Charcot-Marie-Tooth UK

My Child has Charcot Marie Tooth Disease (CMT)

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My CMT Child

Dealing with the diagnosis

Finding out your child has a diagnosis of CMT can understandably cause a parent to feel a whole range of emotions. Shock ,anger, guilt , feeling afraid are all normal reactions but once a person can understand and acknowledge their feelings they can then start to move forward and plan for the future.

Many parents realise there is something wrong with their child long before a formal diagnosis is made. Parents who have CMT often describe how they are constantly looking for signs of CMT in their child. A child with no symptoms who then goes on to be diagnosed with CMT may end up being labelled despite the fact that they are not affected by their CMT, whilst others who remain undiagnosed may not get the support and advice they need earlier enough. Deciding to get a child tested for CMT is a personal decision and one that only the parents can make. There is no right or wrong decision but discussing it with others who have been through the same situation can prove helpful.

As CMT can affect people in such a different way it is not possible to know exactly how the condition will affect your child. Even within a family where the same gene is involved there can be significant differences in levels of function. Here at CMTUK our Chief Operating Officer Karen Butcher s` family, is a good example of this. Karen, like her mother and late Grandfather all have CMT Type 1a. Her Grandfather at the age of 65 was very mildly affected only having flat feet. Karen’s mother developed symptoms at the early age of 2 years old and then went on to have numerous corrective orthopaedic surgery during childhood. Karen’s symptoms developed a bit later on in childhood and like her mother she went on to have various orthopaedic surgery. Despite her reduced mobility Karen who is now in her 50s works almost full time for CMTUK travelling around the country to attend various meetings and conference. Karen's 2 children both have CMT, her daughter is moderately affected and again needed correctional orthopaedic surgery when she was younger but is now in in her 20s doing a job that she loves and generally living a full and active life. Karen's son is so mildly affected that most people don't even realise that he has the condition.

Where parents who have a child diagnosed with CMT but have no family history of the condition the news can be very difficult to come to terms with, especially when they are told that it is progressive and non-curable. Talking to other parents whose children are affected by CMT and knowing that you are not alone and that there is help and support available can really help.

Normally by the time the child is diagnosed with CMT they and their parents are already aware that they may be different from their friends and others in their family so telling them they have CMT is often easier than the parents anticipate..

Telling my child they have CMT

There are some key things to consider when talking to your child about differences and disabilities. It's important to be honest, supportive and clear in your conversation. And it's good to use certain words and phrases that help your child better understand his condition.

Don't think of this as a one-time conversation but a series of talks that happen over time. The way this subject is approached will have lasting impact on how your child sees himself and others.

The first conversation is just the beginning. As your child's level of understanding changes and grows over time, so will your conversations. An ongoing and open dialogue builds trust and helps your child to open up and share their feelings.

Use simple language that is easy for your child to understand, using clinical terms for their CMT can come later, when you feel it's appropriate.

Responding to your child’s concerns

Children of all ages are very observant. Even young kids know that there are some things that are easier for them to do than others. And they also know that among their friends, some children excel at things that other kids have trouble doing.

These observations are a great place to start off your conversation. It’s important to explain that everyone is different and that everyone has strengths and weaknesses. Try to focus on your child’s strengths and also practical things that can actually help them. There are many role models with physical limitations who have gone on to achieve great things – just look at the athletes who compete at the Paralympics. Children can often benefit from meeting others with similar challenges and learning how they not only manage them but also go on to become elite within their chosen pursuit.

Contact Charcot Marie UK for more advise about this.

How do we tell their siblings that their brother/sister has CMT and what do we tell them?

As children are generally so observant depending on the siblings’ age it is likely that they will have already noticed that their brother or sister struggle more with some activities and may have some worries about this. Generally keeping the explanation as simple as possible is best. Again this conversation is unlikely to be a one off and as the situation changes and the children get older new questions will no doubt arise.

What should we tell other family members?

Whilst you are coming to terms with the news you may not feel ready to share this information but in time you will need to talk to other family members. Generally honesty is the best policy (unless there are real reasons not to tell the truth) as it is likely that you will need their understanding and support in future years.

As CMT is genetic it is understandable that other family members may be upset and worried about their own risks of inheriting the condition and may wish to be referred for Genetic Counselling. Like your own journey they too will also need to come to terms with the impact that CMT has on them and their offspring.

What should we say to our friends?

