

THINKING ABOUT YOU!!

When you were younger it was the adults around you who made decisions on your behalf.

But now, like many young people, you are growing up and discovering that your goals and ideas are important and that there are things you may want to change. Perhaps you are feeling more confident and capable about making up your own mind about life.

Maybe you want to have more fun, gain new freedoms and responsibilities, or you may want to be more involved in decisions about your health. Independence often begins with people taking on this sort of responsibility. You may also be exploring 'real life' thoughts and feelings that you haven't yet shared with anyone else.

All this can be exciting, but sometimes a 'bad patch' can leave you feeling a bit uncertain. Talking with other people about how you feel can help. By sharing your thoughts you will find there is a lot of information available and loads of great ideas to help you solve any problems or worries you might have. This booklet will start you off.

So, if you are between 11 and 16 years old and have Charcot-Marie-Tooth Disease (CMT for short), then this is for you.

If you want further information about your condition call CMT United Kingdom on 0800 6526316 or email enquiries@cmt.org.uk Everything discussed will be confidential.

Find out more...



Feeling good about yourself

- ✚ Feeling shy?
- ✚ Want to be more confident?
- ✚ Just be yourself!

This is good advice, but what if you don't feel confident enough to 'be yourself'? You may compare yourself unfavourably to other people like celebrities or even your friends.

The reason the world is such an interesting place to live in is because everybody has different skills, abilities and ideas to contribute.

Self-esteem is about feeling good - And it matters. It matters a lot!

Self-esteem means you can enjoy being with a group of people you don't know and feel comfortable. It allows you to have a laugh with your friends – even you're the butt of the joke. And people with a high level of self-esteem are usually more assertive too (that is, letting other people know what you want and what your opinions are without going into a strop!).

So, how do you 'get' self-esteem? Well, by being both proud of who you are and valuing yourself. One way you can begin to build your self-esteem is by developing your own style and looks.

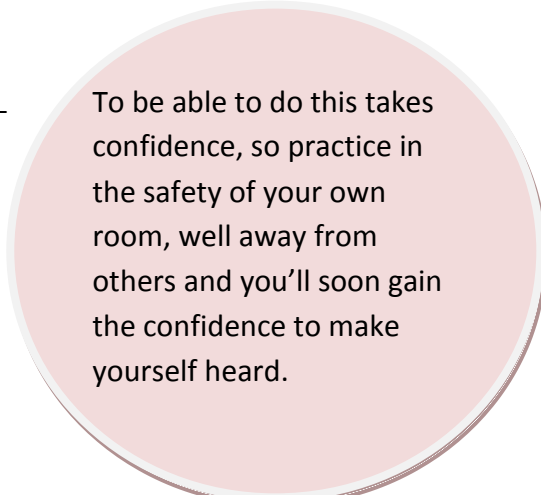
Everyone wants to look good (even though some people don't appear to care – think 'grunge'). Film stars and models always seem to look good but, remember, it's their job to look great, they have lots of people to help them and they get paid tons of cash.

The rest of us have to be realistic about our appearance and there are some things we can't change. So, be positive and concentrate on the good things about yourself. You may have a nice smile, great teeth or great hair gel (= great hair).

One way of dealing with those people who want to 'pat you on the head' or ignore you (sometimes called the 'does he take sugar?' syndrome, because they don't think disabled people can speak for themselves) is to be direct, and speak up with a suitable comment.

Come along to our Young People's Activity Weekend's for 12-20s – when you realise that you CAN climb a climbing wall, cycle, row or do lots of other great activities, you'll get a HUGE boost to your confidence.

Check out the video out http://www.cmt.org.uk/young_people_weekend.php for proof that it works!



To be able to do this takes confidence, so practice in the safety of your own room, well away from others and you'll soon gain the confidence to make yourself heard.

Why worry?

Everybody feels a little scared at some point in their lives – it could be while abseiling over a cliff or when watching a horror film! But you can also feel nervous about a big event, where you may be the centre of attention. Perhaps you have to give a speech at school or deal with a difficult situation and you may feel that if you are not absolutely perfect, people will make fun of you.

One solution is to be positive and imagine it not as a 'problem', but a 'challenge'. Once you start thinking in this way many of your fears will go away and you will give yourself a genuine 'can-do attitude'. You might find it hard to think like this and try to deal with your worries yourself, but this might not be such a good idea. It can be really helpful to talk to someone else, perhaps a friend, a teacher, an older brother or sister or even your parents. All these people can offer support and understanding. Talk, talk and talk is the best advice around.

