

"I HAVE A DOCTOR'S APPOINTMENT SCHEDULED, AND I WANT TO MAKE SURE I GET THE MOST OUT OF IT."

This information is intended to help you keep track of any Duchenne symptoms you notice in your child. 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 have 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 have 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"/> Use of Gowers' manoeuvre to get up from the floor or from a chair, or toe walking |
| <input type="checkbox"/> Delayed speech development | <input type="checkbox"/> Not walking by 16–18 months |
| <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?"

Your child's doctor(s) will determine which tests your child will need.

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

- | | |
|--|--|
| <input type="checkbox"/> Liver enzyme levels | <input type="checkbox"/> Genetic testing |
| <input type="checkbox"/> Creatine kinase (CK) enzyme level | <input type="checkbox"/> Muscle biopsy |

This information is based on International Care Guidelines and not country specific. Your child's doctor is best placed to advise you on the diagnosis and management of Duchenne in your local country.

If your child has been diagnosed with Duchenne, please see the next page.

"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?"

Care for patients with Duchenne is provided by a multidisciplinary team of healthcare professionals. Who your child may see can vary depending on their specific circumstances and your local country practices.

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 has been referred to see
Paediatric neurologist		
Endocrinologist		
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?"

In addition to already existing management strategies, scientists are researching new options to help 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.

