

**HEY, I'M
HERE TOO!**



**Muscular
Dystrophy**
Campaign

**A booklet for the brothers
and sisters of children with
Duchenne muscular dystrophy**

Produced with support from GlaxoSmithKline

Do you have a brother or sister with muscular dystrophy?



Does this ever worry you?

Do you have a lot of questions that need answers?

Well, here is a booklet to help you. It may have some of the answers you have been looking for and it may make you feel a bit better. You don't have to read it all at once, you can read one question and answer and then talk about it with your mum and dad or your teacher.

It won't answer all your questions, but it will get you started and it should help you feel a bit better about your brother or sister, your parents and yourself.

(From now on this booklet talks about your 'brother' with muscular dystrophy. If your sister has muscular dystrophy, not your brother, just replace the word in your mind as you read).

Now, here are some questions that were discussed with a group of brothers and sisters of children with muscular dystrophy. These questions make clear their concerns.



Think about each question:

What feelings do you have?

What is your answer to each question?

How do the questions and the answers we have, make you feel?

You can discuss this with your parents, but don't try to do it all at once.

Take each question and talk it over.

1. Would life be different for you if you did not have a brother with a disability?
2. Do you worry about your brother? In what ways?
3. Do you ever feel that your brother always gets what he wants because he has muscular dystrophy and you don't?
4. Is life different in your house than in the homes where there is not a child with muscular dystrophy?
5. Do you feel that you have been given as much information as you want about your brother's muscular dystrophy?
6. Do you think that more is expected from you because your brother is disabled than from other kids who don't have a brother with muscular dystrophy?
7. How do you feel your parents should act towards your brother?
8. How do you feel your parents should act towards you?
9. Are you ever angry about the fact that your brother has muscular dystrophy? Why are you angry?
10. Are you afraid of asking questions about your brother's condition? Why are you afraid?
11. Do you feel that you are more important to your family because your brother has muscular dystrophy? Or do you sometimes feel less important?
12. Are you ever blamed for something that you are not responsible for, because your brother has muscular dystrophy?
13. Are you ever afraid that you will also have muscular dystrophy?

14. Do you ever feel that your brother gets more attention, presents or love than you, because he has muscular dystrophy and you don't?
15. How are you different from your friends who don't have a brother with muscular dystrophy?
16. Do you ever feel good that your brother has muscular dystrophy?
17. If you could change anything for yourself, what things would you change? Why?
18. Are you ever afraid because your brother has muscular dystrophy? Why?
19. Are you ever afraid of asking questions about muscular dystrophy? Why?
20. What concerns you the most about your brother's muscular dystrophy?
21. Do you feel that your brother gets away with things because he has muscular dystrophy?

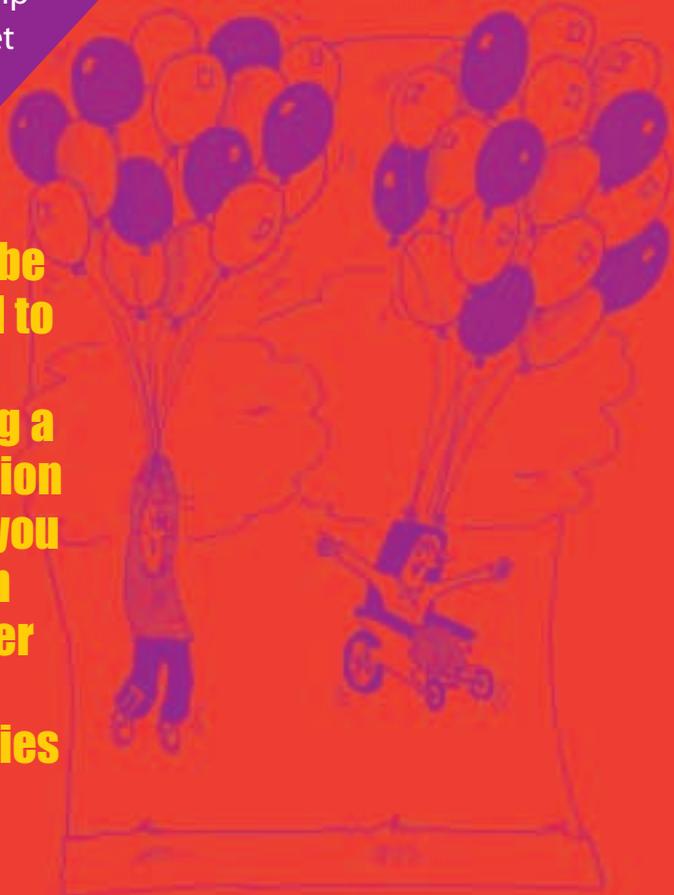
Sharing your feelings by discussing questions like these will help you and everyone in your family, and make things easier at home.