Again you may not initially feel ready to share that your child has CMT friends in the early stages of diagnosis but if/when you do and how much you tell them will depend on how close you are to that person. Avoid telling them when your child /their child is present and may overhear the conversation. It is likely that your good friends will want to do all they can to help and support you. If you don’t wish for people to share this information with others you will need to ensure that people are aware of this.

Sometimes giving them easy to understand literature can help answer questions that you yourself aren’t comfortable to answer.

Contact Charcot Marie Tooth UK for further information.

So what now?

CMT is a progressive condition but changes generally happen over a long period of time (years as opposed to months) so you would not expect to see dramatic rapid changes. Following a child’s diagnosis of CMT some families report to feel abandoned. Here at CMT UK we always recommend that a child remains under the care of a Neurologist and has an annual review. As the years progress your child is likely to need ongoing support from healthcare professionals Some Hospital Trusts have Paediatric Neuromuscular Advisors who can provide practical advice not only about the management of the condition but also about other aspects of life, activities, schools, benefits etc. Physiotherapy can be invaluable. Stretching and strengthening exercises as well and balance and gait training is important. Occupational Therapy can help with maintaining fine finger movement and hand dexterity as well as give advice on adapting everyday tasks to enable the child to remain as independent as possible.

How much will my child be able to do?

Signs and symptoms of CMT vary greatly between any 2 individuals but ensuring your child is as active as possible should be encouraged. Some children with CMT are very self-conscious about participating in sports as they are aware that they may find a particular activity more challenging than their peers who don't have CMT.

Finding an activity that your child enjoys and that also is beneficial to them can be a challenge for any parent but even more so for a parent with a child who has a muscle wasting condition. Exercise for children with CMT should be tailored to their specific needs. Physiotherapists are experts at working out which muscles are most affected by a person's CMT and focusing on other muscles that can be built up to counteract this. Muscles that are weak because they aren't used can be strengthened unlike muscles that are weak because of nerve damage. Talk to a paediatric Physiotherapist to work out the best forms of activity for your child but most importantly try to keep it fun!

Remember though that although it is good for your child to be active they will fatigue much more quickly than a child who doesn't have CMT as their muscles are having to work so much harder so you should ensure your child has frequent rests and not overdo things.

Many children with CMT will need to wear Ankle Foot Orthoses to stabilise their joints whilst mobilising. These can make a real difference to a child's mobility but can often be uncomfortable and take a while for the child to tolerate wearing them. Speak to your Orthotist if you are not satisfied with the splint your child has been given.

If your child is at school have a discussion with your child's teachers about what sort of activity your child is able to participate in but emphasize the need for your child to feel included and not made to feel "different".

What should my child eat?

There is no research to suggest that children with CMT should be on any special kind of diet other than a healthy well balanced one. Some children who have physical limitations are more susceptible to putting on weight through inactivity which can then cause additional health problems so it's important to ensure that your child maintains a healthy weight. Excess weight places a strain on joints and already weakened muscles which in turn can further impact the child's mobility. Healthy eating should be introduced as soon as child is able to tolerate solids. Research clearly shows that a child who is on a healthy diet high in fruit and vegetables and low in fat and sugar from a very young age grows up to enjoy a healthy diet for life.

Losing excess weight can be very difficult especially for children so it is best to ensure that your child maintains a healthy weight.

Future Planning

Some children with CMT may require adaptive equipment in order to help them carry out Activities of Daily Living. Occupational Therapists are the experts in assessment and provision of equipment. Handrails, bath aids and wheelchair provision are all available through the NHS or Local Health Authority (access criteria will apply)

You may also be eligible for financial help if you have a disabled child f you think your child may qualify, contact the social services team at your local council.

A social worker will then talk to you about the needs of your family, including:

- health
- social care
- education

This is called a 'needs assessment' - the social worker will give you advice on what to do next.

You can also ask your council about local support groups for carers and families with disabled children.

Help with costs

If your child qualifies for services from your local council, you'll also have the option of getting direct payments.

These are paid directly to you so you can arrange services you need. They're an alternative to social care services provided by your local council.

You may also be eligible for extra Child Tax Credit for each disabled child you're responsible for or Disability Living Allowance for children.

For more information contact: https://www.gov.uk/help-for-disabled-child/overview

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Charcot-Marie-Tooth
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Supporting people affected by Charcot-Marie-Tooth Disease.

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