



02

Chapter 02 – Child and Family

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In a nutshell — Looking after your child, your family and yourself

1 You can still have a good life with your child

There's fun to be had. Sports to be played. Friends to be made. Hobbies to be developed. Dreams to be pursued.

Right now, all this probably seems impossible. But other DMD families have made good lives for themselves. And with support, so can you.

2 You should tell your child and your other children about the diagnosis soon

You'll be dreading this. But you'll find some guidance from other DMD parents on the next few pages that will help you work out what to say.

3 If you can, ask for help from grandparents, family and friends

Supportive grandparents, extended family and friends can make a big difference to families with DMD.

When you're ready to tell them, we have produced 'A Guide to DMD for Family and Friends' which you can find on our website (www.duchenneuk.org/resourcesforparents). It will make it easier for you to explain DMD to them and ask for their help.

There's fun to be had and dreams to be pursued.



You'll find some guidance from other DMD parents.



Ask family and friends to help with practical things.



We have produced 'A Guide to DMD for Family and Friends'.

4 There's a lot you can do to improve and protect your child's health

Your GP will be able to refer you to a neuromuscular clinic where your child will be looked after by a team of specialists. They will manage the treatments, including steroids which slow down the DMD. Your child may also be referred to healthcare professionals in the community, like an occupational therapist.

You can improve your child's health through diet and exercises, especially stretching.

But be cautious of advice on the internet. There's a lot of false information out there.

5 Make sure you look after yourself and each other too

When you are feeling overwhelmed by the diagnosis and have to arrange your child's medical treatments, it's all too easy to forget about your own needs.

We encourage you to be kind to yourself during this difficult time. Accept any reasonable offers of help. Go to see a counsellor if you can. Spend some time together with your partner, even if it's just a quick coffee.

Please give yourself time to come to terms with the diagnosis. You don't need to reorganise your life or make any big changes at the moment.

Guides to DMD on our website

As DMD parents, we know from experience that it can be difficult to explain the condition to other people — especially when you are still in shock from the diagnosis yourself.

So, we've produced special guides to DMD to help you have conversations with:

- Your family and friends
- Your employer
- Your child's teachers
- Your babysitters

www.duchenneuk.org/resourcesforparents



Having a good life with your child

Children with DMD have brighter futures now than ever before.

They are going to school, university and getting jobs. Some even have children of their own.

Undoubtedly, DMD presents many challenges in childhood and adolescence. But today, there are opportunities for fun, holidays and sport.

You can still have hopes for your child's future.

Telling your child that they have DMD

You're probably already worrying about what to say to your child.

You may not feel like it at the moment – but you are the best person to give this news to them. When children are given information by parents or other people they trust, they're in the best place to be comforted and reassured.

When should I tell my child?

Generally, the best time to tell your child that they have DMD is soon after the diagnosis.

Your feelings are likely to be very different. You may want to shield your child from the news. You may want to wait until you've come to terms with the diagnosis and its implications yourself. You may want to wait until your child is 'ready'.

While these feelings are perfectly understandable, children can usually sense when their parents are upset and worried. They can feel unsettled if they know something is wrong but they don't know what it is.

You won't be able to hide medical appointments from them. So, it's best that they know what's going on before they start seeing doctors and other healthcare professionals.

When you tell your child what they need to know early on, it increases trust between you. And this will be a strong foundation for the care you'll need to provide over the years.

What should I say to them?

Right now, you only have to tell your child what they need to know at the moment. You don't need to tell them about things that won't happen for five, ten or more years.

You'll have many conversations about DMD, how it progresses and how it's treated with your child as they get older.

Here are some thoughts from other parents who have had to tell the same news to their child:

- The most important thing is to make sure that what you say is truthful, age-appropriate and makes sense to your child
- It helps if you think through the questions that your child might have and prepare your answers
- You only need to share what you are comfortable sharing. The way you describe DMD will depend on your child's age and level of understanding. As most children with DMD are diagnosed when they're around four years old, it's likely your child will only understand simple information
- **You may choose to tell your child that they have DMD using words like:** "The doctors have told us that your muscles are different to other children's – and this will make it harder for you to do some things. There are lots of people around the world working really hard to find ways to make this better. There isn't any medicine that will fix it at the moment, but there are a few things we can do that will help (like stretching)"
- Some parents like to use the full term – Duchenne Muscular Dystrophy or DMD. Others use the word Duchenne and others use the term Muscular Dystrophy

Make sure that what you say is truthful and age-appropriate.



