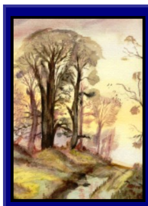


Price £ 3.75 (Free to members)

Pathways

The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Welcome to Pathways 43.

Another name for ME/CFS?

In a document *Beyond Myalgic Encephalomyelitis Chronic Fatigue Syndrome Redefining an Illness* released in February 2015, the US Committee on Diagnostic Criteria for ME/CFS came up with a tighter definition for ME/CFS, and also with a suggestion of a new name Systemic Exertion Intolerance Disease or SEID. Will it make a difference in the UK? Possibly not, unless NICE adopts it. In any case, it just another name to add to many on the list. We are not interested in medical politics.
At Leger ME we are interested in our members, and how we can help them now.

Features in this issue.

Page	Feature	About
2	**You Write**	Leger ME members write in
3	**ME/CFS Management Scottish Style**	A Review of good practice from North of the Border
5	**Making Ends Meet on Reduced Income**	With thanks to Benefits and Work Forum
9	**The Varicella-Zoster Virus Infections**	When the Varicella-Zoster Virus infects humans
11	**Thyroid Connections and some Interesting Books.**	A review by Elizabeth A McDonagh
13	**Abdominal Aortic Aneurism**	A feature about a new local Screening Service
14	**Recipe Corner**	Popular feature by Carolyn
15	**Another Look at Pacing for ME/CFS management.**	Compiled with assistance from the local ME/CFS clinics
18	**Out & About around Doncaster**	Local English Heritage managed sites
19	**Thyroid: The correct prescribing of thyroid hormones**	Independent Opinion by Dr. Sarah Myhill
22	**More on Thyroid Hormones & ME/CFS**	Further clarification by Mike
23	**North of Doncaster on Austin Wildlife Rescue**	A Personal Experience by Trevor Wainwright

You Write by Leger ME members

Ross Writes; - Have you seen the feature ‘sanctions deaths should be independently investigated'?

Sanctions are cuts in benefits applied where a claimant does not comply with the wishes of the DWP. Yes, there has been a lot of publicity about people dying because their benefit have been cut or been stopped, particularly with suicides. Also there have been reports of people being declared fit for work while in intensive care for example. The DWP people take the view that it is the claimants' responsibility to comply with their requirements and keep in touch. The system falls down particularly with people with mental health problems or emergency hospital admissions. Also, it is not the NHS or the doctor's job to inform the DWP. So what can you do about it? Well, if you are aware of a problem you could always take action. If you are a neighbour or relative you should be prepared to take action. With Leger ME members, providing people stay in touch sanctions shouldn't be a problem.

Carol writes— I've heard that, for certain conditions, claimants are to be automatically treated as having limited capability for work-related activity. In other words they don't really have to fill-in in the ESA 50 forms and go for a medical. At a tribunal which I won incidentally, all it said was section 29 applies. Why did I have to go through all the medicals and go through a tribunal if that applied?

You are right and I agree that should happen. However the DWP are laws unto themselves. There is a particular clause which I think should apply to ME/CFS. Part of section 35 goes as follows:

‘If the claimant suffers from some specific disease or bodily or mental disablement; and by reasons of such disease or disablement, there would be a substantial risk to the mental or physical health of any person if the claimant were found not to have limited capability for work-related activity'.

I think that this clause could apply say if someone with ME/CFS suffers from seizures or rebounds. However, the system does not seem to work like that. I am aware that for example if someone is on very strong opiate painkillers which would make them sedated or drowsy for example, they would be a danger to themselves in workplaces and so this should automatically apply. It is however discretionary, and depends on the ATOS examiners, DWP advisors and the DWP decision-makers. With an ESA 50, question 10 covers that. I push this point when assisting members with form fill-outs.

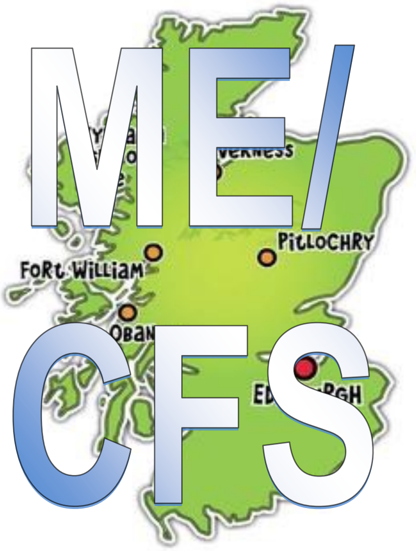
Gillian writes—I've been chatting to several group members who say that they have been helped by taking thyroxine. I've been to see my doctor and he says that he knows nothing about it. Also I've been chatting to another group member who gets thyroxine off the internet. He says it causes him no problem. So what options do I have?

We've covered this issue in the later pages of this edition of Pathways. Irrespective of source of thyroid medicines, they should ALWAYS be medically supervised by a qualified doctor.

Linda writes I've been talking to several members of the Sheffield Group. They are telling me that they are doing quite well on Enzyme Potentiated Desensitisation (EPD). I've been looking on the internet and found that EPD is carried out at the clinic of Dr. Shena Roper. It is a complementary approach to helping people with allergies and intolerances to food, airborne particles and chemicals by injecting minute quantities of the allergen, and says nothing about ME/CFS. Is this safe, and have any members reported that it help them? Is it available from my GP?

Firstly, no medicine is 100% safe irrespective of what it is. Some are safer than others. Secondly members experience suggests that it helps in many atopic (allergic) conditions by scaling down immune system activity. Many cases of ME/CFS are immune-mediated. EPD is about 80% effective. The cost is about £100 per treatment locally. Although in theory it is available on the NHS, in practice it isn't, mainly because it can only be administered by doctors specifically trained in its use. Due to the regulations, every dose has to be meticulously monitored and it is only available on a named patient basis, so cannot be licenced for general use. See Dr Myhill's website for further information.

ME/CFS Management Scottish Style: A Review



Although in a recent referendum Scotland voted to stay within the UK, as far as the NHS is concerned it is already a foreign country. The Scottish Government has produced a Scottish Good Practice Statement for ME/CFS. Here is a review of the section on Interventions, Management and Rehabilitation from their Quick Reference Clinical Guide.

Symptomatic treatments.

Treatment for headache, irritable bowel syndrome, dizziness or depression should follow standard clinical guidelines. For pain, the suggestion is to try simple analgesics first – paracetamol or NSAIDs (oral or topical) - and increasing to co-codamol or co-dydramol if required. They recommend avoiding high dosage morphine-type painkillers and to consider painkillers like low dose tricyclics, gabapentin, pregabalin and duloxetine. For pain, they also suggest a TENS machine, gentle massage, heat treatment, or acupuncture, particularly for headaches. For sleep disturbance, a low dose of a tricyclic or similar should be considered with the aim of normalising sleep rhythm. Sleeping medicines should be used only for a short period.

Medicines management

Start with very low doses and increase dosage over time. Side-effects can be a problem during the first few weeks in introduction. Avoid combining medicines within the same group. They also say that some medicines e.g. beta blockers and some antidepressants are poorly tolerated in ME/CFS.

Dietary advice

Dietary interventions are inconclusive, however some people report food intolerance contributes to their tummy problems. A healthy diet is desirable. The Guide says that some food supplements may be helpful e.g. vitamin B12, vitamin C, coenzyme Q10, multivitamins and minerals. They do add that evidence is poor to support routine use. They do however report that vitamin D levels have been found to be low in many patients. Instead of supplements they recommend foods high in vitamin D and sunlight exposure.

Rehabilitation.

For most cases the aim for management will be rehabilitation or empowering to reach normality but will vary according to needs and circumstances. This should encompass cognitive, emotional and social aspects as well as physical aspects. Any increase in activity should start at a low level and increase gradually. Targets should be small and achievable. People should be warned to engage in activity regularly but within their ability. There should be avoidance of ‘boom and bust’,i.e. doing everything on a good day and then getting a rebound.

Pacing

This is activity-management within the limits of the person and avoiding rebounds. Good quality rest is important, both during relapses and early on in a case. Getting the balance right is not easy. Targets set at a low level should be realised to avoid rebounds. Physical and mental activity have both to be taken to minimise setbacks, including delayed reactions. The Guide recommends that a diary could help to establish patterns of activity. Patients say that this is the most helpful intervention; however the clinical effectiveness is unclear according to research.

