

cmt United Kingdom
Together we are stronger



Living with CMT

Published by CMT United Kingdom



CMT United Kingdom – here to help you

We are the national support group run by and for people living with and affected by CMT. We're here to offer you support, advice and information. We do this through

- leaflets, like this one
- our website: www.cmt.org.uk
- over the phone 0800 652 6316
- our full colour magazine, ComMenT

CMT United Kingdom is a charity and relies entirely on donations from supporters and members. If you would like to help us – through money or your time – or have some suggestions or comments on our work, why not get in touch.

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Keeping this leaflet and others free to you

We really hope you find this leaflet useful – we're delighted that we were able to send it to you free. As a charity we're determined to offer all the support and information we can free of charge – which means we need to raise money through donations and fundraising.

This leaflet costs us £2.00 each to produce, design, print and send out to you. If you're able to support us with £20, you'll be ensuring that ten more people can get this leaflet free of charge.

£15.00 on the other hand, will pay for the production and despatching of ten newsletters, for those few members who cannot afford to pay their subscriptions.

You can send your donations to us by:

- a) Post to the address above
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If you have difficulty reading this document and would like it in large text or on CD-Rom please contact CMT United Kingdom (contact details on back cover)

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Introduction

This leaflet has been written for adults as a detailed guide to living with CMT and getting the most out of life. With ten sections, the leaflet is designed so you can dip in and out of it as and when you need. Roughly speaking the sections are broken into four:

Health messages for everyone – sections 1 and 2

The first two sections are relevant for anyone with CMT. It's packed full of useful information and advice on how to stay healthy. Although it is essential reading, don't get hung up about the medical side, there is far more to life than worrying obsessively about possible health issues.

Dealing with the problems that CMT might cause – sections 3 to 7

Sections 3 to 7 are all about how good life can be if only you know where to go and what to do, to make it easier. Because CMT affects everyone differently, some of these sections may never be relevant to you.

For parents and carers – sections 8 and 9

Whether you have CMT or not, sections 8 and 9 have some useful information for parents and carers.

Organisations that may be able to help – section 10

Section ten is a long list of organisations that may be able to help you. They are structured to match the sections above.

This leaflet has been produced by CMT United Kingdom – the national charity of people with CMT, their families, friends and carers – with the help of Resonant. CMT United Kingdom is a voluntary organisation and relies on the generosity of individuals to continue its work.

We hope that this leaflet answers most of your questions about living with CMT, but please note that it is not designed to replace the relationship between you and your health and social care professionals. You should talk to your doctor and the rest of your care team about your needs. Don't start or stop taking medication without speaking to your doctor.

We have taken every care to make sure that the information in this leaflet is accurate, however we cannot take responsibility for incorrect entries.

There are constant changes and developments in medicine and the benefits available so check with your health and social care professionals.

Please help us keep this leaflet up to date and tell us if there are any mistakes, changes or new information that you think should be included in this leaflet.

Medically speaking: CMT explained

CMT is a condition that affects the nerves in your legs and arms, known as the peripheral nerves.

Our body's system of nerves is similar to a network of electrical wires. Some of them, called sensory nerves, are designed to pass information back to the brain about what you can feel with your fingers, toes, legs, arms, etc. The others are command pathways, telling your muscles to do something, like lift your left foot and are called motor nerves.

Tricky medical words? If you find words that you don't understand turn to page 45 for a long list of explanations

Because CMT affects both types of peripheral nerve you may experience motor problems as the command pathways fail to respond properly, causing weakness and wasting in your muscles and numbness/sensory problems, arising from the problems with sensory nerves.

Everyone's CMT affects them differently, so you will probably find that some of the information in this leaflet is not relevant to you.

Key points to CMT:

- is not life threatening
- affects people very differently, even in the same family
- slowly gets worse over time (is progressive) and will slowly affect the nerves that control the muscles in the legs and arms and may alter your sensation of pain, heat, cold and texture
- can cause the atrophy of muscles in the foot, lower leg, hand and forearm
- can cause foot drop walking gait, foot bone abnormalities (eg high arches and hammer toes), problems with hand function, balance problems, occasional lower leg and forearm muscle cramping, and loss of some normal reflexes
- may cause long-term pain and tiredness
- is usually passed on from parent to child, there is a 50% chance of the child inheriting the condition
- is thought that about 23,000 people in the UK have CMT (about forty people per hundred thousand)
- is affecting all ethnic groups equally throughout the world
- is the focus of major genetic research, bringing us closer to answering the CMT enigma.

Problems some people have with CMT

Because CMT affects people very differently it's hard to say what problems may affect you.

Early symptoms can include:

- slight difficulty walking because of problems picking up the feet
- children may experience difficulty with running and general agility before any other noticeable symptoms – including being “clumsy”
- very high arched feet (affects around one in seven people with CMT by later life), but flat feet can also be a problem
- weakness in the hand and forearms, although the feet are usually affected first.

As the condition progresses, you may also have problems with some (but not necessarily all) of these symptoms:

- some loss of feeling in the feet, lower legs, hands and forearms, although this is rarely troublesome
- loss of fine control in the hand, making it difficult to write, do fiddly things or open jars, for example
- some muscle tremor
- tiredness (fatigue) because of the extra effort needed to do daily activities
- slight curve to the spine
- increased difficulty walking - aids may be needed, such as orthoses and walking sticks
- hip or knee problems.
- Around 10 to 20% of people with CMT have no symptoms at all
- Very rarely people with CMT can develop more severe symptoms. These can include:
 - a severe curve of the spine (scoliosis)
 - speech and swallowing difficulties
 - some difficulty breathing, particularly at night.

Different names, same condition

There are many different names for the condition this leaflet describes, the main ones are:

- Charcot-Marie-Tooth (CMT) – named after the doctors who first explained the condition in the late 1800s. This is the term that is used throughout the leaflet
- Hereditary motor and sensory neuropathy (HMSN) – so called because it is passed on through families (hereditary) and affects both motor and sensory nerves (neuropathy)
- Peroneal muscular atrophy (PMA) – so called because one of the muscles that often wastes (atrophies) first is called the peroneus muscle, found in the shin – a name rarely used these days.

Section 1: Physical and mental well being

Coming to terms with CMT

Having any disability can be difficult, particularly if it is a long-term condition like CMT.

You may find that at different times in your life you face different problems, or you may find something you have been dealing with perfectly adequately for many years becomes awkward. Remember you are not alone and that there are people who are on hand to offer you support when you need it. Apart from your friends and family, there are people with CMT who will be able to share their experiences and methods of overcoming the difficulties you may face (contact CMT United Kingdom). And of course there are a number of other voluntary organisations, not to mention professional carers on hand.

However your CMT affects you somebody has probably dealt with that particular problem before and there is always an answer, technique, or method for dealing with it and living life to the full. It may take a bit of time to find the right solution for you, but do ask and, in the words of Winston Churchill, “ Never, never, never give up.”

Taking control of CMT and your life

It is your body. You are the person who best knows how your CMT affects you on a day-to-day basis. Ultimately, if you don't take responsibility for it, no one else will.

Professionals, in the form of social workers and doctors for example, are there to offer their specialised advice and support on issues such as treatments, drugs and benefits, but they will only be with you for a few short hours. The rest of the time your well being, both physical and mental, is up to you.

