



# The Role of the nurse in supporting patients through practical issues

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# Aim of today's talk

- To provide practice advice on symptom management.
- How to obtain help.
- Services available.
- Making the most of the benefit system in place to help.

# Links with Other health care and social care professionals



# How do I stop my feet hurting?

- Looking after your feet.
- Avoid injury.
- Attend a chiropodist or podiatrist on a regular basis.
- Corns and calluses.
- Attend for orthotic review on a regular basis.
- Take care when choosing new foot wear.
- Take adequate pain relief.
- Rest you feet when possible.
- Attend for surgical review if you have sever deformity which may be helped by surgery
- Keeping Feet warm.



# Physiotherapy and foot care

There is currently no cure for CMT. However treatments can help relieve symptoms, aid mobility and increase the independence and quality of life for people with the condition.

## **Physiotherapy**

- Physiotherapy is one of the most important therapies for improving the symptoms of CMT and reducing the risk of muscle contractures (where muscles shorten and lose their normal range of movement).
- Physiotherapy uses physical methods, such as massage. It usually involves low-impact exercises such as stretching, swimming and moderate weight-training.
- **Aerobic exercise**
- **strengthening exercises.**
- **posture and balance exercises.**

Any exercise needs to be carefully planned as part of a personalised exercise programme. A certain level of exercise may be safe, but you risk making symptoms worse if you don't follow proper instructions or if you over-exert yourself.

**Referrals to physiotherapy** Can be made by the G.P. your neurologist at your out patient appointment or privately

# Handy hints for foot care

- **Clarks odd shoe scheme.** This service is currently offered in selected Clarks stores. To check which ranges and services are available in your local Store, use the [Store Locator](#) or contact Customer Care on 01458 899901 for further information [www.clarks.co.uk](http://www.clarks.co.uk)
- [www.cosyfeet.com](http://www.cosyfeet.com) Cost feet provide extra wide shoes which could potentially provide enough room for some orthotics. It is also possible to claim back V.A.T. on foot wear for some medical conditions.
- [www.taylormadeshoes.co.uk](http://www.taylormadeshoes.co.uk) Hand made shoes and boots.
- Information on the treatment of corns and calluses can be obtained from [www.nhs.uk/conditions/CornsandCalluses](http://www.nhs.uk/conditions/CornsandCalluses) useful information
- [www.nhs.uk/conditions/chilblains](http://www.nhs.uk/conditions/chilblains) useful information
- [www.raynauds.org.uk](http://www.raynauds.org.uk) The Raynauds and scleroderma web site has a useful product page to help keep your feet and hands warm.
- <http://www.amazon.co.uk> for grippers for your shoes in the ice and snow

# Handy hints

- [www.nhs.uk/livewell/fitness/pages/pilates](http://www.nhs.uk/livewell/fitness/pages/pilates).
- Exercise on prescription.
- [www.nhs.uk/change4life](http://www.nhs.uk/change4life)
- <http://www.swimming.org/poolfinder>
- <http://www.amazon.co.uk/s/> pool shoes may help you feel more confident when walking in the swimming pool area and less likely to slip
  
- Getting to the gym or the local swimming pool can be difficult if you don't drive depending where you live you may be able to apply for:
- Black Taxi card [www.transportforall.org.uk/d2d/taxicard](http://www.transportforall.org.uk/d2d/taxicard) London
- Membership of dial a ride [www.tfl.gov.uk/modes/dial-a-ride](http://www.tfl.gov.uk/modes/dial-a-ride) London
- Your local council may have a taxi card scheme which can help you with a subsidy for some of your journeys .

# Orthotics

- It is important that you attend an orthotics clinic to ensure that you have the most appropriate orthotics for you as an individual.
- Your Orthosis (A.F.O.) will be designed to control the foot and ankle, but can also affect your knees, your posture and balance.
- Privately made orthotics [www.dorset-ortho.com/contact](http://www.dorset-ortho.com/contact) for *silicone orthotics*
- *Letters of support.*





# Managing with weak hands

- Preventing injury
- Writing
- Work place
- Adapted equipment
- Physiotherapy and exercise. Hand clinic
- Splinting
- Possible surgery
- [www.rnoh.nhs.uk/clinical-services/peripheral-nerve-injury-unit](http://www.rnoh.nhs.uk/clinical-services/peripheral-nerve-injury-unit) Mr Anthony Macquillan Referrals can be made via your G.P. or local neurologist if they think that surgery may be an option for you.



# Protect your hands from burns

- THERE ARE ALL SORTS OF SAFTY EQUIPEMENT THAT WILL HELP YOU PROTECT YOUR HANDS FROM BURNS.



