

Talking About Neuromuscular Disorders

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Why talk about NMD?

- **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 NMD?

- **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 NMD?

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 NMD?

How does talking about NMD 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 NMD?

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 NMD?

- If you leave it up to the child it might not happen.
- There is never a “good” time to talk about NMD.
- 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 NMD?

- What do I say?
 - Ask questions to see what they know...or think they know:
 - “Have you ever wondered why we go see Dr. Bushby?”
 - “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 NMD?

What do I say?

Key points to cover:

- He did not get NMD 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 NMD 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 NMD you may need to do things in a different way.

How do I talk about NMD?

- 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 NMD?

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 NMD, 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 NMD?

- Some children may become sad or upset when you talk to them about their NMD.
 - 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 NMD, but balance this with hope and a positive message.

Talking to peers about NMD

- When peers do not understand another child's condition, they are more likely to:
 - tease.
 - ask repeated questions (“How can you be in 3rd 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 NMD

- 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 NMD

- 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 NMD

- Basic information only, simple explanations.
- Give examples of how NMD impacts daily activities.
- Child was born with NMD, not his fault.
- Other kids can't catch NMD (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 NMD

- 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 NMD

- 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 NMD, 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 NMD

- Similar to child with the condition, talk to siblings as early as possible.
- Helping care for a sibling with NMD 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.



Special Thanks

David J Schonfeld, MD

Louise Hastings

Janet Hoskins

Action Duchenne

Additional Resources

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

Brainpop video about DMD at www.brainpop.com