It is important that you understand as much as you can about the muscular dystrophy your brother has. Here are some answers to questions that you may have been wondering about.

Read the questions and make sure that you understand the answers. If you don't understand, talk it over with your parents and, if they can't help you, ask them to get an answer from your brother's doctor.

Don't be afraid to keep asking a question until you get an answer that satisfies you.



Q What is muscular dystrophy?

A Muscular dystrophy is a name used to describe a group of disorders which cause gradual loss of muscle size and strength.

Q What causes muscular dystrophy?

A We know that a faulty gene is not producing a very important muscle protein and without this protein a person's muscles weaken.

Q Can I catch muscular dystrophy?

A No, muscular dystrophy is not contagious (catching).

Q Is my brother's muscular dystrophy his fault?
Is it my fault?

A Muscular dystrophy is no one's fault; not your brother's, not yours, nor is it the fault of your mother or father. Muscular dystrophy is not due to any thing over which anyone, at present, has control.

Q Is muscular dystrophy always hereditary (passed from one generation to the next)?

A It is usually hereditary, although sometimes a person can have muscular dystrophy without any past family history of it.

Q

Will I get muscular dystrophy later on?

A

If you don't have symptoms now it is unlikely to develop in the future. If you are bothered tell your mum or dad about your worries.

Q

Even though I don't have muscular dystrophy and won't get it later on, can I still pass the disease on to my children?

A

In one type of muscular dystrophy(Duchenne muscular dystrophy) only girls who are carriers stand a chance of passing the condition on to 50% of their male children. Unaffected boys never carry this type of muscular dystrophy to their children. When boys with Duchenne muscular dystrophy become fathers, none of their male children will be affected but all of their girls will be carriers. In some other types of muscular dystrophy, both boys and girls stand a chance of passing it on to their children, if they have a partner who is also at risk (this is very rare). When you are a little older, if you want to, you can speak to a genetic counsellor who will explain all of this in more detail.



Q Are there tests to tell whether a girl or boy, who has a brother or sister with muscular dystrophy, can pass the condition to their children?

A Yes, sometimes tests are possible, though not always. These are called genetic tests and are carried out in a hospital and may consist just of a simple blood test. A professional person called a 'genetics counsellor' will be able to tell you more.

Q Does muscular dystrophy only affect children? Can adults, perhaps my mum or dad, ever get it?

A The type of muscular dystrophy your brother has is probably only a condition that children have. There are adult onset forms of muscular dystrophy but it would be extremely unusual for a family to have two different types of muscular dystrophy. Remember that all the muscular dystrophies are quite rare.

Q How widespread is muscular dystrophy? Is it a disorder that is found everywhere?

A Muscular dystrophy is found everywhere in the world. There are over 20,000 people with muscular dystrophy in the UK alone.

Q What muscles are weakened in muscular dystrophy?

A Although almost any muscle can be affected, the muscles of the legs, hips, shoulders and back are often involved in muscular dystrophy. Sometimes the arms and hands can be affected too.

Q

Does the heart get weak in muscular dystrophy?

A

Sometimes the heart gets a bit weaker, but usually this will happen only when your brother is older. Tablets are available to help this.

Q

Is muscular dystrophy a painful disorder?

A

No, pain is not usually associated with muscular dystrophy although some boys complain of cramps in their legs.

Q

Will my brother's muscular dystrophy get worse?

A

Yes, muscular dystrophy slowly does get worse.