You only need to share what you are comfortable sharing.



The way you describe DMD will depend on your child's age.



You only have to tell your child what they need to know.

- It's important to tell your child that this is not their fault. Very young children tend to believe that good is naturally rewarded and bad is always punished. So, they may conclude that the reason they have DMD is because they've been bad. You'll need to explain they were born with different muscles so they don't blame themselves
- **Try to keep focused on the here and now** – Talk about what it means in the short term. Avoid looking too far ahead into the future. Young children tend not to be interested in long-term outcomes. Keeping it simple and honest, without being scary, is a good start
- You can then build on this information slowly over the years as they start to ask questions

How should I answer their questions?

It is important that children feel that it is okay to ask you questions about DMD. But there is no single right way to approach these discussions.

Some parents like to give information to their children. Others prefer to simply answer the questions their children ask and not give any further information.

Sometimes, you may not know the answers – and that's fine. You can always take some time to find the answers and talk about them later.

If they ask something you don't want to answer yet or catch you at a bad time, it's okay to tell them that you need time to think about it. This allows you time to think of the answer you want to give. You can always praise your child for asking the question and tell them that you'll sit down with them soon when there's time to talk it through properly.

It's often helpful to ask where the question comes from so you can find out what's on their mind.

Keep
focused
on the here
and now

It's ok to
tell them
that you need time
to think about it

Praise
your child
for asking the question

What are the signs that they're worried?

Often, children find it difficult to put their worries or questions into words.

Sometimes, this affects their behaviour. You may notice they seem more sensitive or they can't sleep or become more clingy, less co-operative or more easily frustrated. All these behaviours may be signs that your child is worried or stressed.

You know your child best, so do what feels right for you and your family.

Is counselling available for children?

Your child with DMD or their brothers and sisters may benefit from play therapy or other forms of therapy from around seven years old.

Your GP should be able to refer you to local services.

Siblings often feel they have to be good all the time and become 'model children'. This can be a sign that they are stressed and need an outlet for their feelings. Your GP should be able to tell you about local support groups for siblings.

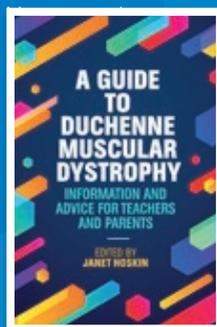
How should I bring up my children now?

You should try to keep a consistent approach to manners, discipline and house rules for all your children. You don't need to change the way that you're bringing them up because of the diagnosis.

For more information

You can find a whole chapter about talking to your child and their brothers and sisters in *A Guide to Duchenne Muscular Dystrophy: Information and Advice for Teachers and Parents* by Janet Hoskin.

You can get a free copy from Duchenne UK by emailing support@duchenneuk.org.



Siblings, including talking to them about DMD

Your other children will still need you. It's important to spend time with them too and involve them in the conversations about DMD as much as possible.

Talking with siblings

Most of the advice about talking to your child with DMD is also useful for talking with your other children. But there are a few other things you should bear in mind.

Here are some thoughts about talking with siblings from other DMD parents:

It's best to tell siblings soon after the diagnosis. Depending on their age, this could be before or after you tell your child with DMD.

