



**“We always try to answer
Archie’s questions as truthfully
as possible. We try to protect
him at the same time too.”**

Louisa Hill, (Archie has Duchenne muscular dystrophy)



When your child has a muscle-wasting condition

A guide to talking with your child about their condition

Coming to terms with the news that your child has a muscle-wasting condition can be extraordinarily difficult. If the diagnosis is recent, you may find that things generally feel overwhelming. You may be worried about what the future holds for your child and how you can help them to live as happy and independent a life as possible.

Many parents wish to hold off from telling their child about the diagnosis for as long as possible; they feel that by doing so they are protecting their child. This may be the case if you have been told your child has a condition which is likely to be life-limiting.

In this leaflet, we bring you some suggestions about why it might be useful to begin having these conversations early on with your child. You'll also find some practical advice on how you might go about doing so, addressing some worries and concerns parents may have.

If you'd like to discuss any of these issues, please get in touch with us:

0800 652 6352

info@muscular dystrophyuk.org

www.muscular dystrophyuk.org

Authors: Dr Sadie Thomas-Unsworth, Principal Clinical Psychologist, South West Neuromuscular Service & Dr Linda Deeley, Consultant Clinical Psychologist, COMPASS team, Musgrove Park Hospital, Somerset

Disclaimer

While every reasonable effort is made to ensure that the information in this document is complete, correct and up-to-date, this cannot be guaranteed and Muscular Dystrophy UK shall not be liable whatsoever for any damages incurred as a result of its use. Muscular Dystrophy UK does not necessarily endorse the services provided by the organisations listed in our factsheets.

Archie Hill was diagnosed with Duchenne muscular dystrophy when he was just four years old.

His Mum, Louisa, says:

“A few years ago our lives were easy, with two young boys enjoying a happy family life. Archie, the youngest was a normal three-year-old boy and then everything changed in January 2009, when Archie was diagnosed with Duchenne muscular dystrophy.

“Every so often Archie will ask us questions about his condition. Things like, ‘Does it only affect my legs? Do I always have to take this medicine? Why do I have to wear night splints?’ We always try to answer as honestly as possible, but try to protect him at the same time. Nonetheless, Archie carries on and always has a smile on his face.

“At the age of nine, Archie is more aware of his condition but he is one extremely happy boy who is doing fantastically well and we are very proud of him.”



Why should I talk to my child about his/her muscle-wasting condition?

Why are they not telling me what's going on? Toddlers and very young children can sense when their parents and other family members are upset or when something is wrong. As they grow older, children will be aware of changes in their physical condition and may make comparisons between what they can do and what their peers or siblings can do.

If children are not given an explanation, children often worry about these changes and develop their own explanations for why people are upset.

Using the Internet

Increasingly, children have access to the Internet from an early age. This could lead to problems if they search for information online, as the information they find may or may not be accurate. They may also develop worries that they would not have if they had a clearer understanding of their condition.

What have children told us?

We know from research that children cope best with the realities of their muscle-wasting condition if they are given honest, age-appropriate information about their condition. It is also important they have the chance to ask questions.

Children have an amazing capacity to understand and cope. They need to be told in ways they can understand and supported to learn how to cope with their condition.

Why can't I wait until they bring up the subject?

Children will generally take their cue from you. They will get a sense of whether or not they can talk to you about how their condition affects them and tell you any concerns they have. If, as parents, you avoid the topic, your child is likely to follow your lead.

In this situation, children may conclude that it is 'naughty' to talk about their muscle-wasting condition because such talk upsets adults. Children are also often very sensitive and may feel the need to 'protect' their parents, so may not bring the subject up. Unfortunately, this means they are forced to bottle up their worries and difficult feelings.

As your child gets older, they will expect to play an active role in managing and making choices about their own medical care. If they are not adequately informed about their muscle-wasting condition, this becomes impossible.

By talking with them openly about their condition, you are also giving them the vocabulary to talk about their condition, not only with their healthcare providers but also their peers. This in turn supports them to develop the skills and independence needed to care for themselves in the future.

So how do I talk about this with my child?

Children like to learn from their parents. Generally, children do best if the adults having these conversations with them are people they have a relationship with. For this reason, your child's medical team will typically look to you to have these conversations with your child.

Any information shared with your child should be appropriate to their age and experience. Children's understanding of their condition develops as a result of maturity, experience and education. So when thinking about talking to your child, it is useful to remember you do not need to tell them everything in one go. In fact, doing so is likely to be overwhelming.

It might be helpful to start with these pointers

What do they already know?

Start the conversation by asking children what they already know about their condition. Ask questions to check their level of understanding.

Do they really understand what they have been told?

Look out for misunderstandings. Sometimes it can be hard to judge how much your child understands, so ask them to explain to you what you have just told them. This is a really useful technique to double-check their understanding.

It's ok to talk about it to me.

Tell them explicitly that they can ask you questions about their condition whenever they want to. Do not presume that they know this.

Be truthful.

Answer truthfully any questions they have. If you do not know the answer, then say so. That's ok too. Often children just want to know that you are there and happy to listen.

Give the condition its correct name.

Use the correct name for the condition your child has. Even for very young children, it is helpful to have a name for something. They will become familiar with the condition over time and, bit by bit, understand more about what it means.

It's not their fault.