Graded Exercise Therapy (GET)

The Guide says that GET is intended to address the lowering of physical fitness because of a low level of activity. They acknowledge the controversy of this form of treatment. GET must be carried out under the supervision of an experienced practitioner in ME/CFS GET therapy. They claim that it may help physical capacity and relieve pain symptoms, especially if Fibromyalgia is present.

Counselling

They say that, as with any major illness, a trained counsellor may be helpful. Although unproven, this could help people find a better way to deal with their problems.

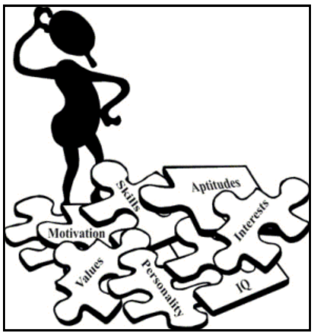
Cognitive Behavioural Therapy (CBT)

CBT provides people with help to develop strategies for coping with symptoms like fatigue, pain and sleep disturbance. They say CBT is of value to people whose symptoms have been complicated by psychological problems.

Grading of Evidence. (They base this on the SIGN Guidelines).

Level 1 Interventions that may benefit some, but not all

- Duloxetine or pregabalin (where neuropathic pain and/or fibromyalgia present)
- Cognitive Behavioural Therapy (when delivered in centres with expertise in treating ME-CFS)
- Graded Exercise Therapy (when delivered in centres with expertise in treating ME-CFS – may also be helpful if fibromyalgia is present).
- Acupuncture (particularly for headache)
- Gabapentin
- Pacing
- Simple analgesics
- TENS
- Tricyclic antidepressant drugs (starting with low dose)



Level 2: Interventions that possibly work and are unlikely to do harm

These are: Acetyl-L-carnitine and propionyl-L-carnitine supplements, Essential fatty acid supplements, Massage therapy and Melatonin.

Level 2+ Interventions for which trials have shown a lack of benefit

These are: Acyclovir, acyclidine, alpha interferon, amino acids, ampligen, clonidine, dexamphetamine, fludrocortisones, fluoxetine, galantamine, ganciclovir, general dietary supplements, growth hormone, homeopathy, hydrocortisone, inosine pranobex, interferon, liver extract, low sugar/low yeast diet, magnesium, medicinal mushrooms, moclobemide, ondansetron, osteopathy, phenelzine, pollen extracts, selegiline, sulbutiamine, terfenadine and topical nasal corticosteroids.

Level 4: Interventions that may do more harm than good

These are: Amantidine, antifungal drugs, baclofen, benzodiazepines, methylphenidate, naltrexone, Nimodipine, thyroxine (unless proven hypothyroid), non-specific advice on activity (e.g. ‘go to the gym and do some exercise’), Immunoglobulins, oral NADH and Staphylococcus toxoid.

Referrals

These should be specialised services to assist management or, where the diagnosis is in doubt, there are Guidelines to deal with those matters.

Prognosis (likelihood out outcome)

Prognosis is variable. Most will show some degree of improvement over time, but a significant proportion will have remission and relapsing course. Those in the community (as opposed to being in hospital) who are mildly affected have a more favourable outcome. The Guidelines, however, say there is a significant number who are affected for many years or decades. An understanding of support-entitlements for patients and carers is important. Adults may also not be able to keep their original job and may need retraining or careers advice.

Overall the document appears to be more ME/CFS friendly than many. But it has to be remembered that these Guidelines like those of NICE, are based on research findings and *clinical economics*, rather than the experience of people with ME/CFS.

Making Ends Meet on Reduced Income

With thanks to Benefits and Work

Benefits and Work *have* had well over 500 replies to their question about what advice you would give to people new to claiming benefits. They cover issues as varied as where to shop, how to cook, what websites to use, where to get advice, how to cope with neighbours and the media's hate campaign. Here is a digest of what is on their website filtered for ME/CFS. You can see the full feature for yourself on:

Benefits and Work
Guides you can trust

Fully paid up Leger ME members have access to these Guides. Please contact the Leger ME Office for further information.

http://www.benefitsandwork.co.uk/surviving-life-on-benefits

1) Shopping

- "Getting to the supermarket at the right time to take advantage of reduced prices for perishables is clearly something that is vital for many claimants."
- "When and Where To find The Best Food Reductions - up to 50% off: Waitrose - 8 am and after 7 pm, Marks and Spencer's - begin reducing food to be sold that day radically at 4 pm, Sainsbury's - begin reducing food to be sold that day radically after 7 pm, Tesco - 7 am and after 7 pm. Local food/ farmers markets - half an hour before closing time. Haggle them way down and you will rarely be refused as they would rather sell than pack the food up again."
- "Shop together with friends and buy in bulk, you will get more for your money."
- "Subscribe to Lidl's and Aldi's newsletters so can keep up to date with their offers when doing the shopping list."
- "Always check reduced sections in supermarkets - you never know what you may find and good way to stock up on tinned food with finds and odd treat or two when bargains found."
- New "Make the most of basics ranges of supermarket own brands which usually have less sugar, fat and salt than the higher priced varieties, therefore healthier for you and your children. What you save on the basic value range can be topped up with fresh or dried fruit or vegetables e.g. a bag of muesli can be topped up with fresh or dried fruit." Online shopping sites: "Some of you recommended online supermarket comparison sites whilst others make use of cashback sites.
- "Shop through Mysupermarket.co.uk online, it checks supermarkets for the best deals. Buy the basic range, look for deals, take your time you have loads!"
- "Don't do all your shopping in one supermarket. I have all the supermarkets delivery sites up on my computer at the same time and put my shopping list in all of them, and then I can compare prices. I have been able to save a lot of money by doing this sometimes as much as £30 a time. Watch out for buying in bulk as quite often (even though it's illegal) buying in larger quantities is more expensive. Look out for prices per kilo or per 100grams not per item."
- "Ensure that you check topcashback.co.uk or quidco when buying on line - as if I have to spend why not get something back such as on house/car insurance and always shop around for best deals. Read moneysavingexpert.com and join their forum for lots of free information on cost cutting from others already doing it...........saved me thousands in the years I have been on there. Farmfoods (freezer food) do online vouchers £2.50 off £25 spends - well worth printing if off to do a decent freezer shop."
- Charity shops: "Don't just go when you need something make it a regular weekly trip. You will be surprised at how many new items you will find." "Check out Facebook for local selling sites, there is one in my area where people who have finished with items they no longer need, sell them on for £1 each item.
- "If you are lucky enough to have friends and family always ask them for supermarket vouchers for Christmas and birthdays, you can save them for emergency food dashes and clothing. It stops them wasting money on things you won't use or need.

2) Cooking

- “Change how you cook - eat more pulses as they're cheaper than meat and full of protein. Add beans or lentils to mince when you cook it - the mince will go much further. When you cook rice or pasta bring the pan to boil then after putting the lid on turn the heat off. Leave it for 25 min and the rice will be cooked. Boil eggs the same way, leaving them for 15 minutes.”
- “Invest in a slow cooker! I won mine at a Christmas Fayre. I have never eaten so well! I can make several meals - which go in the fridge. Then I make use of a microwave!”
- “With regards to food we find you can make minced meat go a long way as you can make a lot of meals with it”
- "Try to eat well and avoid branded foods and ready meals if possible. A good site for healthy meals is Live Below The Line UK on Facebook”
- “Soup is a great way of using leftover vegetables or veg that has been sitting in the vegetable rack and a little past its best and is so easy to make. Hit the supermarket at the end of the day and get some fresh bread to go with it too - yummy.”
- “Occasions: We all know we'd go mad if we didn't see friends and family from time to time for some downtime. Chances are your hosting days are over for dinner/birthday/occasion parties BUT a bring a dish to share get together for an occasion comes into its own when on a very low income and so good for the soul. Think of a theme: Let's say Mexican and ask your guests to bring a dish that they've cooked at home, Fajitas, Chilli con carne, nachos, etc. can be brought to your door hot and kept warm in your oven until all the guests have arrived.”