- If your child with DMD has older brothers or sisters, they may be able to understand more. You can tell them what you feel is appropriate to their age and personality
- Speak with them alone so they can ask direct questions without trying to protect their sibling with DMD. Encourage them to talk about how they feel and what concerns them
- Offer them the opportunity to speak to people outside the family so they can express their feelings freely. Often, children worry about upsetting their parents so they bottle up their feelings
- Explain that their sibling may have this disability, but they are also just like them and love to play and be friends
- They may worry that they could catch DMD from their sibling. So, you'll need to explain that it's a genetic condition and not contagious
- Ask them to be cautious about turning to the internet for information. Let them know that they can ask you or others for more information about anything they find on the internet. Explain to them that the information on the internet is not tailored to individuals so it may not apply to their sibling. Most of it is based on patients in the past who did not have access to new medicines and treatments that their sibling will have
- Talk about their own needs and their future, as well as their sibling's needs. They should feel that they are worthy and important, and not just as support for their sibling and parents
- As your children get older, be sensitive to their need to grow up and pursue their own dreams. There's a big difference between telling a child that you appreciate their help and making them feel that you can't do without them

Grandparents, family and friends

Grandparents, family and friends provide important support for DMD families. So, we encourage you to share the news of the diagnosis with them.

Telling grandparents, family and friends about the diagnosis

Telling other people about the DMD diagnosis is tough – especially when you are still trying to cope with it yourself.

Your family and friends will probably not have heard of DMD. So, people can be uncertain as to how to respond to this kind of news.

If you give them information about DMD and how it progresses, they should be able to better understand the challenges you face.

To help you do this, we've produced 'A Guide to DMD for Family and Friends' which you can download from our website at: www.duchenneuk.org/resourcesforparents.

In this guide, you'll find:

- Resources you can use to explain DMD
- Advice for grandparents, family and friends
- Information about grandparents' associations

Asking for help from grandparents, family and friends

Ask your family and friends to look after you while you look after your children. They can help you by listening. You need to talk about the diagnosis and what it means for your child and family. Just by listening, they will be supporting you.

They can help with practical assistance around the house. The cooking, cleaning, washing and chores still need to be done. They'll make a big difference to you if they're willing to take on some of your chores for a while.

They can also help by babysitting so you can go out together or with other friends. This will give you a chance to relax a little.



Doctors – your GP and the neuromuscular clinic

Your child's care will fall under two separate authorities - your neuromuscular clinic at a hospital and your community care through your GP or local authority.

Unfortunately, there's no single point of contact for the NHS or social services. So, you may have to fight for what your child needs.

Your GP

Your GP should be one of the main sources of support for you and your child.

As well as supporting you themselves, your GP will refer you to the neurologist and local services, like physiotherapy and occupational therapy.

They can also refer you for counselling to help you cope with the diagnosis.

They may also be able to refer your child and other children to a play therapist or counsellor once they are seven years old.

Because DMD is a rare disease, it's likely that they will not have had a patient with DMD before. So, we recommend that you tell them about the Royal College of General Practitioners' e-learning course on neuromuscular conditions in primary care. It will help them to better understand DMD and care for your child.

Neuromuscular clinic

Neuromuscular clinics across the UK bring different doctors and specialists together to treat your child. They are multi-disciplinary clinics.

Your GP should refer your child to the neuromuscular clinic. It's important that your child has their first appointment at the neuromuscular clinic as soon as possible. Early treatment and management strategies give them a much better chance of preserving their muscle strength and function.

For more information

We've produced 'A Guide to DMD for Babysitters' which has all the information they need to look after your child safely. You can download it from our website at:

www.duchenneuk.org/resourcesforparents

Neurologist

Your neurologist is a doctor who specialises in neuromuscular disorders, including DMD.

They will be in charge of your child's treatment. They will monitor your child's development and general physical well-being. They will manage their steroid therapy.

They will coordinate their care with specialist doctors, including a cardiologist (heart specialist), respiratory physician (lungs and breathing specialist) and an endocrinologist (metabolism, hormones and bone density specialist).

They will also work with other healthcare professionals, including a physiotherapist and, possibly, an occupational therapist, orthotist, dietician and social worker.

North Star Network of neuromuscular clinics

The North Star Network helps clinics provide the best possible treatments to DMD patients by sharing information and setting national standards.

The Network has helped improve care significantly since it was set up in 2003. It has led to major breakthroughs, such as the use of steroids.

Ask your GP to refer your child to a neuromuscular clinic that is part of the North Star Network.

Your first clinic appointment

Your first clinic appointment can be upsetting and emotional. But it's important that you try to get as much information as possible from this and future visits.

