



CMTAA

Charcot-Marie-Tooth Association Australia Inc.

A Teens Guide to Charcot Marie Tooth

OK so we all know what CMT is...

a disease that can be a pain in the neck (or the feet more correctly). But did you know that as a teenager with CMT you will be faced with challenges just like every other teenager in the world. Everyone feels a little scared or unsure of themselves at some point in their lives – it could be that you have to do a speech at school, or maybe try a new physical activity you're not sure about. You probably feel that if you don't do this new thing perfectly the first time your friends will laugh at you or make fun of you.

One solution is to be positive and imagine it not as a 'problem' but as a 'challenge'. Once you start thinking in this way many of your fears will go away and you will develop a 'can-do' attitude to life. No one said it would be easy, but you know how to conquer anything – you're a TEEN!!!

Sometimes CMT confronts you with a 'challenge'. You probably face challenges every day of your life. It's how you approach these challenges that matters. It can be really helpful to talk to someone else, perhaps a friend, a teacher, an older brother or sister or even your parents. You will know who will listen to you. Talk, talk, talk – it's the best advice. Get it off your chest...then move on! Life is for living.

Bullying...

stresses people out and can ruin lives. Even the milder forms of bullying such as name-calling or excluding people from groups can be very upsetting. It is a deliberate and hurtful act that could happen to the same person over and over again. Sometimes it happens to people who are a bit different, but most of the time there is no obvious reason. The best thing to do in all cases of bullying is take RAPID ACTION. Talk, talk, talk again – tell someone and keep telling them until something positive happens.

Exercise...

You may have noticed that you feel far more tired than your mates, even when you do physically less than them. You probably go to bed feeling shattered and wake up in the morning feeling much the same.

Unfortunately, this tiredness is just part of CMT and other than staying in bed all day (which is NOT an option), there's not much you can do about it. There are 2 types of tiredness – the type when you just do a bit too much in the gym or at PE, or stand for too long, or walk a bit further than usual – that kind is perfectly normal muscle tiredness, and if you sit down and rest for a bit, it'll get better. The other is a general kind of tiredness, of the whole body, and it doesn't seem to be related to what you do. This kind doesn't get better if you rest! The experts don't really know what is going on with CMT and this type of tiredness, but it's just a matter of learning to live with it, and get on with your life anyway!

Need Help? Check out the CMTAA website www.cmt.org.au