By taking an active interest in your condition and by thinking about your general health beyond CMT, you can:

- feel more confident and in control of your life
- manage your condition and its treatment in partnership with healthcare professionals more equally
- help prevent further complications
- communicate effectively with professionals and share responsibility on treatment
- become more realistic about the impact of your disease on you and your family
- use your skills and knowledge to lead a fuller life

General health tips for CMT

By taking care of your general health you are more likely to avoid problems with CMT and be able to lead a healthier and fuller life. Things that would be good to think about include:

- **Keeping active** – the human body is designed to be active. Long periods of rest or inactivity will actually damage your body. (See Exercise and Nutrition on page 10.)
- **Keeping the weight off** – being overweight or obese – is bad for anyone’s health whether they have CMT or not. For people with CMT carrying extra weight can make matters worse for the following reasons:
 - makes it more difficult to exercise or stay active
 - puts more strain on already weakened muscles and joints
 - increases the chance of back pain
 - increase the risk of diabetes, which can lead to other neurological problems, particularly in the legs and feet
 - puts more pressure on your heart and lungs
 - cuts the amount of oxygen that is available to your body – to work effectively every cell needs a good supply of oxygen

The best way to keep unnecessary weight off is to keep active, rather than trying to diet alone, perhaps taking up a sport such as swimming or walking more. (See the section on Exercise and Nutrition below.)

- **Alcohol.** On the whole there is no reason why you shouldn’t have an alcoholic drink, however you do need to take much more care than someone without CMT and should avoid heavy drinking.
- **Recreational drugs.** Recreational drugs are thought to have a damaging effect on the nervous system and this is likely to be worse for people with CMT.

- **Falls.** CMT can increase the chance of you tripping and falling. However, you should try and take extra precautions to avoid a fall, as fractured bones could take longer to heal. Also, any inactivity because you are recovering from a fall may cause your CMT to get worse. Making sure you are wearing good shoes (with orthoses, if necessary), clearing any trip hazards from your home and taking particular care on uneven ground can all help you avoid falls.
- **Chilblains.** Your blood circulation in any limbs that are not working at full capacity can be a problem, so keep your hands and feet warm. (Again activity is an excellent way to help your circulation.) Chilblains are an unnecessary problem and should be avoided at all costs.
- **Pressure sores.** If you sit a lot, perhaps because you use a wheelchair, take extra precautions to avoid pressure sores. Make sure you use a decent pressure-relieving cushion (talk to your occupational therapist) and stretch out on a bed from time to time.

CMT and anaesthetics

Anaesthetics – general or local – are powerful drugs that have a particular effect on your nervous system and muscles. Because CMT is a condition that affects part of your nervous system you need to take especial care that the anaesthetist understands that you have CMT and well in advance of any operation. This holds true even if you only have mild symptoms, no symptoms at all or have a family history of CMT. By making sure you have told the anaesthetist well in advance, he or she can work out with you what type of pain relief is best for you. As an extra precaution you will probably be asked to stay at hospital longer after the operation to make sure everything is okay, which is why people with CMT are often not able to have day treatment.

Help yourself

Use this checklist to make sure you get the right treatment for you:

- *Does the anaesthetist and the doctor carrying out the operation – usually a surgeon – and their team understand that you have CMT?*
- *Do they all understand what CMT is?*
- *Are they aware of the list of drugs that should not be used on people with CMT? (Ask CMT United Kingdom for a list.)*
- *Have you told them about all the drugs and treatments you are taking, including any over the counter treatments (eg cough mixtures) and any complementary or alternative remedies?*
- *Have they discussed with you all the possible options (including no treatment) and their benefits and risks? This is known as ‘informed consent’ and the Department of Health recognises that you have a “fundamental legal and ethical right to determine what happens to [your body].” This means that everything needs to be explained in a way that you feel comfortable with.*

Exercise and nutrition

Apart from helping to make you feel good, exercise combined with proper stretching has the benefit of helping you to keep up muscle strength, flexibility, stamina and balance. In addition, physical activity is a good way to help stop becoming overweight, or if you're already a bit on the heavy side, to lose it sensibly (see General health tips on page 9).

So what type of exercise is good for people with CMT? Frustratingly, there is no definitive answer.

As with so many issues, because CMT affects people differently it is impossible to give a simple 'one size fits all' answer. Some people with CMT may be advised to do little or no extra exercise, whereas others have been part of the Team GB Para-Olympic squad.

The key thing is to start with a positive attitude. Just because you have CMT doesn't automatically rule out any activity, however strenuous. The best general advice seems to boil down to three points:

- 1 Make an appointment, through your GP, with a physiotherapist that specialises in helping people with neurological conditions such as CMT, known as a neuro-physiotherapist. He or she will be able to work with you to tailor a menu of exercises or activities that not only match your physical capabilities, but also fits in with your life and personal priorities.
- 2 Listen to your own body. Ultimately, you are the final judge about whether any activity – exercise or otherwise – is right for you. Take it at your own pace and, if it hurts, doesn't feel right or is exhausting you, stop. At the very least, stop and talk it over with your physiotherapist.
- 3 Make sure the instructor or trainer is fully aware that you have CMT and really understands what that means (if necessary get her or him to read some literature from CMT United Kingdom).

Healthcare professionals you may encounter

Because CMT is a long-term condition you are likely to come across a lot of healthcare professionals in your time.

In general a neurologist – a doctor who specialises in understanding and treating problems of the nervous system (neurology) – should oversee your overall CMT healthcare.

Healthcare professionals that have particular relevance to people with CMT include:

- *GP – general practitioner. Your family doctor is the gateway to all other health and often, social services*
- *neurologists – specialists in nervous system disorders*
- *orthopaedic surgeons – surgeons specialising in correcting skeletal problems – including legs/ankles/shoulders, etc*
- *physiotherapists (physios) – movement specialists*
- *orthotists – specialist foot support manufacturers*
- *occupational therapists (OTs)- independant living specialists*
- *chiropractors/podiatrists – foot care specialists*
- *paediatricians – child health doctors.*

Starting gently

If you're looking to start gently then often the best place to start is in water. The water in the pool has two advantages:

1. Has buoyancy and so takes the strain off your joints so reducing impact
2. Adds resistance to any exercises you do, so helping you keep fit.
3. Apart from straightforward swimming (bear in mind that breaststroke can put a lot of pressure on your back and hips) most leisure centres offer a number of water-based exercises, just find a class at your level. And remember to tell the instructor about your CMT.

Hydrotherapy is simply a form of water-based exercise which is usually carried out by a physiotherapist. It is carefully managed and is usually in a specially built pool with a warmer temperature, often within a hospital. Unfortunately, getting access to hydrotherapy is often nigh on impossible unless you are very disabled. What's more normal pool based exercises – mentioned above – are probably just as effective for most people.

If you're looking for something a bit more challenging, but well managed, you could try gym based exercises. The benefits of working out in a gym are that you can control the weights and speeds to suit you. Also, resistance equipment can offer some structured support if used correctly. Again, talk to your neuro-physiotherapist before starting a new exercise regime and make sure the gym understands about your CMT.

Something more challenging

It is impossible to give a full list of activities that you could try. You, along with your healthcare team, will have to decide what is in your league. However, as a starting selection, the following sports have specialist groups made up of disabled devotees and should be able to offer you good support:

- Horse riding
- Cycling
- Canoeing
- Skiing
- Water-skiing

For more information on organisations that can help you, see page 35 in Section 10, under Holidays, accommodation and leisure.

Muscle strength and flexibility are difficult to regain once you have lost them. It is much better to stay moderately active, than try and make up for a period of inactivity.

Nutrition

A nutritious diet that is right for you will largely depend on your age, size, gender, lifestyle, eating and food preferences and your overall health. Your diet, therefore, is likely to be different from someone else with CMT. The best way for you to work out what is right for you is to talk to a state-registered dietitian. Your GP can refer you to one on the NHS (although this may take some time), or you can go privately.

