

# Talking with your children about Duchenne Muscular Dystrophy

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# Parents desperately want children to be well

- Not wanting them to be ill is different from not helping them understand and deal with illness
- Often parents try to protect children, so as not to worry them, or assume they can't understand or cope
- Children have a great capacity to understand and adjust

# Need to inform children about illness

- Secrecy creates burden; rarely is successful
- Even young children know or sense that 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 sense questions generate distress in parents → attempt to support parent, giving false impression unaware or unconcerned
- Children are better able to deal with situation if they feel they understand it

# The process by which children come to understand illness

- Result of maturation and experience
- Qualitative differences in way they understand illness at different stages of development
- Very young children rely on magical thinking and explanations which attribute cause to immanent justice – the belief that good is naturally rewarded and misdeeds punished
- Avoid term “bad” in description of illness (e.g., “You have a bad sickness”)

# Problem with immanent justice explanations

- Result in guilt and shame associated with illness and perception that treatment is punishment
- Made worse by threats
- Results in less compliance reporting symptoms, seeking assistance, cooperating with treatments
- Used more persistently where child has had less experience and adequate explanations not provided

# Inform children and help them understand

- Amount of information depends in part on age, personality, and typical coping style
- Ask what they already know; state basic facts
- Concentrate on relevant information
- Ask questions they have and information they would like; answer without unnecessary details
- Focus initial discussions on immediate & near future
- Don't give false reassurances, but don't remove hope. Children need to believe their lives are filled with potential – they are

## Informing children (continued)

- Don't try to cover everything in one session – you are starting discussion that will continue over years
- As they reach new developmental stages and milestones, questions are likely to resurface
- By initiating conversations early, can initially be brief
- Assess children's understanding by asking them to explain back to you what you have discussed
- Children may have different fears than adults – ask explicitly what concerns they have
- May uncover unwarranted concerns based on limited information or immature comprehension

# Help children cope

- May elicit appropriate concerns and serve as starting point for dialogue on how to cope with troubling feelings
- Share your feelings and how you cope with them
- Children are better able to cope if others share distress and model how to cope

# Consider impact on siblings

- Inform them shortly after you find out
- Offer siblings opportunity to meet with others outside family where they can have their own concerns addressed
- Avoid internet for information
- Address need for personal development
- Balance opportunities to assist with care with avoiding burdening well siblings

# Talking to classmates

- Having someone speak to class about DMD allows peers to ask questions directly, instead of indirectly through teasing
  - Focus on basic information that relates to underlying condition (e.g., not communicable) and current impact
  - With child's permission, information can be shared about treatments (e.g., side effects visible to peers), child's functional limitations
  - Children with DMD should be asked preference of what is presented and how (e.g., outside expert, teacher, or parent; extent child wishes to participate)
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