# Where to find the equipment you need

- <http://asksara.dlf.org.uk/>
- <http://www.dlf.org.uk/> go to the bottom of the page and click on living made easy
- <http://www.clos-o-mat.com/index.php/products/shower-toilets.html>  
<http://www.cot.co.uk/leaflets/leaflets> **These leaflets explain how occupational therapy can help you or someone you know get the most from life despite accident, illness or ageing.**



# Fatigue management

- Many CMT sufferers complain of fatigue.
- Strategies that may help:
- Take regular rest periods. Including getting a good nights sleep.
- Forward planning
- Prioritising activities.
- Exercise.
- Start with a small amount of exercise. Build up your physical activity gradually over weeks and months until you reach the recommended goal of two-and-a-half hours of moderate-intensity aerobic exercise, such as cycling or fast walking, every week. If you are able to do this. Alternative exercise may be swimming
- Ask your G.P. neurologist physiotherapist or O.T. for a referral to a specialist fatigue management course.
- Don't be afraid to ask for a work place assessment.



# Mood

- **Cognitive behavioural therapy (CBT) is a talking therapy that can help you manage your problems by changing the way you think and behave.**
- It is most commonly used to treat [anxiety](#) and [depression](#), but can be useful for other mental and physical health problems.
- CBT cannot remove your problems, but it can help you deal with them in a more positive way. It is based on the concept that your thoughts, feelings, physical sensations and actions are interconnected, and that negative thoughts and feelings can trap you in a vicious cycle.
- CBT aims to help you crack this cycle by breaking down overwhelming problems into smaller parts and showing you how to change these negative patterns to improve the way you feel.
- Unlike some other talking treatments, CBT deals with your current problems, rather than focusing on issues from your past. It looks for practical ways to improve your state of mind on a daily basis.
- [\*\*Mind Over Mood: Change How You Feel By Changing the Way You Think\*\*](#)  
10 May 1995 by Aaron T Beck and [Dennis Greenberger](#)

# Driving

- It is a legal requirement to inform DVLA of your neurological condition failure to do so could result in a £1000 fine.
- The information that you need is on the DVLA website under medical links. You will need a CN1 form [www.gov.uk/peripheral-neuropathy-and-driving](http://www.gov.uk/peripheral-neuropathy-and-driving)
- If you have a heavy goods licence or public vehicle licence you will need to discuss this with DVLA you may need to take more frequent health checks to maintain your licence.
- You may have what is referred to as a granddad licence if this is the case you will currently be able to drive vehicles up to 7.5 tons when you get your new licence back check on [www.gov.uk/view-driving-licence](http://www.gov.uk/view-driving-licence) which will instantly tell you what you are able to drive as this may have been reduced to 3 tons.
- You may also be wise to check your car insurance policy
- If you have difficulty walking you may wish to apply for a Blue badge to make parking easier.
- Young people who are disabled may be able to start driving lessons a year earlier at 16
- Help with the cost of driving lessons may be available <http://www.motability.co.uk/understanding-the-scheme/financial-help/eligibility-for-financial-help>
- The Forum of mobility may be able to assist you in the assessment of adaptations that you need for your car to make it easier and safer to drive <http://www.mobility-centres.org.uk/>

# Benefits available to help you manage and optimise your enjoyment of life.

- Personnel independent payments
- Carers allowance
- Attendance allowance You could get extra Pension Credit, Housing Benefit or Council Tax Reduction if you get Attendance Allowance - check with the helpline or office dealing with your benefit. Telephone: 0345 605 6055 open Monday to Friday 8-6pm
- ESA employment support allowance.
- Disabled student allowance. You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.
- Over 24 learning loans.
- Access to work

# Who can help you

- The disability employment adviser at the job centre plus
- Assist with helping you back to work.
- Assist with helping you to access courses that will assist you either to get back into work or what retraining may be available to you if you feel that the job that you are doing now may not be suitable for you in the future.
- How to apply for the access to work benefit.
- How to arrange an assessment of your work station at your place of employment.
- How your employer can be supported in changing your environment to make your working life easier. Advice can be given on meeting the cost for the changes through access to work.
- They will also be able to tell you of disabled friendly employers in your area.
- <https://www.gov.uk/looking-for-work-if-disabled/looking-for-a-job>



# Who else can help me?

- <http://www.shaw-trust.org.uk/individuals/helping-disabled-and-disadvantaged-people/> Shaw Trust is a national charity that helps people to experience work, find a job and live more independently
- [www.adviceguide.org.uk/get\\_advice.htm](http://www.adviceguide.org.uk/get_advice.htm) ( citizens advice bureau) may be able to assist you with the completion of form filling.
- Your specialist nurse local neurologist or G.P. may be able to assist in the provision of additional information related to your CMT when making applications.



# Social care.

- <https://www.gov.uk/apply-needs-assessment-social-services>
- **Apply for a needs assessment by social services**
- A health and social care assessment is carried out by social services to find out what help and support you need - like healthcare, equipment, help in your home or residential care.

## **What you need to know**

- Available in England and Wales only

## **Services can include:**

- home care help with things like cleaning and shopping
- disability equipment and adaptations to your home
- day centres to give you or the person who cares for you a break
- day care for your child if either you or they are disabled
- care homes

**THE END**



**Thanks for  
listening!**

**Any Questions?**

**No?**

**SUPER!**