The basis of a healthy and balanced diet, is one heavy on fruit and vegetables and light on fatty and sugary food and drinks. In practical terms, for most people, this means:

- eating at least five portions of fruit and vegetables every day
- eating only a moderate amount of “simple” carbohydrates like sugar, processed flour, potatoes, pasta etc. Replace these with “complex” carbs in fruit, unprocessed grains (brown rice and pasta etc).
- eating plenty of proteins - meat, fish and pulses – remembering to remove the skin from chicken and excess fat from meat and avoid frying
- having three portions of dairy foods every day. (A portion is about 1/3 pint of milk or a small pot of yogurt, or 25g of cheese.) Where possible choose reduced fat versions, like semi-skimmed milk and cottage cheese for example
- keep fatty and sugary foods to a minimum
- eat as little salt as possible. The recommended daily amount is 5 to 6 grams (about one teaspoon)
- Avoid ready-made (“Convenience”) foods, as they can contain very high levels of sugar, fat and salt.

Keeping mentally well - depression and stress

Although CMT has no direct effect on the brain, people with any long term medical condition may face more challenging problems dealing with day-to-day life than “able-bodied” people and, occasionally, these difficulties can become more acute, leading to a feeling of depression.

Depression is a medical condition in its own right and can respond well to treatment. If you feel depressed you should seek out help from your GP. Your GP may be able to refer you to see a counsellor or a psychiatrist, depending on where in the country you live, and may also prescribe medication.

Stress

A little stress, now and then, is probably good for us. But when it becomes a long-term issue it can damage both our physical and mental health.

The important thing is to recognise stress and work out a way to deal with it – the longer you leave it the harder it is to solve the problem and the more damage it can do to you.

These are some general ways that you may be able to deal with stress successfully:

- change the factors that you can control in your life for the better. Most importantly learn to delegate and say “no”
- exercise regularly – the natural decrease in adrenaline after exercise may counteract the stress response. Exercise will also help make you fitter and healthier and so better able to deal with the problems of stress
- relax – use techniques such as guided imagery, medication, muscle relaxation and relaxed breathing
- find a friend – social support can help reduce stress and prolong life
- recognise when you need help – talk to your doctor or social worker, to help you gain control over your symptoms.

Managing pain

Pain is a very personal experience. What causes you pain and how you feel it is likely to be very different from the person next to you. Evidence, for example, shows that women feel pain differently than men and that some of the drugs that work well for men do not benefit women as much.

It is not uncommon to find that people affected by CMT experience pain, to some degree, at some point in their life – sometimes briefly, but it can become a long-term problem. Generally pain experts believe the earlier you treat pain the better.

There are two types of pain that people with CMT could experience:

- ❖ Neuropathic pain, which means that the pain is caused by a problem in the nervous system. Neuropathic pain is often felt radiating from the spine into the legs and the arms (peripheral neuropathic pain) and often seems to have no particular cause, but this should not mean that doctors take your pain any less seriously.
- ❖ Pain due to tissue damage. It may be caused by stresses and strains on your body due to the CMT, especially the bones, joints, tendons and ligaments (may be called mechanical pain). If, for example, you are walking with difficulty due to foot drop, you are likely to be putting extra pressure on other parts of your body

However pain affects you it is important to remember that there are many different treatments available, including:

- specialist equipment to give your limbs more support (known as orthoses – see page 20)
- re-training how you move with a physiotherapist (see page 21)
- various drugs

- specialist pain clinics

If you have had your pain for a long time you may find that various psychological, social and behavioural training methods, and counselling could help you manage your pain and generally function better.

Drugs for pain

- everyone responds to drugs differently. If one doesn't work another may
- take especial care if you have another medical condition or take other drugs (including over the counter complementary treatments).

Paracetamol

Paracetamol is very effective at relieving pain and is recommended as first option pain relief. It is cheap, easily available and gentle on your stomach.

- Paracetamol is safe as long as you follow the directions on the packet.
- Paracetamol can seriously damage your liver if you take too many.

Non-steroidal anti-inflammatory drugs (NSAID)

NSAIDs, which include ibuprofen, reduce swelling (inflammation) and pain. There are many different brands, so if one does not suit you talk to your doctor about trying another. Newer NSAIDS, called COX 2 inhibitors, may be gentler on your stomach.

- Taking NSAIDs regularly can irritate your stomach and cause problems like ulcers, especially if you are over 65 or take high doses. About one in ten people suffer these problems.
- Serious side effects can include stomach pain and bleeding. Talk to your doctor immediately if you have either of these.
- People with asthma, high blood pressure, stomach problems, kidney and heart failure may not be able to take them.

Strong painkillers

If paracetamol or NSAIDs do not work stronger painkillers, like codeine or tramadol, may be recommended. You may hear them called opiates, opioids or narcotic analgesics. They are sometimes combined with paracetamol.

- Constipation is a common side effect of strong painkillers affecting up to half of people. Plenty of water and foods with high fibre may prevent constipation.
- Some people suffer from drowsiness, nausea and vomiting

- Opioids can be addictive so could give withdrawal symptoms when stopping (although this is less likely with weaker opioids like codeine, but can still happen).
- Some people find that they have to take higher and higher doses of opiates to get the same level of pain relief, although tolerance is not that common.

Muscle relaxants

If your muscles spasm or are tense, a muscle relaxant or sedative, like diazepam, may help. They work effectively, but there is some argument about whether they do more harm than good because of their side effects and now they are not recommended for more than two weeks.

- Danger of addiction, even after a short course of a week
- Seven out of ten people get dizzy or drowsy within a week of taking them.

Antidepressants

Certain antidepressants, in particular a type called Tricyclic antidepressants (TCAs) have been used to treat long-term pain.

- Can give you a dry mouth or headaches, and can make you drowsy, or constipated. Symptoms normally clear up after taking them for a short time.

Anticonvulsants

Some drugs that were originally designed for epilepsy, such as gabapentin or pregabalin can be effective at combating neuropathic pain.

Complementary and alternative treatments for pain

Some people swear by complementary or alternative treatments. However, the medical evidence is often flimsy or non-existent and you should approach them with care as they can be expensive for little or no benefit.

As with all treatments or medicines there are two main dangers with complementary treatments:

- Not receiving the proper treatment – your indirect risk.
- Taking something that harms you – your direct risk

The forms of complementary treatments that are most likely to help relieve pain include:

- TENS machines (which block pain carrying nerve impulses)
- acupuncture
- spinal manipulation, such as chiropractic and osteopathy
- massage

- herbal remedies, such as devil's claw or willow bark (the original source of aspirin).

If you want to be as safe as possible, it is a good idea to go through this checklist before trying a complementary treatment:

- get a conventional diagnosis as well as relying on a complementary or alternative diagnostic method. If you don't you run the risk of not discovering a potentially serious problem
- do not stop taking any medication that has been prescribed by your doctor without telling her/him. Stopping medication suddenly can be dangerous
- make sure the practitioner you are planning to see is a member of a professional association (and check with the association that the practitioner is really a member). Your GP may be able to give you a list of therapists in your area
- tell your GP before starting any treatments as some herbs and other substances don't mix well with conventional medicines, including over the counter remedies
- stop taking any herbal remedies at least two weeks before surgery as they could interfere with the anaesthetic. (Make sure you tell the anaesthetist if you are using any complementary treatments.)
- take particular care if you are pregnant. Treatments may have a harmful affect on your baby
- keep a careful eye on hygiene, especially if your therapist is using any products such as acupuncture needles, for example.

Disability

CMT is a condition that can cause a disability, but there is no reason, with the proper information and support, that anyone with CMT shouldn't lead an active, independent and happy life. To assist you doing just that there is a raft of information, support and benefits available.

Pinning down all the right information and working out who to approach for what can be very time consuming and frustrating, but well worth the effort. The best advice seems to be to start with a four-step approach:

1. Contact one of the many organisations that offer support and information and are run by people with disabilities. They will be able to steer you through the maze of grants, information and benefits available, not to mention offer you a lot of peer support.
2. Get in touch with your local citizen's advice bureau. Although the quality of individual offices varies enormously, they are a good place to find out what is available to you locally. (Remember different authorities may offer very different support.)
3. Contact your local social services department. Although they can be slow in responding they are often wonderful and the gateway to most of the help, grants and support available from the state.
4. Check out www.gov.uk for information on benefits that you may be entitled to.