3) Managing your money

Having more than one bank account, asking for refunds on credit card and looking out for discount schemes were just some of the tips we received in relation to managing your money.

Budgeting Setting up a budget and sticking to it was stressed by lots of people as vital to survival.

- “I add up all bills for the previous year for electricity, gas, water, insurance, etc. Divide by 52 and multiply by 12, this amount is then paid by direct debit into another account which I use to pay all bills. If you are on a monthly pension this can also be calculated to cover the five week months in each year.”
- “Use a simple budgeting tool. I have an app for my phone called Spending. I record all my income and outgoings, and it keeps a running total for me.”
- “Maybe an obvious one but if you are on several medications and do not qualify for free prescriptions it can work out very expensive, so opt for the yearly prescription certificate ...current cost £10.40 a month and you can get as many prescriptions as you need each month for this price.”
- “Pay any council tax over 12 months - makes budgeting easier - check with your council as some want the request in writing to do this.”
- “You need to pay your bills in the same way you yourself get paid. That way you can manage them better, reduce the risk of missing payments or payments bouncing because you simply don’t have the funds. Don’t be afraid to negotiate how and when you pay according to when you yourself get paid. It will make a world of difference.”

Bank accounts. Having more than one bank account is another necessity for many claimants, allowing them to control what comes out and when.

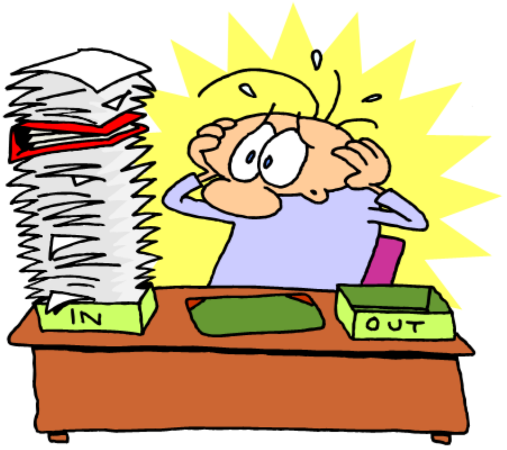
- “I have one bank account in which my benefit goes into, and from this account all my bills are paid, and I worked out how much I have left over each month (difficult for us benefit claimants as we quite often get fortnightly payments from different offices) and what is left over gets transferred across at the start of the month to my other account, which is for spending on food, clothes etc.”
- “I always recommend 2 bank accounts - one for all bills to be paid from and the other for living expenses such as food and travel. I also recommend clients to use the basic bank accounts website to ensure they have a bank account which doesn't charge them for any overdraft facilities and is aimed at people who are on low incomes and/or benefits. I also use comparison sites.”

Help available. A range of other ways of cutting costs was suggested.

- “All schools have a budget that provides uniform and help with school trips for the children who attend that respective school. Our daughter is going to Wales on a trip that we would have struggled to pay but with the school’s help she is able to go.”
- “If you have a cat or dog or maybe a rabbit, instead of paying monthly insurance, sign up to the PDSA.”
- “If you have unsecured debts, one of the first things to do is seek help from a FREE debt advisory service and get all your interest stopped and a token £1 per month payment set up. (I never knew this and sold all my assets, car, mothers jewellery left to me and anything that wasn't nailed down, to keep up the payments and only discovered this after I had nothing left.”
- “Don't forget if you are on certain benefits, you are entitled to an energy rebate. But you have to claim it with your supplier to get it.”
- “When I have interest to pay on my credit card bills, I ask if the interest can be refunded as I have a health problem and I get the interest back.”
- “If you are strapped for cash or need a little breather once, but you know you will have that extra spare cash in a fortnight or months’ time, get in touch with your vehicle insurance and ask them to delay that month’s payment until a certain date. They won’t do this on a regular basis but on a few times within the year there’s a high chance they will, but remember it will mean you pay twice that following month.”
- “Being on benefits will have an effect on family life, with very little money available for family fun. Find cheap or free fun things to do with the children, such as going to the park and feeding the ducks, having picnics in the garden or some other place. Most towns have a Facebook page where things are advertised, and the library and children’s health centre will have lot of resources for free and fun things.”
- *“*The Warm Home Discount scheme: It reduced my monthly payment plan only found about it last year as it is not well publicised.”

Paid work. Some people have managed to find small amounts of permitted work or other ways to get vouchers or discounts.

- “No one at the job centre told us about lower level permitted work (earning no more than £20 per week) and was very obstructive when we asked about it telling us a load of baloney about the rules which weren’t true. So we did our homework and spoke to CAB and looked at the DWP guidelines and found out exactly what we are allowed to do and went back and demanded to be allowed to do it. Later we found out a claimant does not need permission to do lower level permitted work, just is required to tell the job centre they are doing it. Keep records”
  “I earn a few extra pounds a month (legally) by selling home-made jewellery online.”
- “Claimants can apply for market research projects to take part in.”
- “A good way to legally earn some extra funds is to complete online surveys. The advantage is you can do the surveys when you feel well enough, give them a miss when you don't, and the amount of time you spend doing them can be easily kept within allowed work hours and is controlled by you. You can earn cash (Mysurvey for example), which can be paid into an account such as PayPal, or earn points towards vouchers for retailers such as Amazon. If you don`t touch the rewards throughout the year they can add up to a reasonable amount which can go towards your Christmas spending.”
- “Lots of taxi firms need school children escorts to help take kids to school. It just involves sitting in a cab keeping the child company so no bending, stretching etc. Shifts last one hour so easy to fit in. Call around the taxi firms and you may find some permitted work.”



5) Voluntary work

Voluntary work is something that some people find emotionally beneficial. For some, it also gives them a counter argument to the claim that they are not contributing.

- "I've found that doing regular voluntary work is really good for self-confidence and some sense of normality."
- "Present yourself according to your talents and your gifts, keep volunteering even if you can only do something for someone else once every few months, the sense of worth can sustain you!"
- "If you feel ashamed or guilty about claiming benefits, which might be due to all the recent negativity in the media, then perhaps you could try some voluntary work, even just for one day a week. You will be doing meaningful work and you can look at your benefit money as your payment."
- "Do voluntary work for people or organisations outside the home. The spin-off is that you keep warm and they often provide snacks and drinks which will keep you going."
- New "If you can, join a little social group or voluntary group these come with coffee and biscuits and also stop you from being isolated and bored at home."

6) Emotional issues

The financial and practical effects of being on benefits are only part of the picture. There are also the huge emotional effects for many people of feeling stigmatised because of needing to claim benefits.
Coping with the media: People had a variety of ways of dealing with the constant barrage of anti-claimant propaganda in the media.

- "Don't read the papers about claimants; retain a realistic perspective about your situation and share it with friends and neighbours!"
- "I think finding ways to deal with your own shame, others anger, and your own fear is absolutely vital. If you are unable to get work or are unwell, you are entitled to claim benefit. You are not a bad person, there is nothing wrong with you, you are not 'less than' other people who work. Your worth is exactly the same as them. Affirming yourself is vital: you are a good person".
- "Try not to think that whatever is happening is a personal issue - it isn't - thousands of people are going through the same experience every day. Only a fraction of claimants make claims they are not legally entitled to - unfortunately these are the ones who get big press coverage - and unfortunately make things harder for people with a legitimate claim - like you!"
- "For dealing with emotional aspects of claiming, hate rhetoric, waiting for Tribunals for example; I found going onto websites that are concerned with these issues very supportive. DPAC, Black Triangle, The Void, plus Benefits and Work helped me to become well informed and the blogs are great for venting anger and other troubling feelings."
- "The best way to deal with negative press about benefit claimers is to do your own research and find out the truth by looking at reputable websites. When friends, neighbours, strangers and opinion givers express a view, politely explain the true position and take a role in educating people and winning hearts and minds in favour of benefit claimants. Especially those with disabilities."
- "Don't worry about what people say, they don't live your life. There are a lot of support groups, especially on Facebook that can help you and tell you exactly what you should be claiming."
- "Wherever possible I talk to those neighbours who do not understand what is happening. I also challenge any negative stereotyping wherever I go. I talk to press and media, politicians and write articles or provide information to them on various aspects of the cuts, both locally and nationally."

