

Talking with Your Children about Duchenne Muscular Dystrophy



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IT'S TIME TO STOP WASTING!

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If you are reading this booklet, you are probably a parent or caregiver of a young person living with Duchenne Muscular Dystrophy (DMD), or someone quite close to the family.

It is very difficult for even adults to understand well Duchenne Muscular Dystrophy (DMD) and to cope with the impact that the diagnosis has on their family and the implications for the future well-being of their child. Understandably, parents desperately want their children to be and remain well and to be happy and well adjusted. It is tempting, therefore, to wait for a "better" time to inform children of their diagnosis – when they are more "ready" to understand the condition, cope with their feelings, or adjust to the implications it may have for their future. But not wanting children to be ill is very different from not helping them understand and deal with their illness. Children have a great capacity to understand and adjust to their diagnosis, as long as they are told in ways they can comprehend and are helped to learn how to cope. This booklet will provide practical advice on how to do just that.

When should I let my child know that he has DMD?

The first step is to tell children the diagnosis as soon as possible; if some time has already passed since the diagnosis by the time you read this booklet, then consider telling your child now. Secrecy creates a burden for families who then spend a lot of time and energy (when both are in very short supply) trying to maintain the secret. Rarely is such secrecy successful even with very young children. Even preschoolers and toddlers can sense when parents and other family members are upset or something is wrong – not knowing why doesn't help them deal

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with their feelings or concerns. Children who are not told honestly about their condition generally find out inadvertently – often by overhearing a conversation or comment (e.g., “when your son is using a wheelchair, it will be important...”). When children discover that important information has been withheld from them that relates to them personally, they may become angry or distrustful. They realize that their parents either don't think they deserve to know about their own health condition or don't think they can understand or handle the information. If they disagree with that conclusion, they may become angry; if they agree with that conclusion, they may feel overwhelmed. For children to adjust well to their diagnosis, they instead need to understand and feel that they can cope.



What's wrong with waiting for my child to ask?

Silence is rarely comforting in difficult situations. It implies to children that their illness is too horrible to even talk about and teaches children that it is inappropriate to talk about their illness or feelings associated with their illness. Children may conclude that is “naughty” to talk about their illness because such talk upsets adults or that something is wrong with them if they feel upset or worried. They learn to keep their feelings to themselves; to hold their questions; to remain confused, worried and anxious, but to tell no one. They learn to hide their knowledge and join in a mutual pretense that they are unaware – so as to please their parents. The silence makes it impossible for children to become involved in or make choices about their own medical care. Talking about DMD instead gives them the vocabulary they will need to talk with their healthcare providers, to explain their condition to their peers, and to develop a growing independence to care for themselves. Children are better able to deal with a situation if they feel they understand it. So how can we explain it to them in a way they can understand?



How children come to understand illness and how we can explain it

Children's understanding of illness and its treatment develops as a result of both maturation and the accumulation of experience and education. Very young children often believe that there is some form of natural justice by which good is rewarded and misdeeds (even if only bad thoughts) are punished. They may assume that illness is the result of something they did, didn't do, should have done, or merely something they thought or wished. They may be very reluctant to share with you such feelings of guilt and you may have no way of guessing that is the way they are feeling. Even adults feel guilty about their children's DMD – even when they did nothing knowingly to cause it, so it shouldn't be surprising that children feel guilty as well. When talking to young children it is best to avoid referring to DMD as “bad” (such as “it's a bad illness”), since young children may think this means they did something “bad” to cause the condition.

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As children become older, they are better able to understand more about their condition, but may still misunderstand explanations. They may misinterpret specific comments or understand them differently from what you intended. One approach that is quite helpful is to ask children to explain to you what you just told them – let them know you gave them some complicated and important information and want to see how well they learned it. If they can explain it back to you, chances are they understand. As they try to explain, though, you may discover that they forgot important information, didn't understand an explanation, or they picked up other information elsewhere which is inaccurate.

better that more challenging questions be asked of an adult than directly to the child with DMD – although uncommon to be asked in class, it's likely that in the absence of classroom discussion, such questions might be asked directly to the child with DMD on the playground or in the hallway when an adult would be less available or prepared to provide assistance.

