

PREPARING FOR A VISIT TO YOUR DOCTOR

VISITING A SPECIALIST FOR TESTS OR DIAGNOSIS

To further investigate the symptoms you have been experiencing, you may need to visit a specialist with additional knowledge and access to different diagnostic tests.

PREPARE FOR YOUR VISIT:

- You may need to travel to see a specialist. Plan your journey and aim to arrive ahead of schedule. Appointments may be hard to get, and your neurologist will have lots of patients to see, so you don't want to miss your appointment!
- As myotonia in patients 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 the neurologist. 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 direct your doctor to consider genetic diseases.
- Create a list of questions that you want to ask.
- Think about your goals for your appointment, for example, to get your symptoms investigated.
- Ask if it is possible to have a friend, relative or somebody close to you accompany you to your appointment.

DURING YOUR VISIT:

- You may not have long in your appointment, 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 and illnesses, so highlight that you have a problem with your muscles locking up or failing to relax after you have made a movement if that is the case for you.
- 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 specialist. 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 are seeing a specialist for diagnostic tests, don't be afraid to ask questions if you are worried or confused about any aspect of the test.
- If you receive a diagnosis, it can be overwhelming or a huge relief. Both of which may mean you don't think of questions until after your appointment. Ask if there is a way you can contact your specialist or a specialist nurse after your visit to ask additional questions.
- Make sure before you leave that you know what the next steps are for you, whether that is to return for a diagnosis, to monitor your symptoms or initiate a management plan.

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NEXT STEPS

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