



Talking with children and their parents

Questions

- ▶ One of the biggest anxieties for school staff is how to answer questions from children with a neuromuscular condition about their future.
- ▶ Another anxiety is how to answer questions from other children.
- ▶ And how to do this without upsetting any child or their parents.

Communicating with parents

- ▶ When a child first enters a new school or class, or new staff are appointed, ask the child's parents for a meeting.
- ▶ Having a clear understanding about what the child does, or does not, know about their condition is vital (do they know the full name of their condition, do they know it is progressive/life limiting?).
- ▶ Never tell a child something about their condition unless you are sure the parents are in agreement. Explain to parents that questions have arisen and explore the best way forward. It is important the school and parents give the same answers.
- ▶ Having an understanding of the impact of the diagnosis on the family is also vital. Emotional distress, tiredness and complex care routines can be part of daily life for families.
- ▶ Listen (parents often complain this doesn't happen).
- ▶ Raise any concerns at an early stage.
- ▶ Don't be afraid to ask questions or to request further information.
- ▶ Work together to solve difficulties.

Talking to children

Four golden rules

- ▶ Listen more than you talk.
- ▶ Use questions more than answers (to check you are understanding what the child is saying).
- ▶ Follow more than you lead (so you go at the right pace for the child).
- ▶ Be sure you are trying to answer what the child is actually asking (an adult's interpretation can be very different and time scales can be different – 'the future' to a child may be tomorrow).

Guidelines

Do not

- ▶ Give false information – child will lose trust in you.
- ▶ Give no answer at all – this will cause the child to worry even more. You may say you do not know but will try to find out.
- ▶ Burden a child with information they may not yet understand or want to know – remember you can not 'unsay' things.



Possible Questions

- ▶ What do you know about?
- ▶ Do you have any ideas why?
- ▶ So you're wondering?
- ▶ What have you learned or guessed about?

Follow on questions

- ▶ What do you think about what I've been telling you?
- ▶ Do you have any questions you want to ask me?
- ▶ Is there anyone else you would like to talk to about this?

Remember

- ▶ To take on board what is important to the child – what do they wish to achieve?
- ▶ To involve the child in finding solutions “do you have ideas about what we could do?”

“He never asks questions”!

- ▶ Sometimes when children don't ask questions they communicate anxiety or confusion through challenging behaviour.
- ▶ You can open conversations with observations such as:
- ▶ “Has doing x got a little bit more difficult for you? I wonder what we can do to make it easier. What ideas do you have?”

Remember

- ▶ It is important to point out that children with muscle disease have a right to learn about it at their own pace without others forcing the realisation on them.
- ▶ There is a need for balance at all stages between practical realism and acceptance of what is happening. Everyone needs hope, optimism and encouragement.

Other children in the school may ask questions

- ▶ Anticipate this and discuss in advance with parents and, where appropriate, with the affected child, what information can be shared.
- ▶ Ensure the child has an explanation that makes sense and that they can share.
- ▶ Sometimes a talk to the class is helpful – but only if affected child and their parents agree.
- ▶ Never give another child more information than the affected child has and never ask them to keep anything secret.
- ▶ Explain how they can help and what they can do to include their disabled classmate.

Useful Literature

- ▶ *An Introductory guide for families with a child newly diagnosed with Duchenne muscular dystrophy*
- ▶ *Duchenne muscular dystrophy – a guide for families with a child aged 5-12 years*
- ▶ *Duchenne muscular dystrophy – the Teenage years*
- ▶ *The Diagnosis and management of Duchenne muscular dystrophy – a guide for families*
- ▶ *Everybody's Different, nobody's perfect!*



- ▶ *Same but Different*
- ▶ *Hey, I'm here too!* (for siblings/classmates)
- ▶ *Behavioural issues in DMD*
- ▶ *Inclusive Education*
- ▶ *Guide to Transition*
- ▶ All available free of charge from the Muscular Dystrophy Campaign www.muscular-dystrophy.org

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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK's London office are available on **0800 652 6352** or **info@muscular dystrophyuk.org** from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

www.muscular dystrophyuk.org