

Talking with your kids about Duchenne

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Need to inform children about illness

- Even young children sense when something is wrong
- Silence is rarely comforting in difficult situations
- Implies illness is too horrible to talk about and it's inappropriate to talk about illness and feelings
- Children are better able to cope with situation if they feel they understand it

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Inform children early on

- Best time to inform is shortly after you find out – next best time is now
- Parents try to protect children by not telling; children try to protect parents by not asking → conspiracy of silence
- Often children don't feel safe to ask questions of any adult → children have to deal alone with concerns without information and support
- Children may act out concerns → difficulties at home, school and interactions with peers

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Help children understand

- Provide simple, age-appropriate explanations of medical condition and aspects of treatment currently relevant
- Use actual name of condition
- Amount of information depends in part on age, personality, and typical coping style
- Ask what they already know and what questions they have
- State in simple, direct terms the basic facts and information most directly relevant currently

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Help children understand (continued)

- Focus initially on here and now – what they have, what it means for them now and treatments now or in near future
- Help them understand why current treatments are important
- Avoid unnecessary detail or attempts to predict future events or outcomes
- Guilt is common → reassure children there is nothing they did, didn't do, thought about, or wished that caused them to have Duchenne

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Invite questions and discussion

- As children reach new stages in development and new milestones, questions will surface (new and old)
- Some questions will be rhetorical
- Try to create an environment where it is safe to ask questions and share feelings
- It isn't helpful to force children to talk when they aren't ready, interested, or find the need
- Help identify outlets outside the home (e.g., counselor at school; relative or close family friend; physician; mental health professional)



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Advice on use of the internet

- Internet can be resource for information and explanations
- Caution children about looking for medical information about themselves or family member on internet
- Information may be inaccurate, inappropriate for developmental level and confusing, or not directly relevant
- Long-term outcome data may be based on children that didn't have new treatments

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Help children learn how to cope

- Coping involves a lot more than comprehension
- Children need to learn about Duchenne, but also need to learn how to cope with having a serious illness
- Parents often feel it preferable to hide their distress
- Children can sense when parents are not being genuine
- The only way children will learn coping techniques is to see them modeled

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Explore strategies to deal with distress, discomfort, anxiety sadness

- Distraction
- Journaling or blogging, art or music, to promote expression of feelings
- Appropriate use of humor
- Relaxation techniques
- Self-hypnosis and guided imagery
- Cognitive behavioral therapy
- Can be learned before child is experiencing high levels of distress or anxiety

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Family members deal with all of this differently

- Some find it difficult to discuss feelings and some can't stop; some seek companionship or physical intimacy to deal with stressors while others wish to be alone
- Communicate what works for you and listen to what others tell you works for them → try to compromise or find ways to have each other's needs met
- Help children appreciate range of coping mechanisms different family members use; let them pick what seems best for personal coping style

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Consider impact on siblings

- Inform siblings shortly after you find out
- Offer opportunity to meet with others outside family to ask questions and address their own concerns
- Balance opportunities to assist with care with avoiding burdening well siblings
- Siblings may become reluctant to make transitions to independence – think about this early on after diagnosis
- It can be tempting to use older siblings as confidantes and supports – seek assistance of this nature from adults

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Think about talking to classmates

- Allows peers to ask questions directly, instead of indirectly through teasing
- Focus on basic information that relates to underlying condition and current impact
- Help classmates identify ways they can assist
- With permission, information can be shared about treatments (e.g., side effects visible to peers, functional limitations)
- Children with Duchenne should be asked preference of what is presented



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