The Varicella-Zoster Virus Infections

When the Varicella-Zoster Virus infects humans it can results in several different scenarios: It mainly affects the nervous system

Chickenpox

The Varicella-zoster virus (VZV) is the cause of chickenpox. This a highly contagious disease, which follows initial exposure to the virus and is typically a relatively mild, self-limiting childhood illness. Symptoms begin ten to twenty one days after exposure to the virus, especially those involving the nervous system. Pain and paraesthesia are typically the first symptoms of VZV infection. Until the characteristic vesicular rash erupts, diagnosis may be difficult. A prodromal period during which symptoms may vary is common. Pain occurs in 40% of patients, itching in 27%, and paraesthesia's (abnormal sensation e.g. burning) in 12%. Most children remember the itching, and very often scratching causes scarring if not controlled. Complications may occasionally include pneumonia, inflammation of the brain, or bacterial infections of the skin among others. The disease is often more severe in adults than children.

Shingles

After primary infection, VZV remains dormant in sensory nerve roots for life. Any life stress can reactivate the virus, which, upon reactivation, migrates down the sensory nerve to the skin, causing the characteristic painful dermatome rash. This rash very often one sided and follows the area of skin supplied by a nerve. Older people are more prone, but it can occur at any age. The people with ME/CFS who suffer from shingles report the pain as more intense and more fatiguing than when they first got ME/CFS. About 1 in 5 people have shingles at some time in their life. It can occur at any age, but it is most common in people over the age of 50. It is uncommon to have shingles more than once, but about 1 person in 50 has shingles two or more times in their life

Complications involving the eye.

If shingles affects the eye or optic nerve it can cause blindness. It is important that anyone suffering shingles in the eye is cared for by a consultant ophthalmologist to reduce chances of sight loss.

Post herpetic neuralgia.

After resolution, when the rash has dried up, many individuals continue to experience pain in the distribution of the rash. In addition, reactivation of VZV infection can cause a spectrum of atypical unusual presentations, ranging from self-limiting radicular pain without rash to spinal cord disease with weakness. Typically the worst is over in three months, but the pain can persist for many years in some patients.

Post Viral Fatigue Syndrome

Occasionally once the original infection has cleared, a fatigue syndrome may emerge, which is effectively ME/CFS. We all know about that. It has happened to some Leger Members

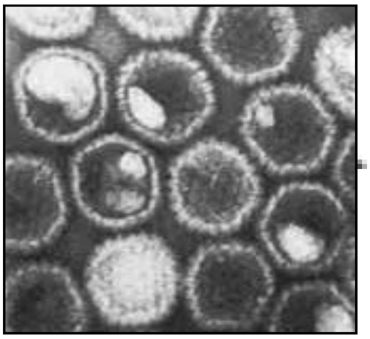
Any painful rash as overleaf
needs immediate antivirals
from a doctor.
Don’t be put off by surgery
receptionists.
If necessary go a to hospital
casualty department .

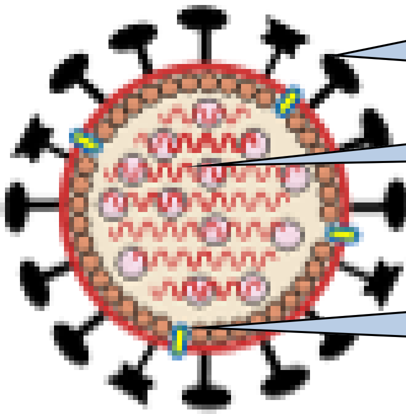
Treatment.

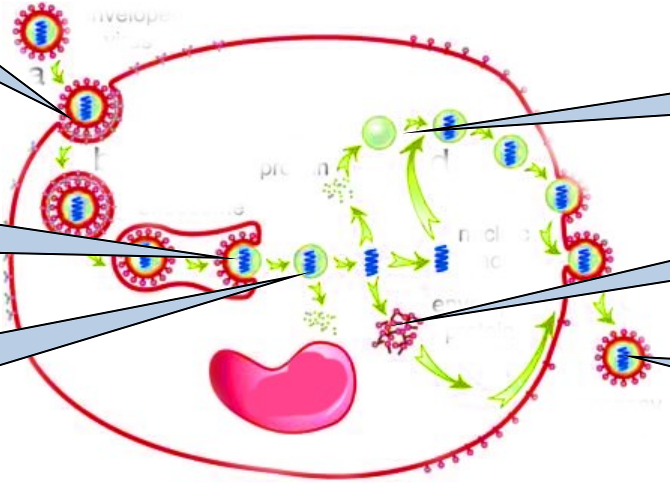
Until few years ago the only treatments were symptomatic. Pain can be controlled by simple analgesics like paracetamol and itching could be controlled by antihistamines. There were also some anti-viral paints available. More recently these have gone out of use, as antiviral drugs have become available like acyclovir. These are usually taken five times a day for a week and are effective in halting the progression of both shingles and chickenpox. More recently a vaccination has become available, and currently it is recommended for people over 70 years of age.

Anatomy and Life cycle of the Varicella-Zoster Virus.

Viruses are simply DNA in an envelope. They cannot reproduce without a host cell.







The virus is absorbed into the host cell

The virus DNA is released by stripping off the capsid.

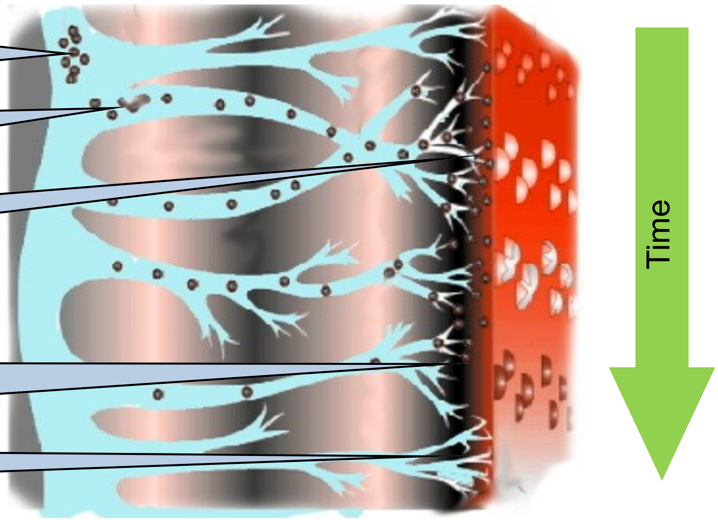
The Viral DNA hijacks the cells' normal function to replicate itself .

A second production line makes new capsid.

Another production line makes new Glycoprotein spikes

Daughter viruses are budded off to infect further cells

Diagrammatic representation of disease process.



Inactive virus in

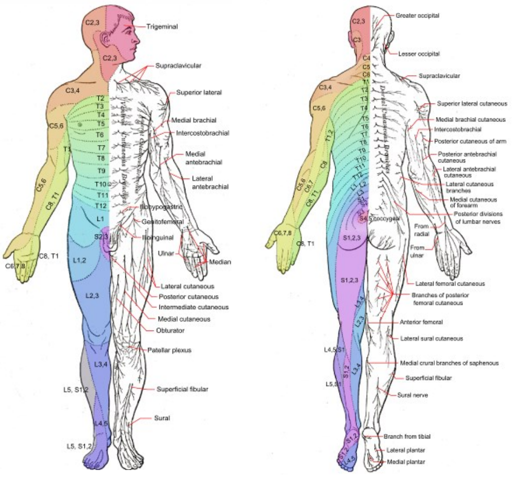
Virus activates

Rash then blisters develop

Blisters burst and dry as immune system kicks in

Healing takes place

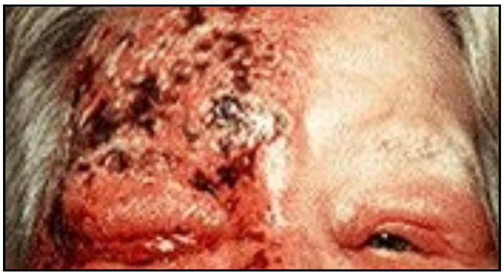
Images, thanks to Wikipedia



Dermatomes (Maps) in nerve endings. The infection follows these templates

Left. Shingles affecting part of the left infrachochear nerve.

