



Understanding a DMD diagnosis

A doctor discussion guide for caregivers of newly diagnosed children with Duchenne muscular dystrophy



1 Diagnosis and early progression

Has your child's Duchenne muscular dystrophy (DMD) diagnosis been confirmed through genetic testing?

- Yes
 No

If your child has not yet undergone genetic testing to confirm a DMD diagnosis, discuss this with your doctor. Genetic testing is important to not only ensure an accurate diagnosis but also to determine the specific genetic mutation, which should be considered in your child's treatment plan.

If a DMD diagnosis has been confirmed through genetic testing, a good next step is to ensure you have a thorough understanding of what a DMD diagnosis means for your child. When speaking with your doctor, the following questions can give you a clearer idea of what to expect. Write down key takeaways below.

▶ **What is your child's current treatment regimen for managing DMD and related symptoms?** _____

▶ **What does a DMD diagnosis mean for my child's health and future?** _____

▶ **How will my child's mobility and muscle function change over time?** _____

▶ **How often should we have medical check-ups?** _____

▶ **What other issues should I watch for as my child grows?** _____

Next steps:

- Request a written care plan to understand the next steps.
- Schedule any recommended tests to confirm the diagnosis and guide treatment.
- Start building a care team, including specialists in neurology, physical therapy, and genetics.



2 Treatment options

Early interventions can help manage symptoms and maintain mobility for as long as possible. Consider asking your doctor the following questions to ensure your child's needs are being met and you fully understand the treatment approach and rationale behind it.

▶ **What DMD medications is my child eligible for? What treatment approach do you recommend, and why?**

▶ **What other medications should my child be on? (e.g., steroids or alternatives, symptomatic treatments, etc.)**

▶ **What are the common side effects of these medications, and what should we watch out for?**

▶ **What about supportive therapies, such as physical or occupational therapy?**

▶ **What adjustments to my child's daily routine should we make (e.g., nutrition and/or activity levels)?**

▶ **What assistive devices or technology are appropriate for my child at this stage?**

3 Planning for long-term care and support


As your child grows, planning ahead can help ensure a smoother transition through different life stages. Once you are armed with all the necessary information about DMD from your child's doctor, here are some additional action steps to consider as you navigate life with DMD:



- Schedule your child's first physical therapy session.
- Ask about mobility aids before they are needed.
- Learn about individualized education plans (IEPs) for school.
- Explore disability benefits and insurance options for long-term support.

4 Other notes



 **Want more information?**

See our guide to [navigating the DMD life journey](#) or scan this QR code.



Muscular Dystrophy