You will find more information on specific areas, such as employment and discrimination, on following pages.

Section 2: Foot management

Care of your feet

Although easily overlooked the human foot is a complex and marvellous machine that needs proper care. Each foot is made up of 26 bones bound together by ligaments, supported by muscles and supplied with blood and nerves.

The feet are often one of the first things to be affected by CMT, with problems including:

- very high arches
- hammer toes
- loss of feeling
- drop foot
- weak ankles.

The all-important day-to-day care comes down to you and should include the following rules of basic foot care (with thanks to the Institute of Chiropodists and Podiatrists):

- wear shoes that are comfortable and offer good support
- makes sure that your arches are fully supported
- keep your feet clean
- apply and unscented moisturiser, baby lotion or olive oil to dry skin
- avoid using hot water and strong soaps
- dry your skin carefully – don't rub hard with a towel
- do not cut corns, calluses or ingrown toenails – see your doctor or chiropodist
- avoid bruises, burns, cuts, cracks, chilblains and frostbite. If you get any of these seek professional advice

Chiropodists and podiatrists

Specialists in foot care have different names in the UK and North America. In general chiropodist is the British name, while North Americans use podiatrists.

You can get to see a chiropodist in one of two ways:

- *on the NHS through a referral by your GP*
- *privately. You can find a private chiropodist through the Institute of Chiropodists and Podiatrists.*

If you can get a referral, or can afford a private chiropodist, it is probably a good idea for everyone with CMT to see a chiropodist once a year for a check up.

- any signs of a problem with a mole on the foot should be checked by your doctor or chiropodist immediately
- avoid exposure to cold and dampness
- seek immediate professional advice if you ever get an ulcer or sore on the foot or leg.

If you ever have loss of feeling (or feel numb) in your feet or legs, the following should also help:

- see a chiropodist at least once a year
- check your feet everyday, particularly look out for any cuts splinters, abrasions or blisters. If you have any of these make sure they are healing properly, otherwise talk to your doctor sooner rather than later. (A mirror on the floor propped up against the wall can help you see your feet. Otherwise ask a friend or a partner to check for you.)
- before putting on your shoes, shake them to get rid of any pebbles and then check the insides with your hands to feel for any rough spots.

Orthotists - supporting you

Orthoses are semi permanent devices that are placed either on the foot or in the shoe to improve how your limbs and joints work, in much the same way that spectacles or contact lenses can improve your eyesight.

For people with CMT an orthosis can be an invaluable aid to help counteract the effects of CMT and help you to keep mobile without putting too much extra pressure on other parts of your body, such as your knees and hips.

The types of orthosis that can help with CMT range from simple insoles, to lightweight plastic splints, to custom made footwear, to traditional metal callipers.

Any external aid can take time to get used to and you may find a physiotherapist helpful when using a new orthosis. Although you may take a bit of time to get comfortable with a new orthosis, it should never cause any problems like pain, sores or bleeding. If it does you should see your orthotist or doctor immediately and have it altered.

Some of the orthoses you might hear being talked about include:

- *FO – Foot Orthosis (insoles)*
- *FFO – Functional Foot Orthosis (insoles)*
- *SMO – Supra-malleolar Orthosis (ankle brace)*
- *AFO – Ankle Foot Orthosis*
- *DAFO – Dynamic Ankle Foot Orthosis*
- *SAFO – Silicone Ankle Foot Orthosis*
- *JAFO – Jointed Ankle Foot Orthosis*
- *KO – Knee Orthosis*
- *KAFO – Knee Ankle Foot Orthosis*
- *HKAFO – Hip Knee Ankle Foot Orthosis*

Everyone with CMT has different needs and the orthotist will care that you receive the right support for you.

Helping you stay on your feet - physiotherapists

A physiotherapist is a specialist in how the human body functions and moves. They are specially trained to understand how the joints, muscles, tendons and ligaments of the body work together and to spot any problems.

If you haven't had a session with a physiotherapist you should ask your doctor to refer you. Although physiotherapists (often called physios) cannot stop the progression of CMT, they can often spot a potential problem – like any stress you may be putting on other joints like your knees or hips – early enough so that it can be treated and prevented. This can help prevent secondary weakness causing more problems than they need too.

Foot surgery

Although foot surgery is fairly common in people with CMT, it should always be the last resort. Even minor surgery has some risks, whether it's from the surgery itself, the anaesthetic (see page 9) or the recovery period.

Some things to bear in mind before going ahead with any surgery:

- take a friend along with you when you discuss why you need surgery – they can help take notes and remind you to ask all your pre-agreed questions
- make sure that the surgeon doing your operation knows all about CMT. If in doubt talk to CMT United Kingdom
- make sure you find out how long you will take to recover. Will you be able to get around or work doing this time? And will you need help from a physiotherapist to recover? If so, make sure that one is lined up for you.

Operations range from straightening out the toes, particularly the big toe, to fairly major surgery on the ankle joint. Terms you may hear include:

- triple arthrodesis – stabilizing a joint by fusing (welding) three bones together (arthrodesis is another term for 'fusing') – rarely done these days, due to the risk of arthritis in other foot/ankle joints.

Your consent

Before having any treatment, particularly surgery, you will be asked for your consent (permission). And before giving your permission you need to understand:

- *what will happen during the treatment?*
- *why you need it?*
- *what could go wrong?*
- *are there any alternative treatments?*
- *what would happen if you did not have the treatment?*

This is called informed consent and is a legal procedure that all medical staff in the UK should follow before giving you treatment. Even after giving your consent, you are within your rights to change your mind.

- tendon transfers – moving a working tendon and muscle group and attaching the end of the tendon to a new place so that it works in a different manner. Often the tendon/muscle causing the deformity is moved to work in the opposite direction to prevent the chance of deformity occurring again
- osteotomy – cutting the bone and repositioning it. Usually the bone is fixed in its new position with plates, screws and other devices.

Section 3: Aids and adaptations

Occupational therapy

Occupational Therapists (OT) are specialists in helping people live their lives as independently as possible.

At a very basic level, an OT is a specialist in assessing your home and suggesting small, but important adaptations. For example, recognising that a handrail in the bathroom may be all that you need to give you the confidence to have a bath or shower by yourself. Small things like this can make a huge difference in how someone lives and copes with CMT.

In addition an OT will also assess your personal needs and be able to suggest other services or benefits that may help you. He or she may also be in a position to help you get these services.

If you think your life could benefit from the professional assessment of an OT, you should talk to your GP or local social services (social care in Scotland). Alternatively, you can try and approach an OT privately by contacting the College of Occupational Therapy (see listings).

Making changes to your house

If your CMT is making it difficult for you to live independently there are various improvements and adaptations that may be available that could make life easier for you.

You may be able to get help to make these adaptations from your local social services or housing association grants (you may be expected, depending on your income, to pay some of the costs).

- **Disabled facilities grant** – is a mandatory grant (subject to means testing). This means that if an OT from social services believes that changes are really needed then the grant will be made. This grant is designed to make changes to your house to make it easier for you to get into and around your home, or to provide suitably adapted kitchen and bathroom facilities. The grant is mandatory to a limit of £30,000, but your local authority may give you more.
- **Home repair grant** –contact your local authority to find out what they may fund in your area. There are limited resources available.

You may also be interested in a **Home improvement agency** in your local area. They can give you advice on what work needs doing and organise it, including sorting out finances and contractors. The service is free and coordinated by Foundations, the national coordinating body for home improvements (see Section 10).