If you really feel that you can't talk about a fear that you have, then apply the strategy that we talked about in the bullying section. You can raise the problem (oops, challenge) as a topic that you have recently read about in a book or seen on a television show, and then you can openly discuss it with someone you trust who can help.

Talking will make it easier to give the challenge a sense of proportion. Not being perfect at something is not a disaster and very likely your worries are needless.

When trying something new, like learning a foreign language or taking up a new hobby, you may quickly feel frustrated and drop it because your skills don't match up to expectations. In these situations your confidence can take a knock, but remember to have that 'can-do attitude' and set yourself realistic weekly or monthly targets.

Think about what you want to achieve. An example could be a school project about a subject you know nothing about. Your ultimate goal is to submit a thoroughly researched and well-written project to your tutor and be confident of receiving a good mark.

Begin by writing down the problem or difficulty.

Break down the 'problem' into achievable chunks or bites by asking yourself:

- ✓ When is it due in?
- ✓ What help do I need?
- ✓ Where can I get help?
- ✓ Where do I want to do the work – at home, at school, at a friend's house?
- ✓ How much time should I give to each part?

Keep checking that you are on course and, if necessary, make changes.

By applying this method to difficult or complex matters you will have a sense of purpose, know where you are going and therefore stand a good chance of succeeding.

A useful saying that can remind you how to use this technique, is 'if you want to eat an elephant – eat it a bit at a time!' It just means, break down a problem and tackle it bit by bit.

BULLYING

Bullying stresses people out and can spoil 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 to take rapid action.

There are other people who can help:

www.pupiline.com offers tips and do's and don'ts on dealing with bullies.

www.getconnected.org.uk is a free helpline to help you find the best help whatever the problem.

The site www.bullying.co.uk offers advice and strategies on dealing with bullies (including text message bullying). It also gives advice to parents and schools and has information about the current legal position on bullying

Unfortunately, people who are being bullied are often reluctant to talk about what is happening to them and they may even keep it a secret.

Why? Well, people often feel upset or ashamed to admit that they have been singled out for this type of treatment. They often think 'Why me? What have I done? What have I said? Perhaps they (the bullies) took something I said the wrong way'.

If you know someone who is having a bad time because of a bully, can you do anything about it? If you have experienced bullying yourself you probably know what action to take. But if the person being bullied doesn't want to talk about it, what can you do?

One strategy is to read a book or story about bullying or perhaps you can remember a TV show about this kind of hurt. You can then bring up the subject by talking about the book or programme – how good the story was, the difficulties the main characters faced, their dilemmas and the choices they made. You can also use this strategy to talk to your parents, teachers and friends about other embarrassing, complex, personal subjects. Remember that bullying is nothing to feel ashamed about and schools take it very seriously.

You have probably heard about Childline. It offers a 24-hour helpline for children and young people. Call 0800 1111 (if you find it difficult to use an ordinary phone you can use textphone on 0800 400 222) and talk to them about any problem, including bullying. The call is confidential (no-one else will know) and they will offer

advice and help. www.childline.org.uk. Kidscape is a charity that works to keep kids safe. It takes bullying very seriously and offers help to any kids being bullied. Its helpline is 020 7730 3300 www.kidscape.org.uk.



WHAT'S ON YOUR PLATE?

Experts say that we all need to eat healthily from a wide range of foods but...

Too much of a 'good thing'?

Foods high in sugar and fat are very tasty, and because they are tasty it is easy to eat a lot of them! But they are loaded with calories. If you eat more calories than you burn up, the result is too much fat. So, as well as cutting down on obvious high calorie foods watch out for those hidden calories too.

How good is your diet?

We all know that what we eat affects our health, but do we manage to eat healthily? Try this short quiz to see how you score:

1. What do you usually start the day with?
 - a. Sugar coated cereal
 - b. Toast with lashings of butter or margarine and some other spread
 - c. Nothing much
 - d. Cereal with very little or no sugar
 - e. Toast with a thin scraping of butter or margarine

2. Do you use...?
 - a. Skimmed milk
 - b. Semi-skimmed milk
 - c. Whole milk (full fat)

3. At lunchtime do you...?
 - a. Have a packed lunch with just sandwiches and fruit
 - b. Have a packed lunch as above with crisps and/or a biscuit (including chocolate!)
 - c. Just have a drink and crisps and/or a biscuit

4. What is the drink you have most often?
 - a. Ordinary fizzy drinks/squash
 - b. Diet or low calorie fizzy drinks/squash
 - c. Milk
 - d. Water
 - e. Pure fruit juice

5. If you are hungry between meals what are you most likely to reach for?
 - a. Biscuits
 - b. Fruit
 - c. Sweets
 - d. Bread/toast
 - e. Crisps

Fast food = healthy food?

