

A Simple Guide to

CHARCOT-MARIE-TOOTH DISEASE



It was the twentieth of April - a special day. My mum and dad and me were going out for the day to Coventry in the Midlands. That's not too far from where I live but I bet you can't guess why we went. There are no theme parks there, or zoos or anything like that.

It was a special day - the Annual Conference of CMT United Kingdom. What do you mean, what's CMT - I thought everyone knew that!

CMT stands for Charcot-Marie-Tooth - that's the weird name for the disease that makes my walking peculiar! I'll explain more later, because it's not simple.



Anyway, there we were going off to this hotel in Coventry for the Conference, where people with the same thing as me get together and have a good chin-wag about our funny feet and hands. It's a good laugh, too! It's always nice meeting other people who have the same problems as me, because you know that no-one is going to laugh at you or tease you, and they all understand what it's like to be different.

Not that it's all bad being different, you know. Wouldn't the world be a very boring place if everyone in it was exactly the same? What would we talk about? How would we know who was who? I know my CMT makes me special and I like that. It's a pain sometimes when I trip up over my feet, or twist my ankle and hurt myself. But ... I don't have to do sports at school, which is great when it's pouring with rain and everyone else is miserable.

Back to the Conference - CMT United Kingdom is a charity and the people who run it for us mostly have CMT, too - so they know what they're on about! A doctor usually comes to talk to all of us about CMT and how it works, and why it makes our legs and arms weak, and why we have it. Sometimes, they use words we don't understand, but they are always nice, and explain it all to us. Besides, I know my mum will explain it to me if I ask her to. She has CMT, too, you know. Oh yes, I did say I would tell you what it is, didn't I? Well, after this meeting I know all about it!



I have CMT because my mum does. When we are made, we get some parts of us from our mums and some from our dads. That's how we might have blond hair, or blue eyes, or be tall or small, fat or thin. It really depends on what our parents look like - we end up looking a bit like our dad and a bit like our mum. All these

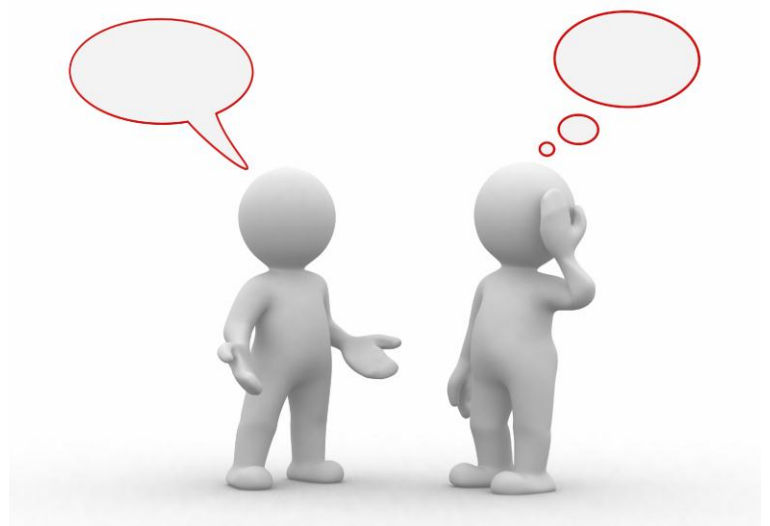
different bits of us are found on things called chromosomes, which have loads of genes on them. Each chromosome is like a recipe book, which the recipe for making a rather nifty person! Now, in my mum's recipe, an ingredient has gone wrong, doesn't do the right thing, and gives her CMT. Unfortunately, I got this wrong ingredient, too, so I have CMT as well.

Mind you, just because my mum has this wrong bit didn't mean I had to have the same thing. Sometimes you do ... sometimes you don't! Who knows? Not only that, sometimes you can have the wrong ingredient, but it doesn't do anything!