Here's some tips from other DMD parents:

- Try to bring a family member with you who can take notes during the consultation, so that you can read them when you get home. It's much easier than trying to remember everything yourself
- Before your appointment, make a list of all the questions you want to ask your consultant

Some of the questions that you may want to ask.

Questions about the team who will look after your child:

- When will my child be referred to a cardiologist? How regularly will their heart be checked? (typically, DMD patients have their hearts checked soon after diagnosis, then annually or more frequently depending on the results)

- When should they see the endocrine team (the doctors who look after hormones)?
- When will they be referred to a physiotherapist and begin stretching? (regular stretching is very beneficial)
- What counselling and therapeutic support is available – for your child with DMD? For siblings? For you and your partner?

Questions about the treatments that your child will receive:

- What are the risks and benefits of your child taking steroids?
- When should they get orthoses (splints) for their legs? Where will they be measured and fitted?
- When and where will they receive flu and pneumonia jabs?

Questions about how the hospital system works:

- What is the process for getting speedy appointments?
- What advice do they have on financial support and grants?

Treat-NMD

Treat-NMD is an international network for neuromuscular doctors and researchers.

You can find the latest care standards in their guide, *The Diagnosis and Treatment of Duchenne Muscular Dystrophy: A Guide for Families*, on their website:

www.treat-nmd.eu

Keep your own records

We also recommend that you request copies of your child's results or make a note of the values yourself. Then, you'll be able to track and record your child's health.

Records can get lost. Or you may have to show these results to another doctor if you travel abroad. So, it's always a good idea to have your own copies. You may want to also create digital copies as back-ups.



Other healthcare professionals

Your child will be supported by a range of healthcare professionals.

Physiotherapists

They will assess their muscles and give them stretching exercises to protect their muscles.

Your child will see a physiotherapist at each six-monthly appointment at the neuromuscular clinic. They will also be referred to the local physiotherapy team in your area.

Your physiotherapist will give your child a North Star Assessment (NSA) at every six-monthly appointment. It measures their flexibility and how long it takes them to perform tasks, like running 10 metres. As we mentioned earlier, it is a good idea to keep your own record of these scores.

Your physiotherapist will also give your child stretching exercises to do at home. These will help protect and preserve their muscles.

We recommend taking photos of the stretch positions and printing them out. This will make it easier for you to do them correctly and explain them to others.

Occupational Therapists

Occupational Therapists help DMD patients by providing specialist equipment designed for children with physical and developmental disabilities. They are sometimes called OTs.

They can provide equipment that improves your child's comfort, mobility and independence, such as supportive chairs and desks. And they will be able to help you meet your child's changing needs as they grow up.

Your child will see a physiotherapist at each six-monthly appointment at the neuromuscular clinic.



They will give your child stretching exercises to do at home.



Take photos of the stretch positions and print them out.



Photos will make it easier for you to do them correctly.

The occupational therapist will discuss the best equipment for your child's needs with you. They will assess your home and your child's school. And they will advise on adaptations you may need to make for them. (You'll find more information about this in a later chapter).

You will most likely be referred to your local authority healthcare for the occupational therapist.

Orthotists

Orthotists help DMD patients by making splints which are special supports for their legs. Splints are also called orthoses. DMD patients typically wear ankle-foot orthoses (AFOs).

Your child's splints will be made-to-measure specially for them. They are light-weight and hold their ankle in neutral position (90 degrees or as close as possible). This supports their feet and calves.

Your child will probably only need to wear their splints at night. They provide a good stretch of their lower leg muscles while they are sleeping. But sometimes, children have to wear them during the day too.

Your child's orthotist may also provide inserts for their shoes to hold their feet in better positions.

Speech Therapist

Speech therapists help DMD patients who may have delays in their speech or language development.

Speech and language therapy can help, especially if they receive treatment as early as possible.

Hospices – a place of support for families with DMD

You may have a strong negative reaction to the suggestion that a hospice could help your child. Many DMD parents have had the same reaction.