Mobility aids and wheelchairs

If you ever find getting about tough, don't feel down – there are a large number of mobility aids available to help you, including walking sticks and walkers that may help you get around in the home. Even just cunningly placed handrails around the walls can assist greatly.

Wheelchairs are often most helpful outside of the home, for covering longer distances and for crossing rougher terrain. Look upon this as a way of taking back some freedom of movement out and about, rather than any sort of failure on your part. Wheelchairs are available through the NHS (not social services), but you will need to be assessed by an OT or a physio-therapist, either at your home, in hospital or at your local NHS wheelchair service. You will be helped to decide on the right chair for you by the wheelchair service. If you need a more expensive chair than is on offer, and the therapist agrees, you may be able to get a voucher to pay the difference (only available in England).

If you want an outdoor powered wheelchair or electric scooter, you will almost certainly have to pay for this yourself. If you are on the higher rate of the Mobility Component of the Personal Independence Payments you may be able to buy a wheelchair on preferential terms through Motability. You can get help choosing the right wheelchair for you from the Disabled Living Foundation and Assist UK (formerly Disabled Living Centres Council).

The key to receiving help with getting around out of the house is the Enhanced rate of the Personal Independence Payments (PIP). Not only does this entitle you to money to spend how you wish on transport, but also opens up other benefits and discounts, including:

- Vehicle Excise Duty (Road Tax) exemption. You will need form DLA404 (MLS303 in Northern Ireland) from the Benefits Agency, presented with your car log and form V10. People who only qualify for the standard rate of PIP can claim a 50% reduction in duty. Check out to claim at <https://www.gov.uk/financial-help-disabled/vehicles-and-transport>
- Motability.

Section 4: Keeping mobile

Driving, CMT, the law and insurance

A diagnosis of CMT means that you must tell the Driver & Vehicle Licensing Agency (DVLA) Drivers Medical Group. You must also tell them if your CMT gets worse or you have any changes to your physical abilities.

People with a neurological condition, such as CMT, will have to fill in form B1 and give written consent to the DVLA for them to talk to your doctor and access your personal medical files. (Form B1 can be downloaded from www.gov.uk.)

Failure to inform the DVLA is a criminal offence that may be subject to a fine of up to £1000. Licence holders need to understand that many insurance companies take the view that insurance cover is invalid if a medical condition is not declared to themselves and the DVLA. The majority of people with CMT are considered to be quite safe to drive, both now and in the future and are given a full 'till 70' driving licence, however occasionally the DVLA may put restrictions on your licence or ask you to make adaptations to your car.

Check out <https://www.gov.uk/health-conditions-and-driving> to find out which conditions you must report to the DVLA – CMT comes under the “Peripheral Neuropathy” heading, and if you click on that heading, you can download the relevant form for posting to the DVLA.

If you're unsure about how to manage driving, or what kinds of adaptations you might require, contact your local Regional Driving Assessment Centre provide a complete assessment service. Check out www.mobility-centres.org.uk to find centres around the country who provide this service (See Section 10).

Motability - getting a car or a wheelchair

If you are getting the higher rate of the Mobility Component of PIP (or the War Pensioners' Mobility Supplement) you may be able to get help, on preferential terms with leasing a car. You can also use your PIP to buy a wheelchair or scooter.

Blue Badge

The Blue Badge scheme provides a range of parking concessions for people with severe mobility problems who have difficulty using public transport. The scheme operates throughout the UK, although there are small variations in its application in Wales, Scotland and Northern Ireland from England.

The benefits of the Blue Badge include:

- free use of parking meters and pay-and-display bays in some local authorities

- exemptions (in most cases) from limits on parking times
- parking for up to three hours on yellow lines in England and Wales (unless there are loading or unloading restrictions), there is no time limit on yellow lines in Scotland

Register with Transport for London in advance of your visit. (If you have registered your car with the DVLA as your “primary mobility vehicle” and they have given you exemption from paying road tax, then – if you are in that car – you are also exempt from the Congestion Charge and do not need to pre-register.)

There are certain places that the Blue Badge does not operate; this includes certain city centres (including some London Boroughs), some airports and private roads.

You may be able to qualify for a Blue Badge if you:

- get the higher rate of the Mobility Component of the DLA/PIP (or get the War Pensioner’s Mobility Supplement)
- are registered blind
- drive a motor vehicle regularly, have a severe disability in both arms, and are unable to operate all or some types of parking meter (or would find it very difficult to operate them)
- have a permanent and substantial disability which means you cannot or virtually unable to walk.

To get a Blue Badge you need to talk to your local social services department.

Disabled Persons Railcard

A Disabled Person’s Railcard is valid for 12 months and will give you reduced rates of up to a third. Contact the Railcard Helpline for more information.

If you need help travelling by train, for example getting from your car to the train, contact National Rail enquiries 24 hours in advance.

Many stations have toilets accessible to wheelchair users that are opened with the National Key Scheme key available from RADAR.

Section 5: Disability, benefits and employment

Disability Discrimination Act and employment

Just because you have CMT there is no reason why you shouldn't enjoy the same job prospects as everyone else. This is no longer wishful thinking, but the law.

Under the Disability Discrimination Act (DDA), passed in 1995 and significantly extended in 2005, anyone who has a progressive condition, like CMT, can classify themselves as disabled as soon as the condition has an effect on their everyday activities. You are then entitled to protection under the law, requiring employers to make suitable adaptations so you can continue working.

If you're having difficulties at work, contact the Disability Employment Adviser (DEA) at your local JobCentre Plus. DEAs can assist with many aspects of keeping you in work, working with your employer to make adjustments as necessary to your workplace.

If you ever face discrimination, in addition to groups like the Disability Alliance, you can also contact the Equality and Human Rights Commission. They have a comprehensive website and a helpful telephone helpline. See Section 10 at the back of this leaflet for more details.

Aims of the DDA

The DDA was passed to help end the discrimination that many people with a disability face. It protects people in:

- *employment*
- *getting access to goods, premises and services*
- *the management, buying or renting land or property*
- *education*
- *motoring and transport*
- *health*

Disability Living Allowance – for children

The allowance looks at the help you need, rather than the condition you have, and has two strands to it:

1. help with personal care
2. help with your mobility out of the house on a daily basis.

The benefit is tax-free, and not income related and is for children up to the age of 16.

To get the benefit you will need to fill in an extensive questionnaire to work out what care or mobility needs your child may have, or you can choose to have a medical examination.

It's worth noting that the benefit cannot be backdated – so get any application formally dated when it is sent out as there is usually a six week turn round period. If your claim is successful, then the benefit will be paid from the date on the form.

Personal Independence Payments

Personal Independence Payments has replaced replacing DLA as from 2013. From June 2013, all new claimants and all people requiring a review of their DLA claim will be assessed under the tougher PIP application process. People with an “indefinite” award of DLA will be reassessed between 2015 and 2018. Like DLA, PIP is awarded for “daily living” and “mobility” and can be awarded at two levels for each, standard and enhanced rates. The award is based on a questionnaire and should include a face-to-face interview, either in your own home or at an assessment centre.

Extra benefits like automatic entitlement to a Blue Badge, Road Tax exemption and the like will be based on the claimant receiving the enhanced rate of the mobility element.

PIP is only applicable to adults between 16 and 65. Children will remain on DLA until they turn 16.

Other benefits

Benefits for disabled people are constantly changing so it is impossible to give a full list. Check out www.gov.uk for the full list. However main benefits, apart from DLA/PIP, include:

- Attendance Allowance – a weekly benefit for people aged 65 or over who need a lot of help with personal care because of illness or disability.
- Child Tax Credit – has replaced the child-related payments in the Disabled Person's Tax Credit.
- Working Tax Credit – a tax credit to top up the earnings of working people and will replace the Disabled Person's Tax Credit

- Employment and Support Allowance – gives working age people a replacement income when they become sick or disabled and stop working or looking for work. You get it through a medical certification followed by a medical test known as the Work Capability Assessment. There are two levels – the Work related assessed group (WRAG) for people who may reasonably be expected to move towards returning to work with suitable support in the future, and the Support Group for people who cannot be expected to work. Both groups will be subjected to regular reviews, although the support group probably less than the WRAG.
- Value Added Tax (VAT) – there are a wide range of VAT relief for things bought by people who are disabled. You can find out more information in VAT Notice 701/7 VAT Reliefs for People with Disabilities – available from your local VAT Business Advice Centre (in your phone book under ‘Customs & Excise’).