Many people would think that the above equation doesn't balance, but you can eat healthy food while on the move as long as you choose carefully.

Baguettes/pitta breads/wraps with salad/cold meat/egg/tinned tuna (in brine or water). If you can't do without mayo use a low calorie version but remember that even these are high in calories so only have a teaspoon. You can also use pickles and relish to add lots of flavour.

Jacket potatoes with baked beans/low fat cheese/prawns/tuna in brine. But don't add butter or margarine, although reduced fat margarine would be OK.

Pizza At home get pizza bases and make your own pizzas rather than getting the high fat, high calorie take-away types. If you are eating out, try to choose the pizza with less cheese and ore veggies.

Beans on toast is a nutritious quick snack that is high in fibre; this means it will keep you feeling fuller for longer than other snacks.

Sausage & mash – but make the mashed potato with skimmed milk and don't add butter or margarine. Try to have only one or two thin sausages and cut them into halves or thirds, then stick them into the pile of mash so they look like more sausages! Reduced fat sausages can taste good too.



Pasta with sauce is very popular and can be quite low in calories. Just boil the pasta then add a ready-made tomato based sauce with tinned sweet corn and/or tuna. To spice it up add a little chilli sauce or a small amount of chopped salami. Try to avoid the creamy, cheesy sauces.

Soups can be really tasty and fill you up without too many calories. There are many ready-made ones, both fresh and tinned, which are low fat. Look at the nutrition label and choose vegetable soups or reduced fat soups, and again try to avoid the creamy ones.

Lower calorie puds

Any type of fresh fruit or frozen or tinned fruits in their own juice (not syrup)

Diet yoghurts (low calorie)

Sugar free jellies

Pack a punch with your packed lunch!

Lunch is an important meal. If you don't refuel in the middle of the day you could well end up over-eating after school because you're so hungry. By choosing a balance of foods you can feel full without having too many calories.

Sandwich fillings

Grated cheese (use only a little), a slice of lean meat, tinned fish (in brine or water), prawns. Always try to have a vegetable in the sandwich. Have lots of fruit – grapes, peeled citrus fruit, apples, pears and banana are excellent. To help you get your five a day you could make up a big mixed fruit salad, but remember to squeeze a little lemon juice over it to prevent it going brown.

Fibre – why eat it?

Fibre means you feel fuller for longer and it keeps the bowel healthy. The bowel is a large muscle which must be given work to do to keep functioning properly, and the fibre in your diet is what this muscle uses to exercise! As the fibre is pushed through the bowel by the muscle, it acts like a sponge and absorbs water. That's why it's important to drink plenty of fluids but make sure it's water or a low calorie drink. You can increase your fibre by eating high fibre breakfast cereals, wholemeal bread, beans and pulses (try lentils and chickpeas), and, of course, fruit and vegetables.

If you like yoghurts get the diet types or at least the low fat ones. And for something else sweet try a fruit bun or scone with a little jam (but not butter) or have a few dried apricots or raisins.

Finally, drink water or low calorie squash and unsweetened fruit juices.

You might ask – why do all this? So, I'm a little chubby, does it matter??? Well, maybe a little doesn't hurt, and you certainly don't want to get too obsessed with how you look – that's not healthy either. Of course, exercise is the thing to keep the weight off and sometimes it's difficult to do if you have a condition like CMT. BUT, extra weight just stresses out those poor legs and feet more than they need to be, and it will take more effort to get about, and you'll feel even more tired than usual.



And whilst we're on the subject of fatigue....

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

Unfortunately, this tiredness is just a 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 two types of tiredness going on – the type when you just do a bit too much in the gym, 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 kind is more of a general tiredness, of the whole body, and 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 ignore it, live with it, and get on with your life anyhow. You're not really going to let it get the better of you, are you? That won't do at all!

Just try to pace yourself – do your exercises by all means, but take your time, do them slowly, stop for a breather now and then. You'll soon get the hang of how much you can do in a day, without wearing yourself out completely – but please, don't use this as an excuse not to tidy your room, or do your usual chores. CMT is a nuisance, but it doesn't stop you getting on with the normal routine of life!

Quiz answers, what did you score?

Scores for questions

1. a.2 b.1 c.1 d.3 e.3 2. a.3 b.2 c.1 3. a.3 b.2 c.1

4. a.1 b.3 c.2 d.4 e.2 5. a.1 b.3 c.1 d.2 e.1

Scores

15+ excellent 10-15 very good

under 10 improvements are definitely needed to this diet!

Remember that eating healthily doesn't mean you have to eat boring food. You can eat the things you like, just don't eat too much of them and balance them out with healthy foods. Why not experiment with unfamiliar foods and new recipes? A little imagination can make a big difference to what's on your plate.