But hospices offer a wide range of services to people with long-term conditions, like DMD, as well as people in the last stages of life. And many of these services are free.

You may find that your local hospice is the best place to access hydrotherapy, counselling, support groups and respite care. They may also be able to introduce you to other local families with a child who has similar needs.

When you are ready, consider having a chat with your GP about your local hospice and the services they offer.

Beware of advice on the internet and social media

Your GP, neurologist and the other healthcare professionals caring for your child are the best people to give you information and advice about DMD.

You can find some reliable information on the internet from DMD charities, especially:

www.duchenneuk.org | www.dmdhub.org

But be cautious of what you find on the internet and social media. There's a lot of mis-information and false hope out there.

Healthcare – What you need to get for your child

You should ask your GP to make sure your child gets all these essential things:

- **Emergency Alert Card** <http://bit.ly/alertcard> – Tells A&E doctors and other medical staff about the special emergency procedures for DMD children. You should also list your child's allergies on the card
- **Medical alert bracelet** – Tells first responders in emergencies (e.g. ambulance staff) what to do. Very important if your child is taking steroids
- **Vaccinations** – Your child will also need to receive flu and chickenpox vaccinations and all recommended childhood vaccinations. They will protect them from preventable illnesses which would put an extra strain on their body
- **Breathing tests** – People with DMD need to have a breathing test from their doctor at least once every year. This is because DMD affects all muscles, including the muscles needed for breathing
- **The A&E Pack app** – The app and its website www.duchenneemergency.co.uk have the most up-to-date medical advice about DMD for A&E staff. The app can also store your child's personal details



Show DMD Card.



Inform about
steroids
and other
medication.



Provide details
to all medical
and hospital
professionals.



Healthcare – Emergencies

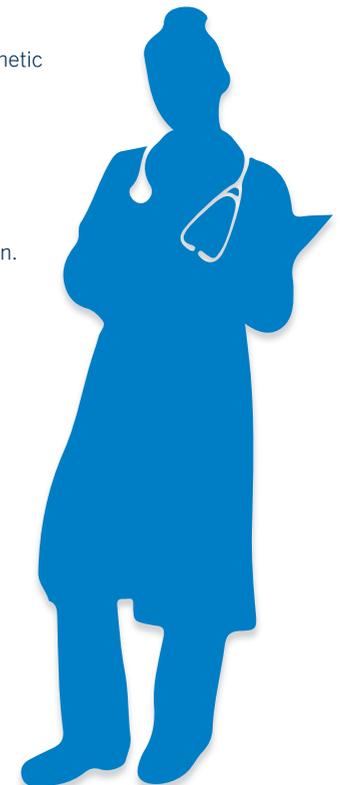
Don't treat your child yourself if they have an emergency. Always speak to your GP or neurologist or call 999.

Because of their DMD, your child needs special treatments if they have:

- **A chest infection** – Must be treated seriously and early with antibiotics and physiotherapy
- **An anaesthetic** – If your child ever needs a general anaesthetic for surgery, you must talk to the anaesthetist before the operation and tell them that your child has DMD

Children and adults with DMD need special anaesthetic procedures. Anaesthetics should not be inhaled. Succinylcholine should never be given. And extra care needs to be taken when administering oxygen.

You should also discuss any surgery with your neurologist before it takes place.



Diet

Children with DMD need a healthy, well-balanced diet. It's important that you work with your child's doctor and dietician to ensure they're getting all the nutrients they need.

They tend to put on weight easily because of their reduced mobility - and this puts more pressure on their already-weakened muscles.

Children taking steroids are at an even greater risk of putting on weight. They can also suffer from constipation because of their weak stomach muscles and immobility. Their doctor and dietician can help you keep them healthy.

Doctors and dieticians recommend a high-protein diet with lots of fibre:

- Fish and lean meats, such as chicken
- Vegetable protein, such as beans and soya
- Lots of fresh fruits and vegetables to provide fibre
- Plenty of water to keep them hydrated

Supplements

If want to try any new supplement, we recommend that you talk to your doctor first. They can work out the correct dose and check if there are any safety concerns.