Section 6: Holidays, accommodation and leisure

Holidays and accommodation

If you're planning to get away, either in the UK or abroad, and you'd like a bit of help in making sure your holiday is what you want, don't feel that you're alone. There are a number of specialist organisations that will help you book the right holiday.

Additionally, in the UK there is the National Accessible Standards for tourist accommodation. Accommodation providers are independently assessed and given a rating.

The ratings are split into three categories for:

- a Mobility impaired and disabled people
- b Visually impaired and blind people
- c Hearing impaired and deaf people

For more information visit the Visit Britain website. Alternatively contact Holiday Care, the UK's central source of information on travel and holidays for disabled people in the UK and abroad.

Both these organisations, along with others are listed in Section 10.

Leisure

After dealing with work, your house, various benefits and having a holiday, you probably need a break and a way to relax and may be thinking of a leisure activity to unwind with.

If you're after something physically challenging, there are various sports organisations for the disabled. The sports they cover include, water-skiing, horse riding and scuba diving to name but a few. Ultimately, you are the best guide to what you can or can't do. If it hurts, stop. Remember, if ever in doubt about whether you should take part, talk to your GP, physiotherapist or the instructor at the sports facility – just remember that he or she understands what CMT is.

For a more sedate approach to leisure time, there are numerous art-based organisations about to help you enjoy culture, even if you do have difficulty getting around.

Or, if you're after ways of staying in the garden there are companies that can help you with specially designed tools and techniques. One of them, the charity Thrive, offers a range of advice and information, including a website called www.carryongardening.org.uk

It is just not possible to go through all leisure activities, but your local organisation of people with disabilities may help you with activity that gives you most pleasure.

You can also contact your local authority social services department and leisure department to see what is available. Many swimming pools and sport centres have special facilities and organised sessions especially designed for people with a disability.

See Section 10 for a list of helpful organisations.

Section 7: Individual Personal Issues

Sexual relationships

If you want to talk to someone about personal or sexual relations there are a number of places you can turn to, including:

- your GP
- specialist voluntary organisations that help people with either family planning, relationship or sexual issues.

Having a baby

In the vast majority of cases there will be no reason why you shouldn't decide to have children of your own. However, there are three issues you need to think about:

1. If you or your partner has CMT then there is a 50% chance that you will pass the condition onto your child.
2. Pregnancy and labour rarely may cause your symptoms to worsen.
3. Your antenatal team needs to be fully aware of the implications of CMT.

Passing on CMT to your child

Because CMT is a genetic condition it is usually inherited from parent to child down the generations. Ultimately the decision is yours, but depending on what type of CMT you have (see the separate leaflet 'What is CMT') there is a 50% chance of passing it onto your child. Talk to your doctor if you are unsure.

There are options for people with CMT – such as antenatal testing of the placenta (chorionic villus sampling or CVS) or even pre-implantation genetic diagnosis (PGD) – effectively IVF, but only reimplanting embryos without CMT. However, CVS would only be done if a positive result would definitely result in termination, and PGD is a costly process, both for the NHS and emotionally – so both need careful consideration. A referral to a genetics counsellor is essential if you would definitely like to avoid having a child that may have CMT.

Possible problems in pregnancy

Pregnancy can be hard work for any woman due to the extra strain on the body. For the majority of women with CMT there should be no specific problems. Difficulties you may face include:

- if you already have walking difficulties before the pregnancy, they may be worse in late pregnancy

- if you already have hand weakness then there may be problems after you've given birth, for example handling the child or breastfeeding.

CMT and your antenatal team

As with other healthcare professionals, most staff on the labour ward will not be familiar with CMT, so you may have to spend some time telling them. Get them to read some of the leaflets available from CMT United Kingdom.

Most women with CMT will have no problems using the usual pain relievers – including gas (entonox), pethidine or vaginal injections – available in labour. However you should make sure that your midwife and doctors understand that CMT is a neurological condition, in particular if you are thinking of having an epidural (a strong local anaesthetic injected into the base of your spine). See the section on anaesthetics on page 9.

Caesarean sections

Some women with CMT choose to have a caesarean section. Again this is a decision for you to make with your healthcare team depending on your own personal situation.

If, for whatever reason, you decide not to have your own children, you may be interested in fostering or adopting a child. There is a huge need for carers nationally. If you're interested, contact your local council or one of the organisations listed in Section 10.

Section 8: Information for carers

If you are caring for someone with a disability or illness you may be able to get some support and help in your own right. This could include benefits, information, money towards a holiday, general support or even a trained carer to help you out or give you a break.

Some of the state benefits that are available to carers include:

Carers Allowance – may be available to you if you are looking after someone who is severely disabled, a disabled child or an elderly person, and you are caring for them for more than 35 hours per week.

Council Tax Benefit – some carers and disabled people can get reductions in Council Tax depending on their level of income.

You can find out more about what benefits are available to you by contacting your local Citizens's Advice Bureau or checking www.gov.uk, or contacting your local social services.

Section 9: Information for parents

Being a parent of a child with CMT can be challenging, particularly if you have CMT yourself. You may have concerns about the progression of your child's disability or you may be worried about how your child is going to get on in school.

There are networks of parents who can offer support, advice and, in some cases, grants, and the Disabled Parent's Network and Contact a Family can be particularly helpful.

Education

You will need to discuss your child's CMT and any resulting disability with her or his teachers to ensure the school is aware of your child's needs. A fine line exists between expecting too much from a child and being overprotective, both for well-intentioned parents and teachers alike. (It's worth noting that the recent Special Educational Needs and Disability Act 2001 gives parents and pupils extra rights to be included in mainstream schools.)

An excellent source of information on all aspects of the maze of rules and regulations surrounding education is the Muscular Dystrophy Campaign's comprehensive publication, 'Inclusive Education'.

Contact a Family is another charity for people with a disabled child (any sort of disability) and they have excellent resources to assist you with benefits, education and any other problems you may have in parenting a child with CMT.

Further help

As a parent you may also come under the category of 'carer' so do read about the support available on page 32 in the section above.

You may also find that the Disability Living Allowance (DLA) is available for your child.

In addition to the professional carers mentioned on page 10 (Section 1: Healthcare professionals) you are likely to build up a relationship with your local paediatrician – a doctor who specialises in the health of children. Just make sure that any paediatrician you are dealing with has a good understanding of CMT in particular and neurological issues in general.

Section 10: Useful information

Organisations that may be able to help

This is not an exhaustive list, but should provide you with a good starting point to find the information and support you're looking for. If you have any suggestions for other organisations that ought to be added, let us know (see our contact details below).

General sources of help and information

CMT United Kingdom – the national charity of and for people with CMT. It offers information, publications and support to people with CMT, their friends, family and carers. CMT United Kingdom, 3 Groveley Road, Christchurch, BH23 3HB Tel: 0800 6526316; Web: www.cmt.org.uk; Email enquiries@cmt.org.uk

Disability Alliance – for information on benefits and your rights you can't get much better than the Disability Alliance. They also publish (for £17.00 or £14.00 for those receiving benefits) the 'Disability Rights Handbook' referred to as the 'bible' for disability issues. Disability Alliance, Universal House, 88-94 Wentworth Street, London E1 7SA; Tel 020 7247 8776; Web: www.disabilityalliance.org

Gov.UK – the website that is supposed to bring together all the government services into one place. Web: www.gov.uk

Disabled Living Foundation – offers a great deal of information, basically has five roles:

1. Information on disability equipment
2. Factsheets on buying the right equipment for you
3. Contacts database of useful information
4. Helpline for queries about equipment for individual living
5. A permanent showroom (not for sales) so you can try equipment out.