Lower. Prompt antivirals can stop progress to a more serious situation when a persons sight may be affected. Note only half the head is affected



Left. More common form of shingles.

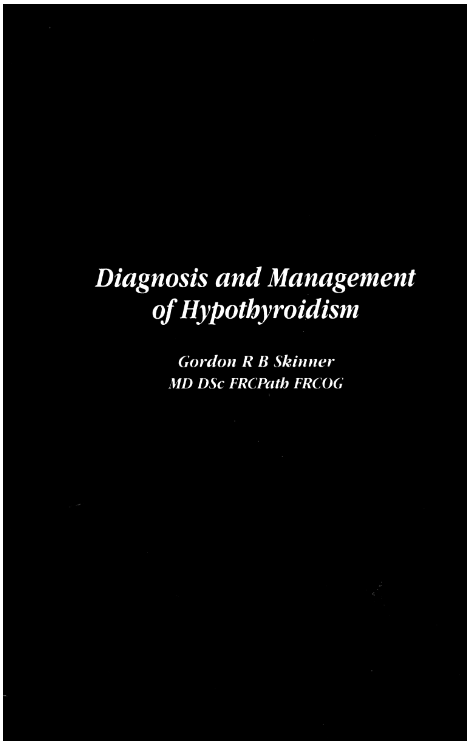
Top middle The rash follows the C5 nerve.

Bottom Middle The rash follows the L1 nerve

Right Distribution of chickenpox for comparison

Thyroid connections and some interesting books.

A review by Elizabeth A McDonagh



Introduction

After reading the first edition of Diana Holmes' book (see below) Elizabeth became interested in the issue of misdiagnosis of hypothyroidism and its links with ME. Many years later, her friend Jane Jones was successfully treated for hypothyroidism and returned to good health by Dr Gordon Skinner after NHS hospital tests had indicated that Jane did not have a thyroid problem. Jane died of breast cancer in 2004 and, soon afterwards, Elizabeth heard that Dr Skinner was called by the General Medical Council to face a tribunal over his treatment of thyroid patients. Elizabeth decided to attend the London hearing and became one of a group of supporters of Dr Skinner who, over approximately ten years, attended many of the subsequent hearings in London and Manchester. In November 2011, Dr Skinner was exonerated of all charges, but in 2013 new charges were brought and the tribunals and restrictions on his practice started again.
On 26 November 2013, while he was attending a medical conference, Dr Skinner died of a massive stroke. His supporters are now campaigning to clear his name and to change the basis on which hypothyroidism is diagnosed and treated under the NHS. They are also, in his memory, supporting The Vaccine Research Trust, a Charity founded by Dr Skinner.

Thyroid connections and some interesting books.

The issue of missed diagnosis of thyroid illness was first brought to popular attention in this country by Diana Holmes. Following polio at the age of ten, Diana's health steadily declined until she was unable to function. She was variously (and incorrectly) diagnosed as having anxiety and depression, epilepsy, coeliac disease, polymyalgia rheumatica, M.E., M.S. and myasthenia gravis. Forty years of her life were lost to illness. Finally, she was diagnosed by Dr Peatfield as suffering from ‘hypothyroidism and hypoadrenalism', though hospital blood tests had recorded normal thyroid function. Within a few months, Dr Peatfield's recommended treatment had restored Diana to good health. In *Tears Behind Closed Doors*, first published in 1998, Diana related her story and called for re-assessment of the value of hospital blood tests in the diagnosis of thyroid illness. The later (2002) edition of her book is expanded to include a chapter entitled “Artificial Fluoride, The Great Thyroid Antagonist”. Dr Peatfield has also written book*Your Thyroid and How to Keep It Healthy: The Great Thyroid Scandal and How to Survive It*.

A call for the official guidelines on diagnosis of thyroid illness to be changed, with the doctor also giving attention to clinical signs and symptoms rather than relying exclusively on the hospital blood test, was made by seven doctors in a letter to the Editor of the British Medical Journal published in BMJ Vol 314: 14 June 1997. One of the authors was a Senior Lecturer at Birmingham Medical School, Dr Gordon Robert Bruce Skinner.

A few years ago, a persistent virus was believed to be responsible for the relatively new illness, M.E. (myalgic encephalopathy). A virologist, Dr Skinner had been consulted by a number of M.E. patients. He had discovered that up to 50% of them, classified as *euthyroid* (within the normal reference range for thyroid hormones) showed clinical signs of *hypothyroidism* (low thyroid hormone production) and they improved on thyroid hormone replacement.

Dr Skinner has written his ‘ain book*‘, Diagnosis and Management of Hypothyroidism,* which explains the rationale behind his treatment of thyroid illness and gives a fascinating insight into the life, thought and decision-making processes of one Scottish, caring, individualist, football-loving, (and some would say persecuted), doctor.

Doctor Skinner was for many years under a regime of restrictions to his practice imposed by the General Medical Council. At a hearing of his case, at the GMC, on June 15th 2006, I was privileged to meet him, a healthy and radiant Diana Holmes and almost forty patients who had turned up in his support.

Twins Donna Roach and Coralie Phillips were there with copies of their book. *Hypothyroidism in Childhood and in Adulthood-A personal approach and scientific standpoint* relates their diagnoses of hypothyroidism as children. Thyroid hormone-replacement restored their health but doctors reduced their levels of medication because of fears that it might induce osteoporosis. They became ill again and one had to give up work. They were full of praise for Dr Skinner who had reassessed their medical needs and restored them to health. Other patients had similar stories, many praising the efficacy of 'Armour Thyroid', a porcine-derived thyroid extract.

There is plenty of evidence that fluoride adversely affects the function of the thyroid gland. According to the US Research Council, "several lines of information indicate an effect of fluoride exposure on thyroid function. Fluoride's potential to impair thyroid function is perhaps best illustrated by the fact that, up until the 1970s, European doctors used fluoride as a thyroid-suppressing patients with hyperthyroidism (over-active thyroid). Fluoride was utilized because it was found to be effective at reducing the activity of the thyroid gland - even at doses as low as 2 mg/day. The treatment was discontinued because it led to severe and permanent hypothyroidism in the treated patients. Today, many people living in fluoridated communities are ingesting fluoride (1.6-6.6 mg/day) that fall within the range of doses (2 to 10 mg/day) once used by doctors to reduce thyroid activity in hyperthyroid patients. While it may be that the thyroid in a patient with hyperthyroidism is particularly the anti-thyroid actions of fluoride, there is concern that current fluoride exposures be playing a role in the widespread incidence of hypothyroidism (under-active thyroid) in the U.S.

Hypothyroidism, most commonly diagnosed in women over 40, is a serious condition with a diverse range of symptoms including: fatigue, depression, weight gain, hair loss, muscle pains, increased levels of "bad" cholesterol (LDL), and heart disease.. The drug used to treat hypothyroidism (Synthroid, a synthetic form of thyroid hormone) is now one of the top five prescribed drugs in the U.S. According to UK pharmacist Paul Clein (formerly on Liverpool City Council) the use of synthetic thyroxin has escalated during his time in practice. As recommended by the US Research Council: "The effects of fluoride on various aspects of endocrine function should be examined further, particularly with respect to a possible role in the development of several diseases or mental states in the United States."

Books about the thyroid gland

Tears Behind Closed Doors by Diana Holmes is available from Amazon, www.amazon.co.uk

Dr Peatfield's book *Your Thyroid and How to Keep It Healthy: The Great Thyroid Scandal and How to Survive It* (Paperback) is now available from bookshops and, at a discount, online from Amazon.

Diagnosis and Management of Hypothyroidism by Dr G.R.B.Skinner is available from The Vaccine Research Trust, 22, Alcester Road, Moseley, Birmingham. B13 8BE.
Telephone 0121 449 8895 The price is £14.95 including p&p.