And finally...

It is always a challenge to raise children to understand and become personally responsible for their own health and well-being. A serious health condition such as DMD makes this much more difficult. But many children and adults with DMD have managed to achieve this goal. The advice in this booklet is intended to help you in this effort. The advice in this booklet may seem simple, but may prove at times difficult to follow. Identify people and groups that you can turn to for support and assistance to help you carry this out. Turn to your family, friends, religious community, healthcare team, and others to assist you when it is hard. Sometimes they may also find it difficult to follow the recommendations covered in this booklet since they too want your child to be well. You may wish to share this booklet with them. In many situations it is helpful to seek guidance or assistance from a counselor or other professionals with more experience of working with children with serious medical conditions. Often parents find it helpful to identify a good support system for themselves, so they are more confident in filling this role for their children.



Working with school and the community

Think about talking with classmates, as well as peers at other community sites where your child may be a part of a group, such as community/religious groups or clubs. Having someone speak to the class/group about DMD and answer students' questions allows peers to ask their questions directly, rather than indirectly through teasing. The focus of the session should be on basic information that relates to the underlying medical condition (such as the fact that it is not contagious) and its current impact on the child with DMD. Classmates can be helped to identify ways they can assist or support their peer with DMD, such as waiting for him when he needs more time to catch up on the playground or offering to carry books in the hallway. Children want to be part of the solution and will welcome the opportunity to be supportive if they know how to do so. With the child's permission, information can also be shared about current treatments, such as steroids, to the extent it can explain side effects visible to peers or explain the child's functional limitations. Children with DMD should be asked for their preference on what is presented and how it is presented – by an outside expert, teacher, or parent. Ask them to choose how they wish to participate, which may range from actively presenting and answering questions, to sitting quietly in the room, or even to not being present during the discussion.



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Share with them this booklet and reassure them that children's interests and questions focus on the current and short-term and give them permission to redirect questions that children raise about long-term outcomes (“It's a good question to ask what might happen to your classmate when he grows up now that you know he has Duchenne Muscular Dystrophy, or DMD. It shows that you are concerned about your friend. But it's hard for us to tell what might happen to anyone that far in the future, especially since scientists are working hard to find a cure for DMD and have fairly recently already found a number of very helpful treatments. Let's focus our discussion today on what DMD is and how it affects young children; if you have more questions, you may wish to talk with your parents when you get home or speak with me after class.”). Remind teachers that it is

Teachers/group leaders may be hesitant to talk to the class about DMD if they are worried that children may ask questions they are unable or unprepared to answer. They can be given educational material that covers the basic information about DMD and told that you will help them find the answers to more advanced questions in the unlikely event they are asked.

In general, start your conversation by asking children what they already know or have heard about DMD. Ask them questions to see what they truly understand. Just repeating facts is not enough – being able to use that information to answer other questions is more important. Then provide basic information in simple and direct terms. Use the correct name of the disorder – Duchenne Muscular Dystrophy – even if they are not yet ready to understand long phrases; it is fine to also explain what that means in very simple terms (“Duchenne Muscular Dystrophy is a medical condition that some children are born with that makes their muscles not work as well as other children – Duchenne was the name of the person that discovered it and the last two words – muscular dystrophy – means that the muscles don't work as well”). Even for very young children, having a name for something is helpful even if they don't yet really understand the terms. They will become familiar with the name over time and bit by bit, understand more of what it means. For example, we begin by naming “refrigerator” for children long before they know how coolants or electricity work or the reason why we refrigerate food. At first, they may just know it is where they find their juice. That may be all they need to know when they are two years old. They come to understand more about it over time.



