Multifocal motor neuropathy
Patient Journey

European Reference Network
for rare or low prevalence complex diseases
Network Neuromuscular Diseases (ERN EURO-NMD)

Patient Advisory Board

STEP 1 Main symptoms and impact

- **Asymmetric multifocal muscle weakness and atrophy**
- **Usually in the upper limbs, but it can also affect the lower limbs**
- **Objects can fall from hands (saucepan, glass, etc.)**
- **Difficulties dressing**
- **Clumsiness**
- **No sensory disturbance**
- **Fatigue**
- **Usually little or no pain (except postural pain)**
- **Symptoms generally worsen over time and all limbs may be**

Professional impact

Often requires an in-depth review of one's professional life. Frequently requires a change of occupation. Recognition of disabled worker status (in some countries), can be important for patients to keep their work.

Social impact

Limited social interactions due to the physical and psychological effects of the disease. Sometimes patient suffer from social isolation mainly in relationship with the gradual loss of independence.

Psychological impact

Often underestimated. Can deeply affect the well-being of the patient.
Significant impact in case of misdiagnosis e.g. amyotrophy lateral sclerosis (ALS), a life threatening a fatal condition, whereas MMN offers potential treatments, especially for its motor symptoms.
Receiving a diagnosis of a debilitating disease like MMN can lead to severe disruption in life and raise questions about the future and the progression of the illness. Uncertainties can trigger anxiety and may have an impact on self-esteem, as the challenges posed by the condition can decrease confidence and self-worth.
Sometimes MMN leads to discrete or even invisible disabilities and handicap, which can make it challenging for others to understand the extent of the difficulties patients face on a daily basis.
MMN is a very rare disease (1-2 / 100 000) misunderstood due to its complex mechanisms, making it challenging for both patients and unknown to the general public.
Many patients diagnosed with MMN want to connect with other patients to share their experiences, gain insights, and find emotional support in coping with this rare condition.

STEP 2 Diagnosis

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It is mainly due to a lack of medical expertise. It underlines the importance of providing training and information to general practitioners and non-expert specialists. Frequent misdiagnoses and or differential diagnosis are: Charcot Marie Tooth disease (CMT), cervical Spinal Canal Stenosis, ALS, chronic inflammatory demyelinating polyradiculoneuropathy [CIDP].

STEP 3 Treatment

The first line treatment for MMN consists of immunoglobulins (plasma-derived medicinal products), which can be administered intravenously (IV) or subcutaneously (SC). The administration of immunoglobulins can be quite intense and, in some countries exclusively conducted within a hospital setting. Patients with MMN often require long-term treatment that may extend throughout their lifetime, emphasizing the chronic nature of the condition. Even if IVIG treatment is very effective and in spite of continuous treatment symptoms may worsen. Other treatments are under investigation and may prove to be effective.
Maintaining regular, adapted physical activity, physiotherapy and occupational therapy, aim to preserve the patient's physical autonomy.

STEP 4 Patient needs

One significant challenge is the lack of expert centers specialized in MMN and the difficulties in referring patients to these highly specialized facilities for optimal care.
Patients may face obstacles in accessing treatments, which can result in lasting negative consequences for their health and well-being.
The variability of healthcare organizations, including options for hospital or home care, can complicate the delivery of consistent and comprehensive care to MMN patients.

MMN is classified as a very rare disease, there is a crucial need for patient education to enhance understanding of the disease (pathophysiology, available treatments, potential outcomes, support...).
Providing access to rehabilitation services and promoting patient autonomy are vital aspects of MMN care, helping individuals maintain their quality of life and independence.
In the event of a decline in autonomy, patients may also require support in adapting their homes and daily routines to accommodate their changing needs.

Updated European guidelines are important for healthcare professionals to stay informed about the latest best practices in MMN management.
Training programs for general practitioners and non-expert specialists are essential to recognize, diagnose, and provide appropriate care to MMN patients.
Raising awareness about the existence of clinical trials is also important, as participation in research studies can contribute to the development of new treatments and therapies for MMN.

STEP 5 Supportive care to be developed

Implementing adapted physical activity programs can help individuals with MMN maintain their physical function and overall well-being. Providing appropriate physical activity recommendations tailored to each patient's needs and abilities is crucial for optimizing their quality of life. Regular psychological / emotional follow-up and support, addressing concerns such as anxiety and self-esteem, can significantly improve the mental health and emotional well-being of MMN patients. Effective pain management strategies, with a focus on preventing compensatory and postural pain, can alleviate discomfort and enhance the daily lives of individuals dealing with MMN.

Follow-up

The organization of follow-up care for MMN can vary from one patient to another, often involving a combination of healthcare providers. Many individuals with MMN can receive periodic follow-up from their general practitioner or primary care physician, who helps managing their routine healthcare needs. In addition to general follow-up, patients with MMN often benefit from specialist care provided by a neurologist who specializes in neuromuscular disorders, ensuring that they receive specialized treatment and monitoring for their condition.

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