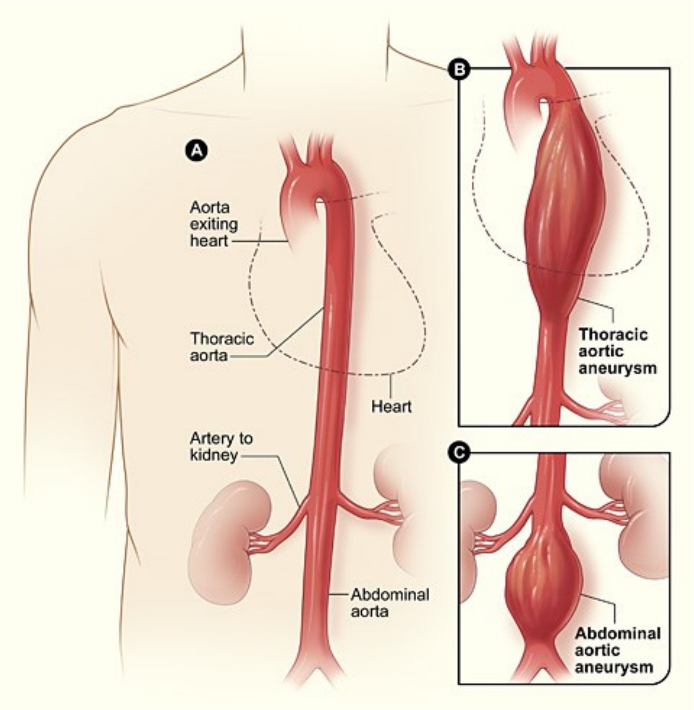
Hypothyroidism in Childhood and in Adulthood-A personal approach and scientific standpoint by C Phillips and D Roach is published by Nottingham University Press. It may be ordered from the authors on 01639 641367 at £13.50+p&p.

The following websites are informative regarding fluoride and fluoridation. Fluoride Action Network (US) and the National Pure Water Association (UK) oppose fluoridation worldwide Please give them your support.

Fluoride Action Network	www.fluoridealert.org
National Pure Water Association	www.npwa.org.uk
Thyroid Patient Advocacy UK	www.tpa-uk.org.uk

Readers might like to watch the YouTube video posted by Diana Simone (formerly Diana Holmes). Here is the link:
https://www.youtube.com/watch?v=KDPhp-rdJLE
and it is entitled: THE MISINTERPRETATION OF THYROID FUNCTION TEST RESULTS IS THE BIGGEST "FAUX PAS" IN MEDICAL HISTORY.
In the video, Diana also requests that we sign the following E-petition, so here is the link:
http://epetitions.direct.gov.uk/petitions/71841

The Local Abdominal Aortic Aneurism (AAA) Screening Service



From time to time I receive information about our Local NHS. The Doncaster & Bassetlaw Hospitals NHS Trust produce a magazine called *Foundations for Health* and in the latest edition there was a feature about AAA's.

What are AAA's

An AAA is when the aorta, the main blood vessel in the body weakens and expands. This condition, if untreated can lead to a rupture of the aorta which creates a serious risk of death due to internal bleeding. Around 3,000 people die every year from ruptured AAAs.

AAA is a silent killer causing no symptoms except occasionally there may be abdominal, back or leg pain except if ruptured. Experienced doctors may pick up an AAA be careful examination. When ruptured massive fatal internal bleeding occurs. Prevention is by decreasing risk factors such as smoking, general cardio vascular risk management like cholesterol, and blood pressure. Like many health problems, preventative surgery is possible if the AAA is found early enough. Emergency treatment is either by open or endovascular surgery which is a major operation.

David's Story

David, a local man attended an Abdominal Aortic Aneurysm (AAA) screening clinic at Retford attended the local screening service. The team performed a simple ultrasound scan a bit like the scan done for pregnant women, which picked up a small AAA. Fortunately in its early stages and he has now been entered into the 12 monthly surveillance programme to keep an eye on the condition. In an interview David said "I'm so glad he AAA team held a local the screening event. I had the scan and it was no trouble at all. It picked up a small aneurysm which I had no idea I had got! I visited the nurse the following week, she explained everything and put me at ease; and I can go for my 12 month surveillance appointments".

Local AAA team top of the tree for self-referrals

In a report released last November, the AAA Screening team were shown to have screened more self-referred men aged over 65 than anywhere else in the UK. Overall in South Yorkshire and Bassetlaw 2,220 men over 65s were screened, with the total for the entire North of England at 5.559 self-referrals. As well as accounting for well over a third of the figures for the entire region, the team also came out on top for the whole of the UK. Men in their 65th year are automatically invited by post to attend a screening clinic but men over 65 who have not previously been screened can make an appointment by contacting the AAA Screening programme on

01709 321189 or by emailing dbh-tr.dbhaaa@nhs.net

Why is this feature relevant to people with ME/CFS

I have known many people with ME/CFS for over twenty years, and I have been able to follow their case histories. What is quite clear is that in later years people with ME/CFS are more prone to cardio vascular problems, possibly because of active lifestyle restrictions. Most of the cardiovascular problems can be successfully treated if caught early enough.—*Mike*

Recipe Corner *by Carolyn*

Asparagus Pasta Salad

Vegetarian and vegan asparagus pasta salad with tomatoes and fresh parsley is tossed in a quick and easy balsamic vinaigrette dressing.

Preparation

Blanch or steam the asparagus, carrots, pepper and tomatoes separately in a small amount of water, until just cooked.
Then, in a large bowl, combine the asparagus, carrots, pepper, tomatoes and add in the cooked pasta and the finely chopped parsley.
In a small bowl or blender, whisk together the olive oil, vinegar, mustard, basil and salt and pepper. Pour this dressing over the pasta, stirring well to coat. Chill before serving, if desired.

Ingredients

2 cups bowtie, shell or macaroni pasta, cooked as per instructions on the pack
½pound asparagus, diced
3 carrots, diced (optional)
1 yellow pepper, diced (optional)
3 tomatoes, diced
3 tbsp chopped fresh parsley
1 tbsp olive oil
2 tbsp balsamic vinegar
1½ tsp Dijon mustard
½ tsp dried basil
salt and pepper to taste

Carrot Cupcakes with white chocolate cream cheese icing

This is a moist and light muffin. It’s not too sweet and not greasy like other carrot cakes can be. The white chocolate cream cheese icing adds just enough sweetness to round it off. Serves 12

Preparation method

Preparation**: 30 minutes** Cooking: **25mins**

Preheat oven to 180C/ Gas mark 4.
Lightly grease a 12 cup muffin tin, or line with paper muffin cases.

Beat together the eggs, caster sugar and brown sugar in a bowl, and mix in the oil and vanilla. Fold in carrots and pineapple. In a separate bowl, mix the flour, bicarbonate of soda, salt, cinnamon, nutmeg and ginger. Mix flour mixture into the carrot mixture until evenly moist. Fold in ½ of the walnuts. Transfer to the prepared muffin tin.

Bake 25 minutes in the preheated oven, or until a skewer inserted in the centre of the muffin comes out clean. Cool completely on wire racks before topping with the icing and sprinkling with remaining walnuts.

To make the icing, melt white chocolate over low heat. Stir until smooth, and allow to cool to room temperature.

In a bowl, beat together the cream cheese and butter until smooth. Mix in white chocolate, 1 teaspoon vanilla and orange extract. Gradually beat in the icing sugar until the mixture is fluffy. Mix in double cream.

Nutrition: *Calories* 638.9kcal. *Protein* 6.1g. *Sugars* 67.5g. *Total Fat* 32.2g. *Saturated Fat* 12.5g. *Salt* 310.7mg.

