

UNLOCK THE FACTS ABOUT NDM


NDM refers to a group of diseases that affect the muscles¹. It is a rare disease that only affects around 1 in 100,000 people worldwide¹.

The disease is caused by a mutation in a gene, which prevents muscles from relaxing normally².

NDM is not a single disease, it is a group of disorders, which share similar symptoms¹.

The four main types are commonly known as^{1,3}:

- Becker myotonia congenita
- Thomsen myotonia congenita
- Paramyotonia congenita (Eulenburg)
- Sodium channel myotonias (including potassium-sensitive)



Struggling to open your hand after clenching your fist may be a sign that you have NDM.

SYMPTOMS TO LOOK OUT FOR

People with NDM commonly experience “myotonia”^{1,2}. Myotonia means that your muscles are not able to relax immediately after they have been used².

You may experience myotonia as stiffness, cramps or locking of your muscles during everyday tasks and activities

Patients with NDM may experience stiffness, as well as other symptoms like weakness or pain in different areas of their bodies; one person’s symptoms may not be the same as another^{1,4}

MANAGING YOUR SYMPTOMS

There is currently no cure for NDM, however most people can manage their symptoms by adapting the way they do things.

Myotonia triggers are different for different forms of NDM and an individual’s symptoms may also vary from day to day¹

Understanding when your NDM symptoms are better or worse may help you manage them. Try tracking your symptoms in a diary to unlock any patterns

Finding ways to avoid triggers or doing more of the things that keep your symptoms at bay eg, making sure muscles are warm before using them, may help reduce the impact of NDM on your day-to-day life

Changing the way you exercise or avoiding some foods that are high in potassium might also help

References

1. Hahn C & Salajegheh MK. Iran J Neurol 2016;15:46–53
2. Matthews E et al. Brain 2010;133:9–22
3. Trivedi JR, et al. Brain 2013;136:2189–2200
4. Stunnenberg BC, et al. Muscle Nerve 2020;62:430–444