

# Talking About DMD

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# Why talk about DMD?

- **Parents (and professionals) may avoid talking to children about their condition because they:**
  - want to protect the child from distress. (“I just want him to be happy.”)
  - don’t want to ruin the child’s vision of the future. (“I want him to have the same goals as other children.”)
  - don’t know what to say or how to start. (“I’m afraid that I’ll say the wrong thing, or make things worse.”)
  - are waiting for a better time to do it. (“I want to wait until he is older and can deal with things better.”)
  - don’t think the child will understand. (“He has a developmental delay and it would only confuse him.”)
  - do not want the child see them become emotional or upset. (“I’m afraid I won’t be able to talk to him about it without crying.”)
  - want to avoid their own feelings of discomfort or distress.

# Why talk about DMD?

- **Silence about NMD:**

- takes a lot of energy, causes stress, and doesn't usually work.
- teaches children they are supposed to keep secrets and not talk about problems.
- can result in false assumptions/misinformation.
- may cause child to get information through other sources.
- child does not learn to be their own advocate or make their own medical choices (limits independence).
- tells children that parents don't have confidence/trust in them.

# Why talk about DMD?

Children can understand and cope with serious medical conditions better than you think (including NMD)... **but they need information in order to do so.**

Goal of parenting is not to protect children from life's problems, but teach them to cope with and succeed despite life's problems.

# Why talk about DMD?

## **How does talking about DMD help them cope?**

- Children (and adults) can better deal with a situation if they understand it.
- Provides accurate information.
- Allows them to express feelings.
- Helps with problem-solving.
- Talking about their condition helps children learn how to talk about it with others (promotes independence).

# Why talk about DMD?

## **REMEMBER:**

- It's usually a bigger deal to us than to them.
- It's OK if you make a mistake.
- It's OK to not have all the answers.
- It's OK if you cry.

# When do I talk about DMD?

- If you leave it up to the child it might not happen.
- There is never a “good” time to talk about DMD.
- Earlier is better: the longer you wait, the more difficult and awkward it becomes.
- It is an ongoing conversation that will change with time.
- Most children can start to understand a basic explanation by the time their mental development is at a 3 or 4-year-old level.

# How do I talk about DMD?

- What do I say?
  - Ask questions to see what they know...or think they know:
    - “Have you ever wondered why we go see Dr. Wong?”
    - “Have you heard us talking about your muscles? What did we say about them?”
  - Use simple explanations for younger children:
    - “Your muscles work different (than other children’s muscles).”
    - “Your muscles are not as strong and get tired faster...”
  - Explanations “in the moment” or related to daily activities make more sense:
    - At the playground: “Your running is not as fast because your muscles work different.”
    - At the doctor’s office: “We are at the doctor’s today to help your muscles.”
    - At home: “We do this stretching because your muscles are different.”



# How do I talk about DMD?

What do I say?

Key points to cover:

- He did not get DMD because he is bad or did something wrong.
- You are not mad at him.
- He can't spread it to someone (like spreading a cold at school).
- His DMD won't go away (like a cold does).
- We (the family) will work hard to keep him as healthy as possible (with doctors, therapies, etc.).
- Sometimes when you have DMD you may need to do things in a different way.

# How do I talk about DMD?

- For children of all ages, ask them to explain in their own words what you have told them.
  - Give reminders/repetition, additional explanations, or correct misinformation as needed.
  - May need to ask them questions in order to see what they know.
- Start including the correct name of the disorder from the start
- Avoid using negative descriptions:
  - “bad”, “wrong”, “terrible”, “suffers from...”
  - Disease (implies it could be contagious)
  - Crippled

# How do I talk about DMD?

## DIFFICULT DISCUSSIONS:

- Don't try to discuss long-term prognosis.
- Don't avoid difficult questions.
- Be honest but hopeful.
- It is OK to cry while talking about DMD, but explain why you are crying.
- Some children will disagree or argue that their muscles are fine, they don't have the disorder, etc. That is OK.

# How do I talk about DMD?

- Some children may become sad or upset when you talk to them about their DMD.
  - This is a difficult, but NORMAL and temporary reaction.
  - Don't be too quick to minimize his concerns.
  - Validate his feelings and provide emotional support.
  - Remind him that you are a team and will work together to solve problems.
  - OK to acknowledge challenges of DMD, but balance this with hope and a positive message.

# Talking to peers about DMD

- When peers do not understand another child's condition, they are more likely to:
  - tease.
  - ask repeated questions (“How can you be in 3<sup>rd</sup> grade when they are so short?”, etc.) or state the obvious (“You’re short.”).
  - reject/ostracize the child.
  - attribute medical symptoms to personality flaws (he’s stupid, weird, etc.).
  - think the condition is contagious.

# Talking to peers about DMD

- Research shows that when peers are given information about a child's condition, they are:
  - less likely to engage in teasing.
  - more likely to be accepting and inclusive.
  - more likely to be protective and stick-up for the child.

# Talking to peers about DMD

- Notify your child that you (or the counselor, etc.) intend to talk to his classmates.
- Ask if he wants to be involved, and how much.
  - Leading the discussion.
  - Talking about one aspect.
  - Answering questions.
  - Present in class but not involved.
  - Absent from class during the discussion.

# Talking to peers about DMD

- Basic information only, simple explanations.
- Give examples of how DMD impacts daily activities.
- Child was born with DMD, not his fault.
- Other kids can't catch DMD (not contagious).
- Discuss medical treatments (with child's permission)
- Frame in the context of individual differences, everyone has strengths and weaknesses, etc.



# Talking to peers about NMD

- Visual aids or physical demonstrations can help:
  - Strap 5 kilo weights on volunteers and ask them to run on playground or walk about class for a few minutes.
  - Have local fire dept come and have volunteers put on their heavy boots (similar to leg weights).
  - Add glue to a bowl of noodles and let dry. Explain that these are normal muscles, and dystrophin holds muscles together. Compare to noodles without glue.

# Talking to peers about NMD

- Answer questions.
- Help peers think of ways that they can help and support the child:
  - Waiting for him to catch up on the playground.
  - Help him carry his books or pick up dropped materials.
  - Being less rough when playing.
  - Changing games/rules so he can be included.

# Talking to teachers about DMD

- Provide teachers with basic information about NMD, and any potential impact on learning and daily activities (as specific as possible).
- Teachers may feel uncomfortable/unsure what to say or not say (e.g., if asked a question by a classmate about the child).
- Give them permission to share basic information and short-term impact.
- Ask them to defer more serious or long-term questions to you.

# Talking to teachers about DMD

- Give teacher a one-page student profile about your child.
  - Helps teacher learn who your child is.
  - Written from the child's perspective.
  - Don't focus on DMD, provide more broad picture of who the child is.
  - Put picture of child at the top.
  - Provides opportunity for bribery (attach gift card of choice)

# Talking to siblings about DMD

- Similar to child with the condition, talk to siblings as early as possible.
- Helping care for a sibling with DMD can promote maturity, but don't put the burden on them or make it their job.
  - “Thanks for helping me with your brother today” vs. “I couldn't do it without you.”
- Spend individual time with sibling, promote their own interests/development.



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# Additional Resources

“Talking with your child about Duchenne Muscular Dystrophy” Action Duchenne

Brainpop video about DMD at [www.brainpop.com](http://www.brainpop.com)