

“I have a doctor’s appointment scheduled, and I want to make sure I get the most out of it.”

Refer to the questions and tips on this page if your child has not yet been diagnosed with Duchenne muscular dystrophy or on the next page if your child has already been diagnosed.

“I think my child might have Duchenne.”

My child has been having problems with their development milestones and I think it might be Duchenne muscular dystrophy. What are the signs and symptoms that indicate a potential Duchenne diagnosis?

Tip: Take photos or a video of your child to show the doctor any signs that you’ve observed. Visual images can help the doctor gain a better understanding of your child’s condition and perhaps lead to an earlier diagnosis.

Tip: Tick any of the signs or symptoms listed below that you’ve observed in your child and discuss them with the doctor.

- | | |
|--|---|
| <input type="checkbox"/> Frequent falling | <input type="checkbox"/> Difficulty keeping up with friends during play and physical activities |
| <input type="checkbox"/> Large calf muscles | <input type="checkbox"/> Lessened reflexes |
| <input type="checkbox"/> Learning and behaviour problems, including poor attention and memory skills | <input type="checkbox"/> Breathing difficulties |
| <input type="checkbox"/> Delayed speech development | <input type="checkbox"/> Use of Gowers manoeuvre to get up from the floor or from a chair |
| <input type="checkbox"/> Delayed motor development | |
| <input type="checkbox"/> Unusual waddling way of walking | |

“What type of test(s) would be most useful to help diagnose Duchenne?”

Tip: To better keep track of the test(s) that your child’s doctor recommends, tick the relevant test(s) below:

- | | |
|--|---|
| <input type="checkbox"/> Blood tests | <input type="checkbox"/> Genetic testing |
| <input type="checkbox"/> Liver enzyme levels | <input type="checkbox"/> Full gene sequencing |
| <input type="checkbox"/> Creatine kinase (CK) enzyme level | <input type="checkbox"/> Muscle biopsy |
| <input type="checkbox"/> Electromyography (EMG) | |

Duchenne | and YOU

“My child has been diagnosed with Duchenne.”

“Based on my child’s current signs and symptoms, which specialists should we be seeing? Are there other specialists to consider in the future?”

Tip: Use the following table to keep track of the names of doctors your child has seen or may need to see.

Specialist	My child has seen	My child should see
Paediatric neurologist		
Physical therapist		
Occupational therapist		
Orthopaedic physician		
Cardiologist		
Respiratory physician		
Social worker		
Psychologist/psychiatrist		
Genetic counsellor		
Dietitian/nutritionist		
Gastroenterologist		
Speech therapist		

“Given the different disease management strategies available and my child’s current signs and symptoms, how do we create a care plan that’s appropriate for my child?”

Tip: In addition to already existing management strategies, scientists are researching new options to manage Duchenne. Talk to the doctor about potential new strategies that might be appropriate for your child.

Use the next page to write down additional notes.

