

# PREPARING FOR A VISIT TO YOUR DOCTOR

## FOLLOW-UP VISIT WITH A SPECIALIST

When you have received a confirmed diagnosis of NDM, you may need to return to your specialist to check that your symptoms are being managed in the best way possible.

### PREPARE FOR YOUR FOLLOW-UP VISIT TO A SPECIALIST IN NEUROLOGY:

- 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 appointments!
- As myotonia in patients with NDM may be variable and unpredictable,<sup>1,2</sup> your symptoms may be better or worse than normal when you visit your neurologist. Consider continuing your symptom diary, noting which of your daily activities you are still struggling with and any management strategies you have been using.
- Create a list of questions that you want to ask.
- Think about your goals for your appointment, for example, to get more advice on managing your symptoms.
- 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, and if you are finding that you are still struggling with daily activities.
- 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 feel that the management plan you currently have in place is not clear or not helping, ask if there are other strategies you could try.
- Make sure before you leave that you know what the next steps are for you, whether that is to seek help from another healthcare provider (for example, a physiotherapy referral), return for a diagnosis, or initiate changes to your management plan.

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### NEXT STEPS

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