

"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 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 symptoms.

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

0-6 MONTHS

2 months:

- Cannot lift head up while on tummy

4 months:

- Does not make sounds like 'ah' or 'ooh'

6 months:

- Does not try to reach for toys
- Cannot roll over

6-18 MONTHS

9 months:

- Cannot sit up without help

12 months:

- Does not say words like 'mama' or 'dada'

15 months:

- Cannot crawl

18 months:

- Difficulty getting up from the floor to stand
- Not walking well

2-3 YEARS

2 years:

- Gets up from a sitting position by pushing with hands to 'climb up' their legs
- Not walking smoothly (e.g. walking on tip-toes)
- Not jumping

3 years:

- Difficulty running or climbing
- Does not speak in sentences

OTHER SIGNS AND SYMPTOMS

- Weak or floppy muscles
- Falls over frequently
- Developing at a slower pace than their brothers or sisters
- Cannot keep up with other children of the same age
- Problems with learning, thinking or problem solving
- Abnormally large calf muscles

"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:

- Creatine kinase (CK) blood test
- Genetic testing with multiplex ligation-dependent probe amplification (MLPA)
- Liver enzyme blood tests
- Full gene sequencing
- Muscle biopsy

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?"

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?"

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.

