



Navigating DMD care conversations

A doctor discussion guide for parents/caregivers of children with Duchenne muscular dystrophy



1 Symptoms check-in

Have you noticed any of the following new or worsening symptoms in your child since your last visit? Place a check next to any symptoms that you would like to discuss with your child's doctor.

- | | |
|--|---|
| <input type="checkbox"/> Delayed walking, running, or standing | <input type="checkbox"/> Fatigue or shortness of breath during activities |
| <input type="checkbox"/> Frequent falls or stumbling | <input type="checkbox"/> Swallowing difficulties |
| <input type="checkbox"/> Using hands to stand up (gower's sign) | <input type="checkbox"/> Constipation |
| <input type="checkbox"/> Swaying or unusual walking patterns | <input type="checkbox"/> Learning delays (e.g., trouble with language or following instructions) |
| <input type="checkbox"/> Enlarged, firm calf muscles | <input type="checkbox"/> Behavioral challenges (e.g., difficulty focusing, social struggles, or frustration with tasks) |
| <input type="checkbox"/> Difficulty climbing stairs or keeping up with peers | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Gradual loss of walking ability | |
| <input type="checkbox"/> Scoliosis (uneven back or leaning to one side when sitting or standing) | |
| <input type="checkbox"/> Contractures (stiff joints making it hard to straighten arms, legs, or fingers) | |

Use this space to provide specific examples or additional notes about your child's symptoms:

2 Medications and therapies



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

► Do you have any specific issues with your child's medications you would like to discuss with a doctor?

► What specialists is your child currently seeing?

- | | |
|--|--|
| <input type="checkbox"/> Pediatric neurologist | <input type="checkbox"/> Orthopedic physician |
| <input type="checkbox"/> Endocrinologist | <input type="checkbox"/> Cardiologist |
| <input type="checkbox"/> Physical therapist | <input type="checkbox"/> Respiratory physician |
| <input type="checkbox"/> Social worker | <input type="checkbox"/> Gastroenterologist |
| <input type="checkbox"/> Psychologist/psychiatrist | <input type="checkbox"/> Speech therapist |
| <input type="checkbox"/> Dietitian/nutritionist | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Occupational therapist | |

If your child has not been referred to some of the above specialists, this may be worth bringing up with your provider to see if they should be added to your child's care team. Write down any discussion points below.

3 Mobility and accessibility



Take time to think about your child's current mobility and whether there are challenges that need to be addressed. What questions or concerns do you have about your child's mobility that you would like to discuss with a doctor?

Would you like more information about any of the following devices that your child may or may not currently use? Be sure to ask your child's doctor about these at your next appointment to see if changes should be made.

- | | |
|--|--|
| <input type="checkbox"/> Wheelchairs (pediatric, manual, or power) | <input type="checkbox"/> Gait trainers |
| <input type="checkbox"/> Adaptive strollers | <input type="checkbox"/> Standing frames |
| <input type="checkbox"/> Ankle-foot orthoses | <input type="checkbox"/> Speech-generating devices |
| <input type="checkbox"/> Knee-ankle-foot orthoses | <input type="checkbox"/> Sip-and-puff devices |
| <input type="checkbox"/> Wrist and thumb splints | <input type="checkbox"/> Other _____ |

4 Other notes



Use this space to write down anything else you want to discuss with a doctor about your child's care plan.



Want more information?

See our
[DMD caregiver's guide](#)
or scan this QR code.

Muscular Dystrophy