EXERCISES

And there are even better reasons for doing exercises. But first, you need to make sure that you are doing the right type of exercise. Ideally, you should see a physiotherapist regularly as they will make a programme of exercise to suit the exact way that your CMT is affecting your legs and arms.

Q. Why do I have to exercise?

A. Any exercise is good for us – it doesn't matter whether you have a condition like CMT or not! It can help keep the weight off, and also, exercise makes you feel good, and can actually help you feel less tired, which does sound weird, but it's true.

Obviously, some types of exercise will be easier to manage than others – jogging may be way beyond what you can do, but exercise bikes and rowing machines are easy! Anything that is “non-impact” – not taking the weight directly onto your legs, and sitting down, is good to do.

It's very important to keep the muscles in your legs and arms working as much as you can. Although there's no proof of this, it might well help keep your CMT under control for longer.

Q. How much should I do?

Your physio will be able to advise you best, but you need to work your muscles fairly gently. If you imagine a scale of exercise, with 1 as yourself doing absolutely nothing, or being a “couch potato” and 10 as the hardest work you could possibly do, then you need to keep the level of exercise to about 4 or 5. Not too much, and not too little!

Q. What about swimming?

A. Swimming is probably the best way to exercise if you have CMT. The warm water supports your body and relaxes your muscles, which makes stretching exercises much easier. The best thing about swimming though is being able to move much more freely than you usually can and it's really good fun!

Q. What is the point of stretching exercises?

Stretching exercises are perhaps the most important exercises for all ages. If you have a condition like CMT, the muscles can become shortened and stiff, as the nerves leading to those muscles become damaged. At the worst, the stiffness can become permanent if the muscles and joints are not moved and stretched, and then the feet and ankles will become fixed in the wrong positions, making it harder to walk and stand. Physios and doctors call this stiffness a ‘contracture’. It is possible to stop this happening by doing all the right stretching exercises. In CMT, particularly good ones to keep stretched are the ones in your shin and ankles – but you need to know the proper techniques of stretching these without doing any damage to yourself. Talk to your physio about stretching techniques.

Q. If my muscles are weak, can I use weights or exercise machines to strengthen them?

A. Yes, you can – but gently does it!! CMT affects the nerves that lead to your muscles, not the muscles themselves, so it is possible to keep them strong-ish, by using weights or exercise machines. Some of the muscles will be too badly affected by CMT, and won't strengthen but others won't be too far gone. BUT, and it's a big BUT, don't push yourself too hard, and don't increase the weight as you get stronger, just increase the number of repetitions you do. And you should never have sore, aching muscles for longer than two days – if you do, you've overdone it!

It's also possible that by strengthening the muscles in your upper legs that you'll also help with the process of walking. You may have noticed that you have to pick your feet up a bit more than others so that you don't trip. This is your leg's way of compensating for the weakened muscles in your lower legs – the muscles in the hips take over some of their job – so if you strengthen them, you'll reduce the effort it takes to walk and stand.

Q. What about my feet?

A. Looking good is important to many young people. Your funny feet might make it difficult to wear the sort of trainers or shoes you prefer, but you need to work on the confidence that we talked about at the very beginning of this leaflet, so that it doesn't matter anymore! Wearing splints every day will keep your feet in the right position so that you can walk better (and yes, there are stretches which will help too!).

Splints can be difficult to get just right for you. You will have to work with the orthotist (the guy who makes them) to get the right balance of support and comfort. Comfort is very important – if they're uncomfortable to wear, you're not going to, are you? And make sure YOU do have your say as to what you want them to look like – they don't have to be boring, white plastic – they can be made in a whole range of different colours and patterns. There are also non-rigid splints, that wrap around the ankle with elastic/Velcro strapping that can be just as helpful as the plastic kind, and are much more discreet and comfortable. Don't let the orthotist make all the decisions – they're your feet and you've got to wear the wretched things! But, properly made, comfortable splints can make a HUGE difference to the effort it takes to walk, balance, stand – so don't write them off without trying to get them right.

Q. What about my hands and arms?

A. Hands and arms need to be stretched too. Playing computer games is very important to most kids whether they have CMT or not. Keep your fingers flexible, especially if you play for long periods of time. You can use special "putty" to squeeze and mold, in order strengthen those fingers.

Ask your physio what you can do (yes – it's more stretches!).

SOME HIGHLIGHTS FROM RECENT YOUNG PEOPLE'S WEEKENDS!



To find out how to go along, email Karin Rodgers on Karin.rodgers@cmtuk.org.uk



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