Disabled Living Foundation, 380-384 Harrow Road, London W9 2HU; Tel: 0845 130 9177, www.dlf.org.uk

Muscular Dystrophy UK – provides practical, medical and emotional support to people with all forms of muscular dystrophy and has a wealth of excellent information and publications that are relevant to people with CMT. Contact them at, Muscular Dystrophy UK, 61A Great Suffolk Street, London, SE1 0BU; Tel: 020 7803 4800; Web: www.musculardystrophyuk.org; Email: info@musculardystrophyuk.org

Organisations for physical and mental well being (Section 1):

BackCare – the charity for healthier backs with lots of information available. Tel: 020 8977 5474; Web: www.backcare.org.uk

Chartered Society of Physiotherapists – mainly a professional body, but some limited information for the general public. They can help you find a private physio in your area. Enquiry Service: 020 7306 6666; Web: www.csp.org.uk ; Email: enquiries@csp.org.uk

Expert Patients Programme – Training and support for people with a long-term medical condition. Tel: 020 7922 7860; Web: www.expertpatients.co.uk ; Email: get.info@eppcic.co.uk

Pain Concern – Information and support for people who suffer from pain. They offer a Listening Ear helpline – a chance to talk to another pain sufferer. Tel: 01620 822572 (9.00am – 5.00pm Mon- Fri, and 6.30-7.30pm Fri); Web www.painconcern.org.uk ; Email: info@painconcern.org.uk

Royal College of Anaesthetists – mainly a professional body, but with some excellent free information on having anaesthetic. They have a whole website targeted at people worried about having an anaesthetic. Tel: 020 7092 1500; Web: www.rcoa.ac.uk ; Email: info@rcoa.ac.uk

Weightwise – website from the British Dietetic Association (see above) on healthy eating for a healthy weight. Web: www.bdaweightwise.com

Organisations for foot management (Section 2):

British Association of Prosthetists and Orthotists – the professional body for orthotists, unfortunately it does not have any general information for the general public, but can help you find a private orthotist. Tel: 0845 166 8490; Web: www.bapo.com ; Email: lorna@bapo.com

Institute of Chiropodists and Podiatrists – has some general information for the general public on good foot care and orthoses on its website and can help you find a private chiropodist in your area. Tel: 01704 546141 . Web: www.iocp.org.uk

Chartered Society of Physiotherapists – see Section 1.

British Orthopaedic Foot Ankle Society – can help you find an orthopaedic surgeon who specialises in foot/ankle surgery www.bofas.org.uk

Organisations for aids and adaptations (Section 3):

Assist UK – free and ethical advice and information about products that can help you stay independent. Tel: 0870 770 2866; Web www.assist-uk.org ; Email: general.info@assist-uk.org

British Association of Occupational Therapists – some general information, but the Association recommends that you contact your GP to find an OT, unless you are able to go private. Tel: 020 7357 6480; Web: www.cot.co.uk

Foundations – national coordinating body for home improvements agencies in England. Tel: 01457 891909. Web: www.foundations.uk.com
For Wales: Care and Repair Cymru. Tel: 029 2057 6286
For Scotland: Care and Repair Forum Scotland. Tel: 0141 221 9879
For Northern Ireland: Fold Housing Association. Tel: 02890 428314

Leonard Cheshire Foundation – a provider of services to people with disabilities. Tel: 020 3242 0200; Web: www.lcdisability.org ; Email: info@LCDisability.org

Motability - the government funded charity that can, if you are on the higher level of the Mobility Component of the Disability Living Allowance, help you buy or loan a car or an electric wheelchair. Tel: 0845 4564566; Wheelchair and Scooter Scheme – Tel 0845 6076260; Web: www.motability.co.uk

National Centre for Independent Living – information and advice on all aspects of independent living. Tel: 0207 587 1663; www.ncil.org.uk ; Email: ncil@ncil.org.uk

Social Servies – contact your local authority

Organisations for keeping mobile (Section 4)

AA – along with the RAC is the main motoring organisation in the UK. Has a disability helpline and discounts for Blue Badge holders. The AA operates a priority response for drivers who breakdown and feel vulnerable, for whatever reason. Tel: 0800 262050; Web: www.theaa.com

DVLA – www.gov.uk Download the relevant form from the “peripheral neuropathy” page.

Forum of Mobility Centres – for advice about your driving, the forum will direct you to the centre nearest to where you live. Tel: 0800 559 3636 (open 9am-5pm Monday-Friday); Web: www.mobility-centres.org.uk

Disabled Motoring UK – offers support and information of all issues to do with disabled driving. Tel: 01508 489449 Web: www.disabledmotoring.org

Disability Rights UK – for the National Key Scheme. Tel: 020 7250 3222; Web: www.disabilityrightsuk.org – purchase the excellent Disability Rights Handbook from here and RADAR keys

National Rail Enquiries – for information on travel, including help travelling. Tel: 08457 484950; Web: www.nationalrail.co.uk

RAC – along with the AA the Royal Automobile Association is the main motoring organisation in the UK. Tel : 08705 722722 www.rac.co.uk

Railcard Helpline – for Disabled Person’s Railcard. Tel: 0845 605 0525; Web: www.disabledpersons-railcard.co.uk

Transport for London – Tel: 020 7222 1234; Web: www.tfl.gov.uk ; Email: travinfo@tfl.gov.uk

Organisations for Disability, employment and benefits (Section 5):

Citizens Advice Bureaux – with a network of local offices throughout the UK this is one of the best places to find out what is available to you in your local area. Find your nearest Bureau in your phone book. Web: www.adviceguide.org.uk

Department of Health Publication Line – see Section 1

The Disability Alliance – see Section A

Equality and Human Rights Commission – this new commission brings together the work of the Disability Rights Commission, Equal Opportunites Commission and Commission for Racial Equality. Helpline Tel: 0845 604 6610 (England), 0845 604 5510 (Scotland), 0845 604 8810 (Wales);
Web: www.equalityhumanrights.com

Jobability – run by the Leonard Cheshire Foundation and totaljobs.com this is the main disability jobs website. Web: www.jobability.org

JobCentre Plus – find your local JobCentre Plus in the phone book. All JobCentre services online are now found at www.gov.uk

Organisations for holidays, accommodation and leisure (Section 6):

Visit Britain – the British Tourist Board. Tel: 020 8846 9000; Web: www.visitbritain.com

Social Services – may be able to help you with holidays and transport.

