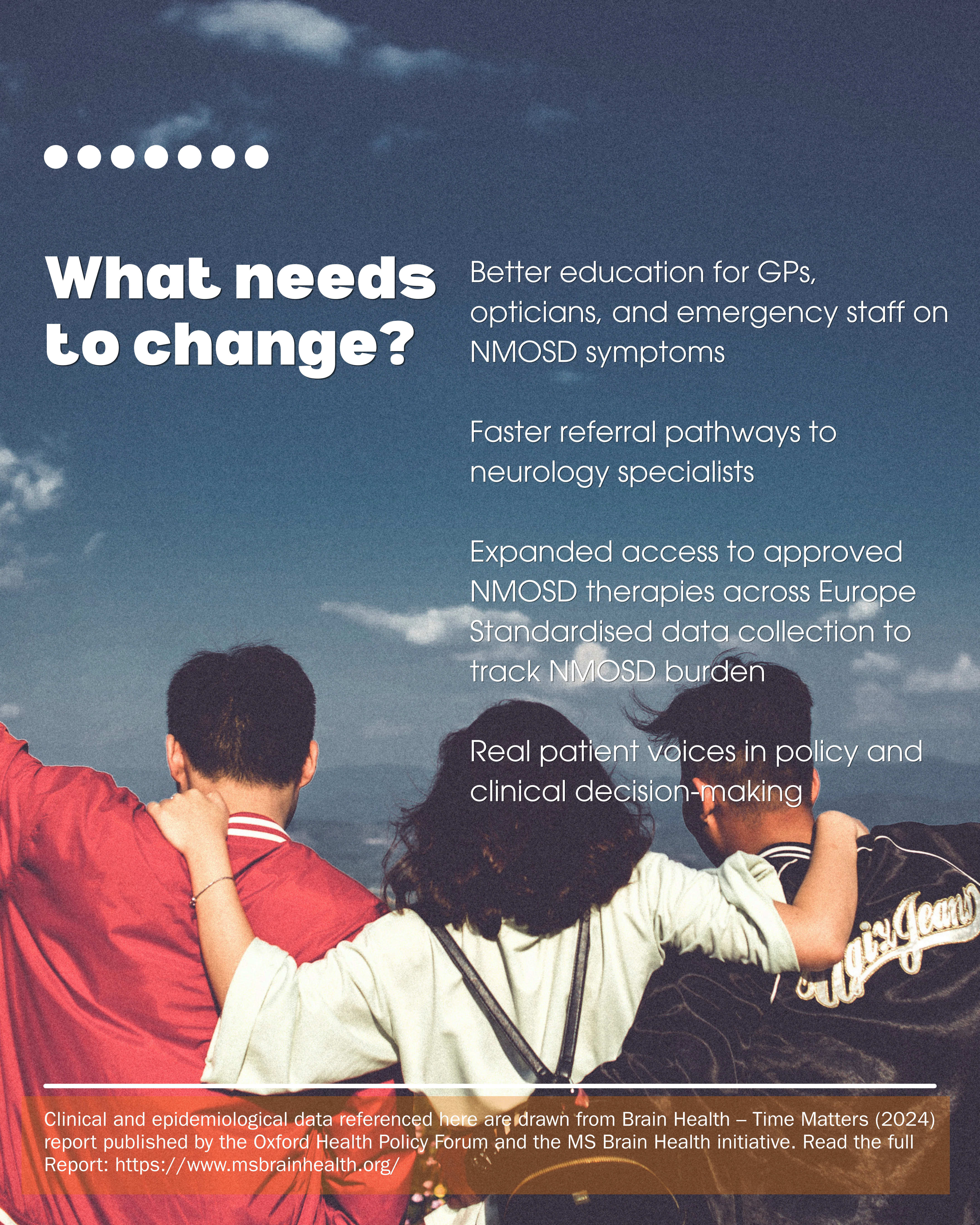
The Human & Economic Cost

A German study estimated a mean annual cost of illness per person with NMOSD or MOGAD at **€59,574** — rising to €129,687 for those with substantial disability.

Beyond finances: employment is lost, caregivers are overburdened, and families bear enormous emotional strain.

Each relapse has the potential to require hospitalisation and can cause irreversible disability. It is these relapses that predominantly drive disability worsening.

Prevention starts with **accurate, timely** diagnosis.



What needs to change?

Better education for GPs, opticians, and emergency staff on NMOSD symptoms

Faster referral pathways to neurology specialists

Expanded access to approved NMOSD therapies across Europe
Standardised data collection to track NMOSD burden

Real patient voices in policy and clinical decision-making

Clinical and epidemiological data referenced here are drawn from Brain Health – Time Matters (2024) report published by the Oxford Health Policy Forum and the MS Brain Health initiative. Read the full Report: https://www.msbrainhealth.org/