Q

Will my brother have trouble with breathing and swallowing?

A

If a boy with Duchenne muscular dystrophy has trouble, help is available.

Q

Will the muscular dystrophy affect my brother's ability to see, hear, talk, think and learn?

A

Most children with muscular dystrophy have no difficulty with their senses, and some children with muscular dystrophy are the cleverest in their class.

Q

Is there any treatment for muscular dystrophy?

A

There are no known cures for muscular dystrophy, but there are a number of things that can be done to help a person stay as active and independent for as long as possible.

Q Will my brother's legs get stiff?

A Yes, probably, because the muscles are weak and he can't move his legs easily.

Q Will exercises help my brother?

A Stretching exercises are essential to keep your brother as mobile as possible. General exercise (avoiding over-exertion) cannot hurt and swimming is also very good. A physiotherapist is a professional person who can help and advise on these matters.

Q After my brother's legs get so weak that he can't stay on his feet, is there anything to help him?

A Sometimes splints can help. Occasionally a small operation to the ankle is necessary before splints are fitted (these are more often called ankle foot orthoses). These are lightweight and usually go under the trousers so that you can't see them. Sometimes boys use a standing frame but again the physiotherapist will help.

Q Do the hand muscles get weaker in muscular dystrophy?

A Sometimes, but not badly enough to interfere with any of the hands' normal functions until very late in the disorder.

Q

Will my brother sometimes feel stronger on some days and weaker on other days?

A

Yes. Just like everybody else, your brother will have good days and bad days.

Q

Will my brother require more rest than I do?

A

Usually not, although some boys may get tired more quickly if they have had to make an especially big physical effort.

Q

Will my brother always know when he wants to use the toilet?

A

Yes. These functions are usually normal in muscular dystrophy.

Q

Will my brother need a wheelchair?

A

All boys with Duchenne muscular dystrophy will eventually need to use a wheelchair whilst other children with other types of muscular dystrophy may not.

Q

Will my brother be able to go to an ordinary school? College? Can he ever have a job?

A

These days many boys with Duchenne muscular dystrophy go to an ordinary school because the schools have been adapted to include everyone. And yes, many boys go on to college, training and get jobs.

Q Can my brother be active in sports?

A As long as he is strong enough. Most children with muscular dystrophy enjoy swimming even after their muscle weakness prevents them from taking part in vigorous sports, and lots of boys enjoy being part of a team by helping with training and organising fixtures etc.

Q Could I ever hurt my brother because I am stronger?

A Yes, if you are too rough.

Q How does my brother feel about the fact that he has muscular dystrophy and I don't?

A Why don't you ask him?

Q What should I do about any strong feelings or concerns I have about my brother and his muscular dystrophy.

A Talk these out with your mum or dad or an adult you trust. Remember that it's okay to have feelings and nothing to be ashamed about.



Q How long will my brother live?

A No one knows. Many top scientists and doctors are working very hard to find the cure for muscular dystrophies and we all hope that some day a cure will be available.

Q What can I do to help my brother now?

A You and you alone, can provide the answer to this question.

Think about it. Ask your parents. Ask your brother. Sometimes, just being there and being an ordinary brother or sister is all that's necessary. Each situation is different so you have to decide for yourself.

**Sometimes
doing
something
special
will
show
that
you
care.**



These are just some of the questions you might have in mind. There are probably others, some of which might be more important to you than the ones listed here.

So, if you have questions, ask them. And remember, there is nothing wrong with having feelings, even strong feelings (like resentment, anger or shame). It's natural to feel upset, especially if you don't share these feelings with someone.

Talk to your mum, dad, teacher or doctor, a social worker or physiotherapist or someone close, like a best friend. Keep talking, keep asking, keep putting across your feelings and get help with your worries and never, ever stop telling people that, **HEY, I'm here too!**



The Muscular Dystrophy Campaign is here to help, so if you want to find out more about the muscular dystrophies, and all the research that is going on, or just talk to someone then log on to www.muscular-dystrophy.org or e-mail us at info@muscular-dystrophy.org.

Or contact us at the address on the back of this booklet.



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