



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Your child may need surgery: what does this mean for children and young people diagnosed with Duchenne Muscular Dystrophy?

This information sheet from Great Ormond Street Hospital (GOSH) explains some of the potential risks and benefits of your child having an operation as well as some other things to consider when discussing surgery. Your child may not need surgery for many years, if ever, but we would like you to be aware of the potential risks and benefits in advance so that you and your child are prepared when surgery is needed.

Duchenne Muscular Dystrophy (DMD) is a genetic condition that affects mainly boys, causing gradual deterioration of muscle strength eventually leading to full-time wheelchair use. Advances in management and treatment have led to boys with DMD remaining mobile for longer and living longer with a better quality of life.

Boys with DMD often require surgery under general anaesthetic at some point in their life. Particular operations could include muscle biopsies, foot surgery, insertion of a feeding tube or spinal surgery to correct spinal curvature caused by scoliosis.

Any surgery under general anaesthetic carries a risk because it puts the body under an unusual stress. Risks and benefits may be different for boys with DMD than other children. When your child is being considered for surgery, the Neuromuscular team at GOSH will discuss the benefits

and risks of the specific operation relating to your child. Any referral to another team at GOSH will consider every aspect of your child's DMD and will be discussed fully with you and your child.

Pre-operative assessment

Having a general anaesthetic will affect your child's heart (cardiac) and breathing (respiratory) system in a number of ways. In order to assess how your child's body will cope with the anaesthetic, you and your child will be invited for a full preoperative assessment.

This will consist of a variety of tests on your child's cardiac and respiratory systems, which will provide valuable information for planning the anaesthetic and operation. You will also have the opportunity to discuss any concerns with the anaesthetist and/or surgeon at this appointment.



Breathing (respiratory) system

DMD affects the muscles that control breathing, gradually losing power and strength so that breathing becomes less effective, with less oxygen circulating. This may not cause any problems in day to day life, but could become a concern under anaesthetic.

Your child will be assessed against a set of criteria developed by the Respiratory team at GOSH to decide whether further specialist tests might be needed and/or a review by one of the Respiratory team consultants.

Heart (cardiac) system

The heart is a muscle and, like the respiratory system, becomes less effective in time due to DMD. This is called cardiomyopathy (weakening of the heart muscle). Mild changes in the heart muscle are usually present from an early age in boys with DMD and do not usually cause any problems in day to day life. However, they may become a concern under anaesthetic.

Up to the age of 10 years, your child will have an echocardiogram (Echo) every two years as part of managing their condition. After the age of 10 years, this will increase to an annual Echo.

If a general anaesthetic is required for surgery, an additional Echo and another test called an electrocardiogram (ECG) will be arranged within three months of the proposed anaesthetic. For some operations, a Cardiac Magnetic Resonance Imaging (MRI) scan may also be required.

Other concerns

All surgery carries some risk including infection, bleeding and, in rare circumstances, death. While the risk of infection and bleeding can be quantified to some level, there is an unknown risk of death for children with DMD that needs to be discussed before any procedure. This risk of death is only becoming apparent with the improved life expectancy following better management, so we cannot currently calculate or fully understand it.

Your referring consultant, surgeon or anaesthetist will discuss this with you and your child when they need surgery. We cannot predict the outcome for your child, but we will give you all the information that we have and explain what it means for your child wherever possible.

Things to consider

When you meet the consultants involved in your child's care, it is important to ask them any questions you or your child may have, regardless of how minor they might seem. Some questions to think about asking include:

- Is surgery the only option?
- What is the short-term and long-term impact of surgery?
- How long will my child be in hospital?
- What are the potential benefits of having the operation?
- What are the potential risks of having the operation?
- What could happen if my child does not have the operation?

There will be many other questions that you and your child will want to ask, so



we suggest bring a pen and notebook to your appointments. It can help to write down the questions in advance so you remember to discuss everything you want to and also to make a brief note of the answers you are given. If you do not understand something, please ask us to explain again – we will not mind.

Further information and support

If you would like to learn more about DMD, please talk to the Neuromuscular Team at GOSH on 020 7405 9200 ext. 0632 or visit their section of the GOSH website at www.gosh.nhs.uk/medical-conditions/clinical-specialties/neuromuscular-information-for-parents-and-visitors .

The Muscular Dystrophy Campaign is the main UK support group for all types of muscular dystrophy. You can call their free helpline on 0800 652 6352 or visit their website at www.muscular-dystrophy.org .

Another organisation for anyone affected, directly or indirectly, by DMD is called Action Duchenne. Their website is at www.actionduchenne.org where they also have an online community you can join.

Notes

Compiled by the Spinal Pathway and Neuromuscular teams in collaboration with the Child and Family Information Group

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