Now this bit gets even more weird! As you know, I don't have any brothers or sisters but mum does. She has a brother and two sisters and they all have kids, too. Now - only Uncle Dave has CMT the same as mum, but he's much worse - he has to use a wheelchair all the time, because his legs have got so weak he can't stand at all. But only Jenny, one of his kids has got it, and she's not even as bad as me - she just twists her ankle sometimes. And all my other cousins, mum's sisters kids, can't have CMT ever, because their mums haven't got it. So you see, just because your mum (or dad) has it, doesn't tell you that you'll have it the same everyone is different.

OK - so we've got where we've got it sussed - what about how it actually works? Do you know what nerves and muscles are? Muscles are the long elastic band type things under your skin, that are attached to your bones.

When they stretch and relax they make your legs, arms move. Your brain tells them when to move and how to do it - fast or slow, or whatever you need to do at the time. Your brain is joined to your muscles with nerves which are long thin things like wires. Think of it like the Internet - some connections are fast, some are slow, aren't they? Your computer is like your brain, and your foot is like the website you're trying to get into. In my case, the connection is so slow, that the website doesn't open at all. You know, the kind where you give up and go home!



Going back to the muscles, this slow connection in the nerves means that the muscle gives up and stops working - ending up with floppy feet, and wobbly legs! And sometime dodgy hands - that's why I ask you to open my Coke bottle sometimes, coz I can't open the stupid thing.

Really, what happens is the wrapping around the nerves gets all thin and no good, so the "connection" whizzing down the nerve is really slow. Because of this, some of the muscles in your hands and legs don't move quite as they should. The ones that still work pull hard to move; the other ones don't pull against them the other way, and waddya got? CMT!

How do they make it better? Well, the doctor can't make it better - I mean, there is no medicine that makes a difference, and as I get older, it will probably get worse. Hopefully, not too much worse, but I'm not going to worry about that yet, I'm only ten. My mum sometimes uses a wheelchair when we go out shopping, because she gets really tired and her feet hurt a lot, but then she's really ancient - thirty-five.

There are lots of things that the doctors can do to help me, though. I have these special plastic splints in my trainers to help my feet stay straight. They were made for me by a bloke at the hospital called an orthotist. He made a really cool mould of my leg with plaster and then made the splint in that, so that it fit. It goes under my foot and up the back of my leg and straps hold it tight in place. I can walk without it, but my feet drop down a bit without them and then I trip over my toes.



I'm not allowed to use them all the time, I've got to give those muscles that still work some exercise. Hopefully, that'll keep 'em going for a good while yet! Mind you, the splints are NOT very comfy to wear and sometimes I get sick to death of wearing trainers all the time. Still, ordinary, boring shoes hurt my feet even more than the splints and if I don't want my knees to be like one mega graze all the time, I have to put up with them - I think I'd rather not fall, if you don't mind!

I also see a physiotherapist sometimes. She's a really nice lady who gives me special exercises more of them - to do at home. They're supposed to keep everything up to speed! I don't much like that - sometimes I'm fed up or aching, or bored, and mum makes me do the exercises anyway.

I also might have to have some operations on my feet when I'm older. Bet you can't guess what my mum has in her ankles - metal screws. Mega cool!!! Sounds weird actually. Course, when the doctors are doing the job, you don't know about it - you're sound asleep! It hurts afterwards, of course, but mum says they give you stuff to make the pain go away, and it doesn't hurt for too long. They usually put your foot in a cast afterwards for a while - so you can't jump about and undo all the good work, but that does mean you don't have to go to school for a while!

So, all in all, CMT is not too bad - hey, I know lots of people who I meet at the physiotherapists who have much more serious conditions than me. Some can't walk at all, or are in pain all the time. My mum has a blue badge, which helps us park our car near the shops, and she even gets some dosh from the government so she can have a new car every three years - can't be bad!



Anyway, with all these great people at CMT United Kingdom, it's not like our family are on our own anymore. We used to think there was no one else in the whole world with CMT, but we have lots of friends with the same problems now, and do you know something - that's great!

Contact CMT United Kingdom for more information at
www.cmt.org.uk or find us on Facebook.

98 Broadway, Southbourne, Bournemouth, BH6 4EH

Email: info@cmtuk.org.uk