Dietary considerations when starting Corticosteroids

Steroids have many benefits for children with DMD. But steroids also put a strain on their bodies. So, it's even more important that they have a healthy diet that meets all their needs.

Steroids increase the risk that children will develop osteoporosis which is a thinning and weakening of the bones. Bisphosphonates may be recommended to help protect the bones.

Also, give them lots of opportunities to play outside because of the vitamin D in sunshine.

If they experience gastroesophageal reflux (GORD), then it may help to have a low-fat, high-fibre diet with lots of whole grains, fruits and vegetables.

Children using corticosteroids, such as prednisone or deflazacort, and those with heart problems may also need a low salt diet.



Exercise

Moderate exercise can help your child to stay active, manage their weight and feel better. But some exercise should be avoided as they could damage their muscles.

Stretches

Daily stretching is of enormous benefit for children with DMD. You should aim to start a stretching routine for your child as soon as possible.

Stretches will keep your child's muscles and tendons supple. This helps preserve a full range of movement in their joints for as long as possible.

Stretching prevents or delays contractures when the muscles around a joint (such as the ankles, knees, hips, elbows, wrists, and fingers) shorten and become fixed. It occurs because not all muscles lose strength at the same time or pace. This tightening of the muscles limits the full range of movement in the joint.

The physiotherapist at your neuromuscular clinic will show you the stretches that you'll need to do with your child every day (or at least four to six times per week). Try to take notes and photos at the clinic to help you get the stretches right when you get home. The physiotherapist should also give you handouts.

You can find videos about stretches for children with DMD on:

- The Duchenne UK website
www.duchenneuk.org/physiotherapy-advice-muscles-and-stretches
- The Scottish Muscle Network's website
www.smn.scot.nhs.uk/patients-and-families/education

Splints

Your physiotherapist will also recommend braces and splints (which were explained earlier in this chapter). They will keep your child's hands, feet, knees and back in the correct positions.

Your child should begin using leg splints at night as soon as possible. These splints will keep their feet in the most comfortable position while they sleep and stop their bedclothes pulling them in other directions.

Exercises which are helpful and should be tried

Moderate exercise will help keep your child active, manage their weight and make them feel better psychologically. But some exercises can damage their already-weakened muscles.

You'll need to ask your child's neuromuscular consultant and physiotherapist for advice on the appropriate level of exercise for them.

These exercises are all helpful for people with DMD:

- **Hydrotherapy and swimming** – Many experts recommend swimming for children with DMD. The water helps them to tone their muscles and improve their respiratory function. It also protects their muscles from strain and injury. Your child may be able to perform exercises in the water which they cannot do on land
- **Cycling** – Your child may enjoy using a low-g geared bike if they struggle to use a regular bike. Tomcat Trikes www.tomcatspecialneeds.co.uk has a good range
- **Soft play centres** – Strengthens children's muscles and improves their balance while they're playing and having fun. But you do need to supervise your child while they are climbing and sliding to make sure they are not over-doing it
- **Walking** – Improves children's balance, especially when they are walking over different surfaces, such as grass, slopes and pebbles

You can find more information about exercise and sport in the 'Fun and Holidays' chapter.

Exercises which are harmful and should be avoided:

Children with DMD should avoid exercises that put undue strain on their muscles or only exercise only one side of their body. This can damage their muscles.

These exercises are harmful for people with DMD:

- **Scooters** – Because they only use one side of your child's body
- **Trampolines and Bouncy Castles** – Because they require your child to use eccentric exercise which means that their muscles have to work twice as hard to jump. Eccentric exercise can lead to severe fatigue, pain and muscle damage



Steroids

Steroids are currently the only medicine which has been proven to slow down the progress of DMD. But they can cause serious side effects.

This makes deciding if or when a child should start taking steroids very tough for their parents and doctors.

Steroids have been prescribed to children with DMD for over 20 years. They are now part of the international standards of care guidelines for DMD.

Doctors think that corticosteroids help because of their anti-inflammatory properties and by improving muscle regeneration.