Ingredients

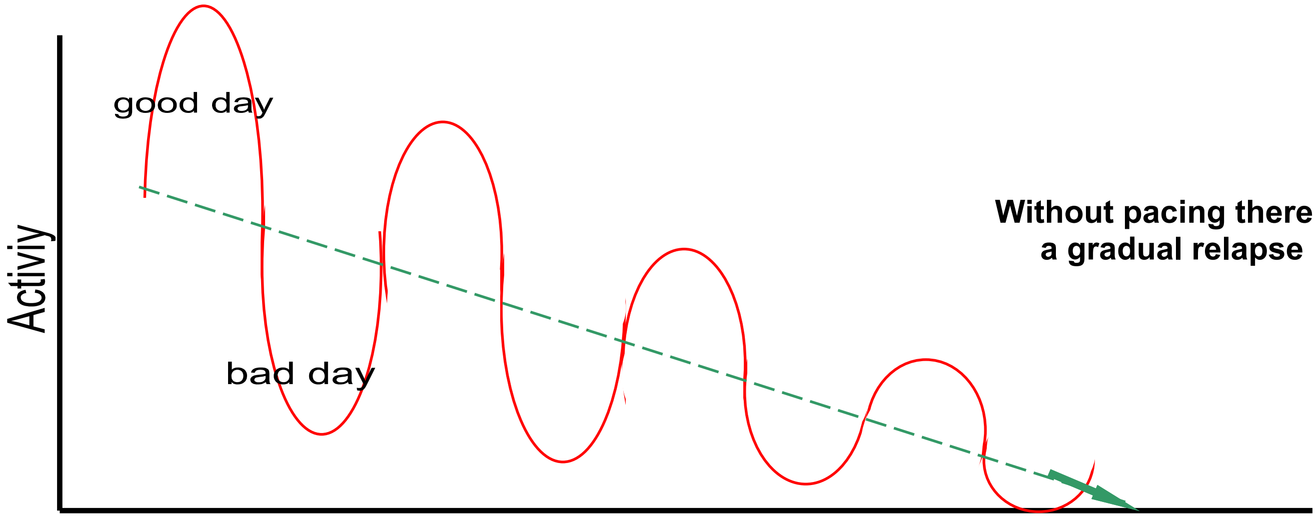
For the cupcakes:
2 eggs, lightly beaten
225g 8oz) caster sugar
5 tablespoons dark brown soft sugar
100ml (4 fl oz) vegetable oil
1 teaspoon vanilla extract
250g (9oz) grated carrots
125g (4½oz) crushed pineapple
200g (7oz) plain flour
1¼ teaspoons bicarbonate of soda
½ teaspoon salt
1½ teaspoon ground cinnamon
½ teaspoon ground nutmeg
¼ teaspoon ground ginger
100g (4oz) chopped walnuts

For the icing
50g (2oz) white chocolate
1 (200g) tub cream cheese, softened
100g (4oz) unsalted butter, softened
1 teaspoon vanilla extract
½ teaspoon orange extract
500g ($1^{1}/_{4}$lb) icing sugar
2 tablespoons double cream

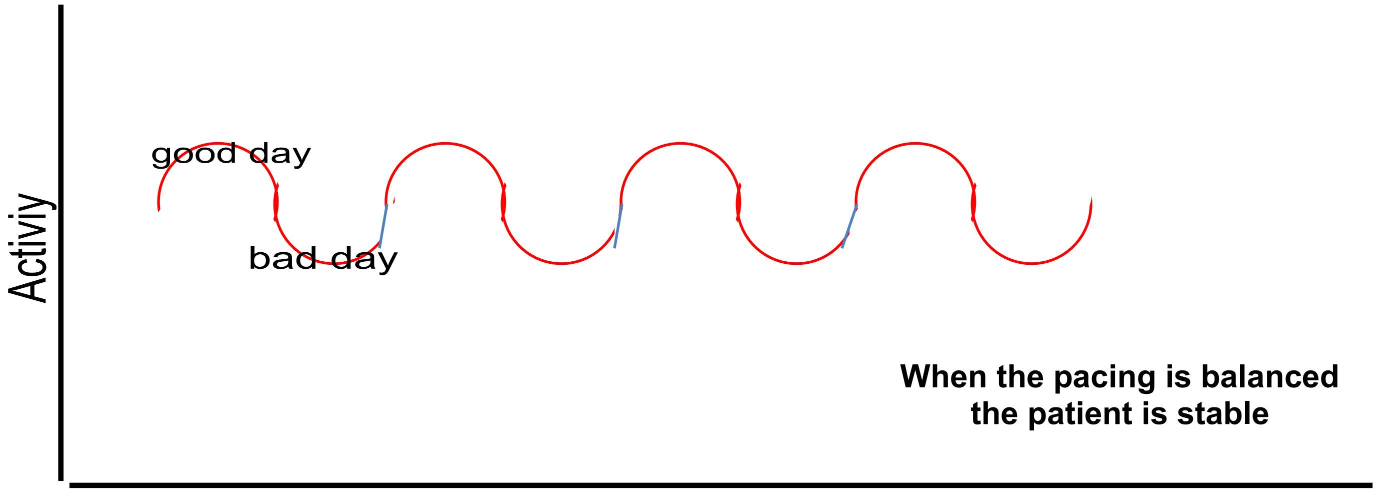
Another Look at Pacing for ME/CFS management.

Pacing is one the cornerstones of ME/CFS management. It is the only common strategy that seems to work with everyone and is advocated within the NHS and private sector. The theory of pacing involves limiting your activity during the day in a disciplined way in such a way as not to induce a rebound of problems and give yourself sufficient extra energy for the recovery. The usual outcome if ME/CFS is managed correctly is a low recovery over a number of years, and setbacks and relapses.

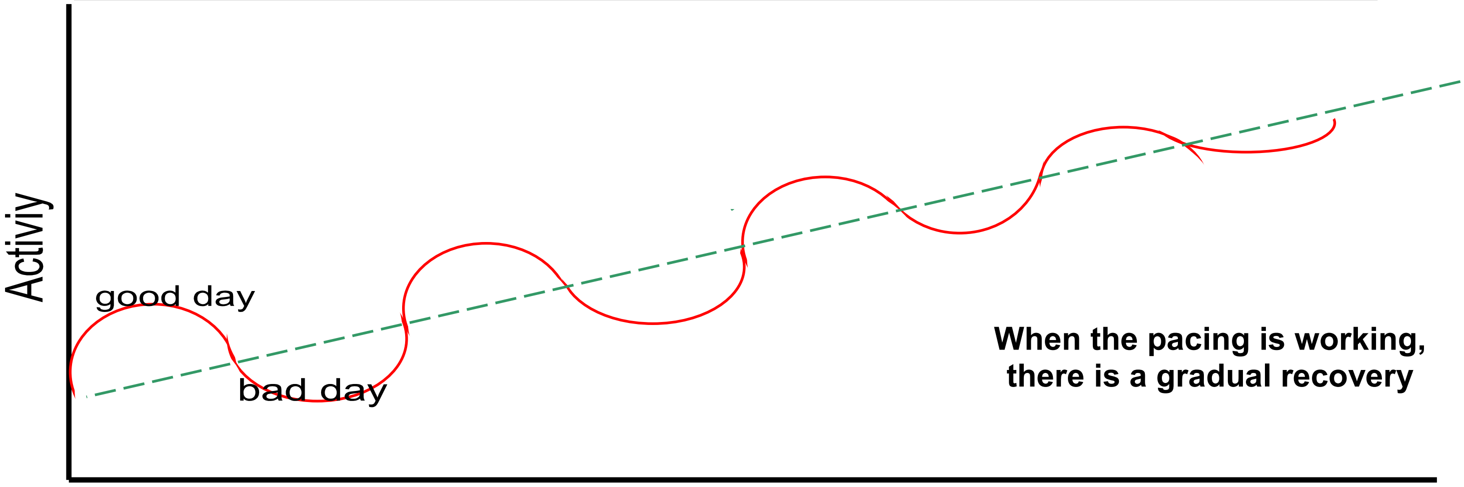
Several years ago, Anne Nichole, head of the NHS Sheffield ME/CFS clinic came to Doncaster. The following diagram is taken from part of her presentation and illustrated the theory behind pacing.



Without pacing there is a gradual relapse



When the pacing is balanced the patient is stable



When the pacing is working, there is a gradual recovery

Hints & Tips on Pacing

Although the concept is simple, many people find difficulty in putting pacing into practice.

- Divide activities up into manageable-sized chunks and spread these out across the day/week.
- Identify what your own limits are and stay within them.
- Use a diary sheet to identify when you are active and when you rest to indicate your individual pattern of energy use.
- Remember to pace anything that requires physical, mental energy and/or emotional energy. This includes watching TV, sitting up at a table, talking on the phone or using a computer.
- Identify what activities you find restful. Ideally rests are physically, emotionally and mentally restful.
- Preventative rests - don't wait until you feel tired or in pain (or have other increases in other symptoms) before stopping for a rest. Ideally spread rest out across the day.
- Try to re-plan your days and weeks so that activity and rest are spread more evenly across each day and across the weeks.
- Practice not overdoing things on your good days.
- If people are willing to help out, let them and don't soldier on pushing yourself beyond your limits.
- Try to ensure that some of your energy is used for something you enjoy to do, each day if possible.
- Focus on what you can do and not what you can't do.

