

PREPARING FOR A VISIT TO YOUR DOCTOR

WHEN YOU FIRST RECOGNIZE SYMPTOMS

When you first recognize that you are experiencing some unusual symptoms, your first stop is likely to be with your primary care physician or GP. NDM is a rare disease and the major symptoms of NDM may overlap with many other more common illnesses, consequently it is not unusual for doctors to diagnose one of those more common conditions before the correct diagnosis of NDM is made.

To help your doctor differentiate between the many possible illnesses, provide as much information as you can about your daily experiences.

PREPARE FOR YOUR VISIT:

- As muscle stiffness (myotonia symptoms) in people with NDM may be variable and unpredictable,^{1,2} your symptoms may be better or worse than normal at the time of your visit to your doctor. Consider keeping a diary of your symptoms beforehand, noting the activity you were involved in and situations when symptoms are better or worse.
- Ask family members if they have ever experienced similar symptoms. This information may be useful for your doctor to take into consideration when assessing your symptoms.
- Create a list of questions that you want to ask.
- If you find similarities between the symptoms you experience, their impact on your life and the NDM related symptoms described, print information about the condition to share with your primary care provider. This information could be helpful to explain your symptoms. NDM is a rare disease and your doctor may never have come across anyone with NDM before and may not know much about the condition.
- Ask if it is possible to have a friend, relative or somebody close to you accompany you to your appointment.

DURING YOUR VISIT:

- The time you have with your doctor may be short, so it is important to communicate clearly and concisely what symptoms you have been experiencing.
- Explain which muscles are affected and the times when your symptoms are better or worse.
- “Muscle stiffness” may apply to many different injuries or illnesses, so highlight that you have a problem with your muscles locking up or failing to relax after you have made a movement.
- Tell your doctor when you started to notice the symptoms, and how activities you were able to do without problem in the past became more difficult for you.
- Tell your doctor if you have any other family members who have been diagnosed with NDM or who experience similar symptoms.
- Explain to your doctor how the challenges you face are affecting your mental health or quality of life if this is the case for you.
- Don't be afraid to ask questions and take notes about the conversation you have with your doctor. If you struggle with note taking, ask if you can record the discussion or have a friend, relative or the person who came with you take notes for you.
- If you and your primary care doctor agree that NDM is a possibility, don't be afraid to ask for a referral to a neurologist who is specialized in neuromuscular disorders for further investigation.

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NEXT STEPS

You can use the space below to note down the plan agreed with your doctor