When you first start to talk with your child about their condition, make sure you explain that it is not the result of something anyone did. It's also not an illness that can be spread to other people. Young children are prone to misunderstandings; under the age of five or six, they generally think in very concrete terms. This means they can end up thinking things are the result of their being naughty or bad in some way.

Keep it in the present.

When thinking about discussing your child's muscle-wasting condition with them, it can be helpful to remember this is just the beginning of a conversation that you will repeat and expand on over time.

Keep the focus on the day-to-day information they need to know now, particularly when talking with younger children. Children do not need to know everything at once. They will quickly feel overwhelmed if you give them too much information.

Increase the amount of information with age.

As your child reaches new stages in development and new milestones, their information needs will increase. These include milestones, such as entering secondary school, as well as those associated with the progression of their muscle-wasting condition.

If things have changed with their muscle-wasting condition or they have upcoming hospital appointments, use these times to check in with them about how they are doing. Check whether or not they have any questions.

Questions for the doctor – giving your child a voice.

As your child gets older, ask if they have any questions for the doctors before and after they attend appointments.

Prepare them well for transition to adult services.

As your child approaches transition to adult services (which usually occurs between the ages of 16 and 18), it is likely they will become more actively involved in their treatment and treatment decisions. It is really important that they are prepared for this and know enough about their condition and its prognosis to do so.

In adult services, the young person may be asked specific questions about their wishes with regard to treatment in the future. It may be distressing for them if they are not already fully informed about their condition and prognosis.

What about siblings?

Siblings are likely to have questions (and often worries), about their brother or sister too. It can be difficult to judge

how much to tell siblings, particularly if there is a large age gap. Generally speaking, it is important to ensure the siblings do not know more about the condition than the affected child.

It is a big responsibility to expect a child to hold on to this sort of information and it is rarely helpful for children to be asked to keep secrets. In general, when thinking about talking to siblings, the guidance above is still relevant.

Can anyone help me with this?

This is often a really difficult area for parents to think about. You may still feel unsure about how to go about it or when.

If you would like further help thinking about this, or to seek specific advice for your family's situation, your child's consultant paediatrician or neuromuscular care advisor can assist you with this. Some teams also have access to specialist psychological support that may help too.

If you'd like to discuss any of these issues, please get in touch with us:

0800 652 6352

info@muscular dystrophyuk.org

www.muscular dystrophyuk.org

A family's perspective

"It was helpful when my Mum listened and answered my questions truthfully without showing too much grief."

Vivek Gohil has Duchenne muscular dystrophy



A family's perspective

Manjula's son, Vivek, is in his 20s. He has Duchenne muscular dystrophy and was diagnosed when he was a young child. Here, Manjula and Vivek share their experiences:

Manjula:

"It's important to maintain open and honest communication with your child. Even though the information about neuromuscular conditions is tough to accept, giving snippets of truthful information is necessary. This information may sometimes bring up anger but it is best to explain that it is better to express anger than to bottle it up. Parents need to equip their child with the tools to focus on mentally adapting to their life and accepting their condition.

"As a mother, I found counselling very helpful. Being able to talk about my feelings to someone outside the family helped enormously through the toughest period when Vivek stopped walking.

"It is important to remember that siblings will also find it extremely tough to cope with their brother's/sister's condition; they may find it hard to separate their brother's/sister's personality from the condition and feel it is somehow their fault if *they* do not have it.

Again, openly talking and listening to siblings' concerns over a long period of time helps. Supporting siblings can be challenging as parents may be accused of paying more attention to or loving the child with the condition more, but it is important to comfort them too."

Vivek:

"I found it very difficult to deal with the loss of [the use of] my legs but more importantly, the small things that I lost affected me more. It felt like my life ended and I was forced to become someone I did not want to become.

This frustration was the hardest thing to cope with, but it was helpful when my Mum listened and answered my questions truthfully without showing too much grief. What helped was to think what I gained; for example, my wheelchair, which gave me some independence back, and trying to think positively. Being told information about my present and focusing on the now rather than future information helped too."

If you need to speak to someone

Dealing with a diagnosis can be challenging and isolating. It often helps to speak to someone who understands exactly what you're going through. We can support you through the challenge of speaking to your child about their muscle-wasting condition, and we can also put you in touch with another parent.

If you'd like to talk, please get in touch with our care and support team.

You can call our Freephone helpline on **0800 652 6352** between 8.30am and 6pm Monday to Friday, or email us any time at **info@musculardystrophyuk.org**

At Muscular Dystrophy UK, we offer a personal support system for individuals and families at their point of need. We are the UK charity bringing individuals, families and professionals together to beat muscle-wasting conditions. We provide a range of services and opportunities to help individuals and their families live as independently as possible.

Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions. We're providing a range of services and opportunities to help people live as independently as possible.

We're here for you at the point of diagnosis and at every stage thereafter, and can:

- ▶ **give you accurate and up-to-date information about your child's muscle-wasting condition, and let you know of progress in research**
- ▶ **give you tips and advice about day-to-day life, written by people who know exactly what it's like to live with a muscle-wasting condition**
- ▶ **put you in touch with other parents living with the same condition, who can tell you about their experiences**
- ▶ **tell you about the services, equipment and support you're entitled to.**

0800 652 6352

info@muscular dystrophyuk.org

@MDUK_News

www.muscular dystrophyuk.org

Muscular Dystrophy UK, 61A Great Suffolk Street, London SE1 0BU

Registered Charity No. 205395 and Registered Scottish Charity No. SC039445