The discussion will change as children enter new stages of development

“**You are starting a discussion that you will continue over years**”

In a similar manner, don't try to cover everything in one session. You are starting a discussion that you will continue over years. In the initial conversation, it is important to tell children that it is an illness that they were born with (and not the result of anything anyone did) and that it isn't the type of illness that can be spread from one person to another person who is in the same room. You might tell them it is “a muscle problem that can't be cured – which means that even with the help of doctors and medicine it won't go away and never come back – which is why it is important to see the doctors as you grow so we can look after you.” You should focus on the practical information they need to know now – for example, “In children with DMD, the muscles are missing something that makes the muscles stronger, so that is why the muscles get tired or sore more than those of other children” or “The steroids help to protect the muscles from getting damaged, but they also can make people gain more weight or slow down how fast they grow taller – it's more important to keep the muscles from being damaged – we may have to do other things to deal with the weight gain or to help you grow taller if those become major problems.” Avoid technical terms. And don't try to discuss long-term prognosis – it's hard to know what the future holds many years from now and in general, children are most focused

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on the immediate and short-term future. “Soon” to a child may mean minutes, hours or days, rather than months or years.

Pause the discussion periodically to ask children what questions they have and what further information they would like, and answer their questions honestly and directly. Don’t try to cover too much information, especially about potential long-term complications. Don’t give false reassurances, but don’t remove hope either. Children need to believe their lives are filled with potential – and they are – even if they have DMD or another potentially serious medical condition.

Take advantage of opportunities to continue the discussion as questions or challenges arise. Ask your child what questions he may have before a visit to the doctor or what questions remain unanswered after the visit. When he is frustrated about difficulty keeping up with peers or upset about a muscle cramp, he may be more ready to share some of his feelings at that point or shortly after he has calmed down. Look for such naturally occurring experiences to resume or broaden the discussion.

As children and adolescents reach new stages in development and new milestones (whether positive milestones, such as completing secondary education, or those associated with loss of function as the illness progresses), questions will surface. Some of these will be new questions they hadn’t asked before or considered that now become important as they have a new capacity to understand or because they have been exposed to new information or experiences. Children will also return to some old questions for which they still aren’t satisfied with the answers. Some questions will be rhetorical (such as “why did I have to get this illness – it just isn’t fair!”) and don’t require answers. Sometimes just being with your children and providing support is all they are looking for.



Remember it’s a dialogue

Ask children what concerns they may have. This may uncover unnecessary concerns based on their limited information or their immature understanding. But it may also identify very accurate and appropriate concerns and serve as the starting point for a dialogue on how to cope with troubling feelings. Share with your children your feelings and how you cope with them. Children are much better able to cope with distressing feelings if they see others in their lives, such as their parents, share their distress and model for them effective ways to cope with it.

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Don’t forget brothers and sisters

Consider the impact on siblings. It is best to inform them shortly after you find out the diagnosis and continue to include them in discussions. Offer them the opportunity to meet with others outside of the family (such as a nurse or doctor on the medical team) to ask questions; they can ask questions of these people without worrying about upsetting family members. If they do not have a ready source for information, they may look elsewhere in less appropriate places.

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Make sure that you address the needs of siblings for their own personal development. It is difficult, but important, to balance offering siblings appropriate opportunities to assist their brother with DMD and help their parents with his care, with avoiding burdening the siblings with care responsibilities. As older siblings enter adolescence, they may become reluctant to make appropriate transitions to independence. Think about this from early on after the diagnosis. Comments such as “You have been such a great help watching your brother while we went out to dinner alone” is important positive feedback. But be cautious about making comments such as “I don’t think I could take care of your brother without your

help.” At some point, we want children to be able to make the difficult transition to living independently to pursue college or a career. It’s hard to do that when you have a serious medical condition such as DMD and also difficult if you are a sibling of a child with DMD and feel that your assistance at home is critical.

Using the internet

The internet can be an excellent resource for information on new research findings and useful explanations for conditions like DMD can be found there as well. However, it is important to caution children (siblings included) about looking for medical information about themselves or a family member on the Internet. Information they find on the Internet may be inaccurate, inappropriate for their development level, or not directly relevant to their own (or sibling’s) medical status. For example, long-term outcome data may be based on children with DMD that didn’t have the benefit of new treatments now available (and certainly those not yet available). Let your children know, though, if they do find information on the Internet or elsewhere and have questions or concerns, they should feel free to come to you to discuss.