The benefits of steroids are that they slow the progression of weakness in children's muscles, reduce the development of scoliosis (curvature of the spine) and delay breathing and heart problems. On average, children who take steroids can walk for three years longer than children who don't.

But there are side effects of the long-term use of steroids. The most common are weight gain, mood changes (irritability and hyperactivity) and a round, puffy face known as cushingoid. Other possible side effects include difficulty sleeping, headaches, stomach irritation, growth suppression, delayed puberty, raised blood pressure, cataracts, bone fractures and increased susceptibility to infection.

Benefits	Side Effects
<ul style="list-style-type: none"> • Slows the progression of weakness in children's muscles • Reduces the development of scoliosis (curvature of the spine) • Delays breathing and heart problems • On average, children who take steroids can walk for three years longer than children who don't 	<ul style="list-style-type: none"> • Weight Gain • Mood changes • Round puffy face (Cushingoid) • Difficulty sleeping • Headaches • Stomach irritation • Growth suppression • Delayed puberty • Raised blood pressure • Cataracts • Bone fractures • Increased susceptibility to infection



You are not alone

Duchenne UK supports a lot of families. You can speak to a member of our Patient Advisory Board. Or we can put you in touch with other families.

Please email us at: support@duchenneuk.org

We will connect you with someone who can help.

The process for prescribing steroids

Children usually start taking steroids between four and six years old when their motor skills have stopped improving, but have not yet begun to decline.

There is recent evidence that starting earlier is more effective - but this must be weighed against the risk of side effects.

The type of steroids used are 'corticosteroids' (also known as 'glucocorticoids'). They are not the same as the anabolic steroids used by some body builders. Prednisolone and Deflazacort are the two types of corticosteroids prescribed for DMD. They each have benefits and side effects. Since Prednisolone is much cheaper, it is usually tried first.

Before you decide if your child should start taking steroids, it's important that you discuss your concerns with your child's doctor.

If they do begin taking them, their doctor will monitor the benefits and side effects. If the side effects are outweighing the benefits, the doctor can reduce or taper off the dose completely.

It is very important that your child does not suddenly stop taking corticosteroids. Doses need to be reduced slowly – and only your child's doctor can properly manage this process.

Looking after yourself and your partner

Hearing that your child has a life-limiting disease is the worst news a parent can get. The feelings of shock, anger, fear, helplessness, guilt and loneliness can be overwhelming.

You are not alone

You can read the stories of some of our family supporters on our website at: www.duchenneuk.org/Pages/Category/parent-stories.

You may find it helpful to join a support group too. There are Facebook groups or your local hospice may have one where you could meet other families in your area.

Look after yourself

Remember to take care of yourself and keep your own health on track. You also need good sleep, physical activity, balanced nutrition and medical check-ups.

Don't expect too much of yourself – especially in the first few weeks and months. You need time to adjust to the diagnosis and plan this new future. And that's ok.

If you're a single parent, you'll need extra support from friends and family. So, try to ask for their help as soon as you can.

Look after your relationship with each other

Your child's DMD will have an impact on your relationship. Romance and fun can seem impossible in these circumstances.

But it's important to look after each other and protect your relationship.

Try to make time to be together on your own. Dates don't have to be long or expensive. An hour walking round your local park or a coffee in a local café will do you both a lot of good.

Counselling and psychotherapy

You may want to get counselling and support for yourself, your other children and the wider family. Many DMD families have found counselling very helpful.

You can ask your GP to refer you to a counsellor. Some neuromuscular clinics may be able to refer you to paediatric and family psychologists. But you'll need to be assessed for this.



You'll have good days and bad – times of joy and desperation – but these will level out as you start to come to terms with your child's diagnosis

Checklist before starting steroids

You should make sure that all these things are done before your child starts steroids:

- Baseline assessments – Their current measurements for height, weight, urine, bloods, DEXA, FVC and, if possible, ECHO. Take these baseline assessments to your child's doctor appointments and to A&E if they have an emergency (if you can)
- Routine immunisations
- The missed dose procedure
- The procedure if they have a sudden stressful event (such as illness, an accident or surgery where doctors need to increase dosage)
- Medic alert bracelet
- Completed emergency information card