Family Holiday Association – gives money towards holidays and transport, but your social worker needs to apply on your behalf. Tel: 020 7436 3304; Web: www.familyholidayassociation.org.uk ; Email: info@FamilyHolidayAssociation.org.uk

Vitalise – respite for carers and holidays for people with severe disabilities at their centres in the UK and abroad. Tel: 0845 345 1972; Web: www.vitalise.org.uk ; Email: info@vitalise.org.uk

Leisure

Sport

Disability Sport Wales – Tel: 0845 045 0904; Web: www.disabilitysportwales.org ; Email: scw@scw.org.uk

British Canoe Union – Web: www.bcu.org.uk

British Ski Club for the Disabled – Web: www.bscd.org.uk

British Disabled Water-ski Association – Tel: 01784 483664; Web: www.bdwsa.org ; Email: info@bdwsa.org

Riding for the Disabled – Tel: 0845 658 1082; Web: www.rda.org.uk

Scottish Disability Sport – Tel: 0131 317 1130; Web: www.scottishdisabilitysport.com ; Email: admin@scottishdisabilitysport.com

Sport England – includes advice for disabled sporty people <http://www.sportengland.org/our-work/disability/>

Art

Arts Council of England – offers details of organisations involved in arts and disability issues. Tel: 0845 300 6200; Web: www.artscouncil.org.uk

Artsline – free information and advice for disabled people on arts and entertainment in London. Tel: 020 7388 2227; Web: www.artsline.org.uk ; Email: admin@artsline.org.uk

Arts Council of Wales – Tel: 029 2037 6500; Web: www.artswales.org.uk

Scottish Arts Council – Tel: 0845 6036000; Web: www.sac.org.uk

Shape – runs workshops, projects, events and courses. Tel: 0845 521 3457; Web: www.shapearts.org.uk

Gardening

Thrive – gives training courses, advice and information on gardening as a therapy as well as advice for disabled gardeners. Tel: 0118 988 5688; Web: www.thrive.org.uk ; Email: info@thrive.org.uk

Organisations for individual personal issues (Section 7):

Disabled Parents Network – support and information for parents who are also disabled. Tel: 0300 3300639; Web: www.disabledparentsnetwork.org.uk ; Email: information@disabledparentsnetwork.org.uk

Disability, Pregnancy and Parenthood International – Tel : 0800 0184730; Web: www.dppi.org.uk ; Email: info@dppi.org.uk

Outsiders – a nationwide self-help, community where people meet up and practice socialising. Sex and disability helpline: 0707 499 3527; Web: www.outsiders.org.uk

Regard – information and support for gays and lesbians with a disability. Web: www.regard.org.uk ; Email: secretary@regard.org.uk

Relate – counselling for adult couples (whether married or not) who are having relationship difficulties. Tel: 0300 100 1234; Web: www.relate.org.uk

British Association of Adoption and Fostering – Tel: 020 7421 2600; Web: www.baaf.org.uk ; Email: mail@baaf.org.uk

Fostering Network – Tel: 020 7261 1884; Web: www.fostering.net ; Email: info@fostering.net

Organisations for carers (Section 8):

Benefits Enquiry Line for Disabled People – 0800 882200

Carers Online – produced by Carers UK provides carers and those supporting them with local and national information. CarersLine 0808 808 7777; Web: www.carersuk.org ; Email: info@carersuk.org

Citizen's Advice Bureau – find your local office in your phone book or through the national website of Citizen's Advice Bureau: www.adviceguide.org.uk

Carers Trust – help support and advice for carers. Tel: 0845 450 0350; Web: www.carers.org

Vitalise – respite for carers and holidays for people with severe disabilities at their centres in the UK and abroad. Tel: 0845 345 1972; Web: www.vitalise.org.uk ; Email: info@vitalise.org.uk

Social Services – contact your local social services to find out what support is available to you.

Organisations for parents (Section 9)

Contact a Family – by bringing together families with children with disabilities they offer support, advice and shared experiences. Tel: 0808 808 3555; Web: www.cafamily.org.uk ; Email: helpline@cafamily.org.uk

National Childrens Bureau – acts as an umbrella organisation of many organisations concerned with helping children with a disability. Tel: 020 7843 6000; Web: www.ncb.org.uk

Muscular Dystrophy UK – see their excellent ‘Inclusive Education’ (see section A)

Parents for Inclusion – parents helping parents so their disabled children can learn, make friends and have a voice in ordinary schools and throughout life. Tel: 0800 652 3145; Web: www.parentsforinclusion.org ; Email: info@parentsforinclusion.org

Social Services – your local social services should be able to provide help for you and your child, including home visits, advice, information on local nurseries, childminders or playgroups, respite care and loan of equipment and play materials.

Glossary

This is just a brief explanation of terms you are likely to hear. If you ever hear something you don't understand make sure you are given a full explanation of what it is and what it means. It could be important.

Anaesthetic – an agent that reduces or stops sensation. It can either be general (whole body) or local (affecting a particular part of the body).

Atrophy – wasting away. Usually refers to the muscles.

Chirpodist/Podiatrist – foot care specialists.

GP – general practitioner. A doctor who is a general health specialist. They are the gateway to most other health and social services.

Neurologist – specialists in nervous system disorders.

Neurology – the study of the nervous system.

Neuropathy – any disease of the peripheral nervous system.

Occupational Therapist (OTs) – independent living specialists.

Orthopaedic – to do with bones.

Orthopaedic surgeons – surgeons specialising in correcting skeletal problems – including legs/ankles/shoulders, etc

Orthosis– a mechanical device which provides very specific support to your joints and weakened limbs.

Orthoses – plural of orthosis

Orthotics – the assessment of patients using biomechanical principles to design, provide and monitor the ongoing use of orthoses

Orthotist – specialist foot support manufacturers.

Osteotomy – cutting the bone and repositioning it.

Paediatrician – child health doctors.

Peripheral – when talking about nerves (neurology), means nerves in the arms and legs (away from, on the periphery of, the central nervous system).

Pes cavus – medical name for a highly arched foot.

Physiotherapist (physios) – movement specialists.

Progressive – when talking about a disease, is the term used to explain that the disease gets worse (cannot be stopped).

Scoliosis – sideways curving of the spine

Tendon transfers – moving a working tendon and muscle group and attaching the end of the tendon to a new place so that it works in a different manner. Often the tendon/muscle causing the deformity is moved to work in the opposite direction to prevent the chance of deformity occurring again.

Triple arthrodesis – stabilising a joint by fusing (welding) three bones together (arthrodesis is another term for 'fusing').

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Want to find out more?

The information in this booklet has come from three sources:

1. The medical advisors above
2. The books and leaflets listed below
3. The specialist organisations listed in Section 10.

What is CMT, CMT United Kingdom 2014

Charcot-Marie-Tooth: A Practical Guide, (3rd edition) CMT United Kingdom, April 2015

Charcot-Marie-Tooth Disease, Muscular Dystrophy UK, October 2004

The Disability Rights Handbook, Disability Alliance 2004

A Practical Guide for Disabled People and Carers, Department of Health 2004










NHS Clinical Knowledge Summaries (www.cks.library.nhs.uk)

Best Health (www.besthealth.bmj.com) (previously Best Treatments – clinical evidence for patients)

To find out more about any of the subjects covered in this booklet, you can get copies of the titles listed above from the organisations listed in Section 10 direct.

This is a publication produced by CMT United Kingdom.

We also produce a range of leaflets dealing with various aspects of CMT disease which are available to members of CMT United Kingdom.

-  CMT United Kingdom Awareness Leaflet
 -  What is CMT
 -  A Young Persons Guide to CMT
 -  Fact Sheet 1 – Holiday Insurance
 -  Fact Sheet 2 – Holidays
 -  Fact Sheet 3 – Benefits
 -  Fact Sheet 4 – Legacies
 -  Fact Sheet 5 – A Guide for Teachers
- produced by CMT United Kingdom
-  Charcot-Marie-Tooth Disease

produced by the Muscular Dystrophy UK
✚ Getting the best from Neurological Services
produced by the Neurological Alliance

And of course, our book, Charcot-Marie-Tooth: A Practical Guide, available from the webshop at www.cmt.org.uk or by phone 0800 6526316

So why not join us at CMT United Kingdom?

- ❖ Receive the full colour magazine, ComMent – packed full of information on CMT and how to live with it – published three times per year
- ❖ Subsidised rate to Annual Conference with AGM, and speakers from the Medical Profession.
- ❖ Additional In-Depth Information about CMT available exclusively to members.
- ❖ Phone a committee member for advice or help.
- ❖ Membership card which doubles as a medical alert card – additional cards available for family members.
- ❖ Activities for children which include a Young Persons Weekend.
- ❖ Local contacts and groups around the UK.

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