Dealing with Others

When Pacing is put into practice, major problem are often experienced with employers, schools, social events and the DWP. It is important that that following is made clear.

- Chronic Fatigue Syndrome I Myalgic encephalomyelitis (CFS/ME) is classified as a neurological condition by the World Health Organisation.
- CFS/ME is a condition which involves a complex range of symptoms including overwhelming fatigue, muscle and joint pain, malaise, headaches, sleep disturbance, difficulties with concentration and memory.
- The symptoms can be as disabling as other chronic conditions such as multiple sclerosis and rheumatoid arthritis and are exacerbated by increasing level of physical and/or mental activity.
- The fluctuating nature of the condition means a person may be able to do a task one day or for a period of time, but may not be able to then do the same task a day or several days later.
- ME/CFS it is difficult to diagnose and there is currently no proven cure. Most people who get ME/CFS have an atopic tendency, and also commonly suffer from asthma and allergic conditions
- Most people with CFS/ME are likely to fall under the remit of the Disability Discrimination Act 1995 and will be entitled to reasonable adjustments in the workplace
- Treatment interventions are based on strategies which 'enable individuals to self manage their condition’.
- Pacing is one of the main strategies which can enable individuals to manage their symptoms and develop predictability and consistency in their life in order to minimise erratic energy demands.
- Activities need to be interspersed with frequent breaks in order to balance energy use and rest throughout the day.

In the Workplace or School

.

CFS/ME is a condition which usually involves prolonged management and requires ongoing adaptations in the workplace to accommodate the needs of the individual. Individuals returning to work after a period of sick leave will require a phased return, at a rate that is appropriate for the individual, in order to establish a baseline that can be maintained. Gradual increases in activities can be made once the individual is coping on a regular basis. In order that pacing is manageable in the work place it is usually necessary for appropriate adjustments to be put in place. This may require adaptations such as Changing location of work, Modifying work hours and Reducing workload.

Responsibility of the School or Employers in Limiting or Reducing Physical Tasks

The employer needs to ensure that:

- Activity levels are manageable within the individual's energy capacity
- Predictable and stable working patterns are established which are interspersed with regular and frequent breaks
- Any alterations to working patterns are made collaboratively with the individual taking into account their current coping levels
- Additional stresses are minimised as these can exacerbate symptoms and further delay improvements
- Any increase in activity levels is carefully monitored in order to minimise the likelihood of a relapse in symptoms

Employers need to regularly review the situation and ascertain whether further adjustments are needed Over time significant improvements can be made, but the timing of any changes made is completely dependant on how each individual responds. Employers may unwittingly put an employee under pressure by setting unrealistic expectations regarding returning to longer hours, taking on more work tasks, or operating within a time scale that is not based on the individual's current capabilities.
Any decisions regarding changes to working practice do need to be made collaboratively between employer and employee to maximise potential and take account of the fluctuating nature of CFS/ME. Occupational Health, Human Resources and trade union representatives can provide additional guidance and support.
It is important that reasonable adjustments can be negotiated between employer and employee.

In any situation involving employment, volunteering or school it is important that some sort of supervision is put in place and regular reviews are made. From Leger ME members' experience, the best people to provide this service are the Local ME/CFS clinics.in Sheffield and Leeds. The Yorkshire Fatigue Clinic in York provides an excellent service privately. Further information is available form the Leger ME helpdesk.

Recipe Corner *by Anne*

Flapjack as enjoyed at the group meeting.

FLAPJACK, The basic recipe comes from The St Michael All Colour Cookery Book

Method
Place butter, sugar and syrup in a saucepan and heat gently until melted. Place remaining ingredients in a bowl and stir into warm mixture. Press the mixture into a shallow greased 8in square baking tin and bake for 20-30 mins at 180C/350F or Gas 4 until golden and firm to touch. Allow to cool for 5mins then cut into squares.

Allow to cool fully before removing from tin.

Variations- the following can be added
Dried fruit, additional or different nuts, seeds or seed mix or chocolate chips

Then enjoy!

Ingredients
4oz Demerara sugar
4oz butter or marg
3 tablespoons golden syrup
6oz porridge oats
2oz desiccated coconut
1tsp baking powder
1/2 tsp salt
1 egg beaten

Out & About around Doncaster with English Heritage

In South Yorkshire, English Heritage has four properties which can be visited.

Brodsworth Hall and Gardens is 5 miles North West of Doncaster. It is one of the most complete surviving examples of a Victorian country house in England. It is virtually unchanged since the 1860s. The house has more than 30 rooms, ranging from grand reception rooms with original furnishings to the servants' quarters. The house is surrounded by Victorian period gardens, which are used for special events throughout the summer. It is constructed in ashlar limestone with lead and slate roofs. The main block is a 2-storey rectangular range having a 9-bay frontage.

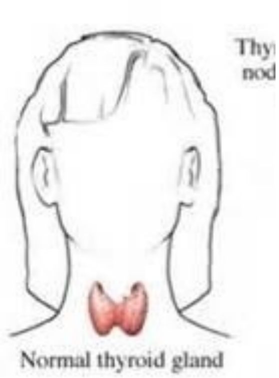
Conisbrough Castle is a medieval fortification as was initially built in the 11th century after the Norman Conquest. Conisbrough fell into ruin, its outer wall badly affected by mining subsidence from the local coal mines. The state took over the management in 1950, but by the 1980s the visitor facilities were felt to be unsuitable, leading to a three-way partnership being created between Doncaster MBC, English Heritage and a local charitable trust to develop the castle. The keep was re-roofed and re-floored in the 1990s with the help of European Union funding. English Heritage took over control of the castle in 2008 and continues to operate the property as a tourist attraction.

Monk Bretton Priory This was originally a monastery under the Cluniac order; Monk Bretton Priory is located in the village of Lundwood, near Barnsley, England. It was founded in 1154 as a Priory. Excavations concentrating on the church and cloister took place on the site in the 1920s which were published by the Yorkshire Archaeological Society and other largely unrecorded digging by the Ministry of Works took place during the 1950s. More recently the site has been the focus of a survey and excavation project run by the University of Sheffield. The site is a Scheduled Ancient Monument and now in the care of English Heritage.

Roche Abbey Roche Abbey was founded in 1147 in the fields to the south of Maltby, and was built for the Cistercians (White) Monks. It is in a headwater valley of Maltby Beck and King's Wood. The site is now in the care of English Heritage. The cliff path walk provides access to a view across the abbey grounds where its layout can be appreciated. Many of the buildings are low-standing but the walls of the church still stand to full height. The monks' quarters were accessed by a bridge which still stands. The monks had latrines which were over Maltby Beck so the running water took away the waste. They dammed the stream higher up to ensure fast flowing water; quite a modern facility for the 13th century. There are several local legends concerning ghosts, tunnels to other buildings, and even a lost wishing well. Pilgrimage is still made today on Trinity Sunday..

Thyroid: The correct prescribing of thyroid hormones

By Dr. Sarah Myhill



In February 2015 following further research, I have updated this on my website

There are four reasons why UK citizens are not subject to "best practice" with respect to prescribing thyroid hormones. All relate to the prescribing of thyroid hormone for under-active thyroid glands (hypothyroidism). The threshold for thyroid stimulating hormone (TSH) is set too high. When levels of thyroid hormones in the blood start to fall, the pituitary gland increases its output of thyroid stimulating hormone (TSH), which kicks the thyroid into life and increases output of thyroid hormones. If the thyroid gland starts to fail, this is reflected by levels of TSH rising. The question is at what point should the prescription of thyroid hormones begin?

The normal range for TSH in this country varies enormously from one laboratory to another. This means in some locations in the UK a thyroid prescription would not be given until the TSH rose above 5.0mlU/l. As a result of research, the normal range for TSH in America has now been reduced so that anybody with a TSH above 3.0mlU/l is now prescribed thyroid hormones. This research has shown that people with a TSH above 3.0mlU/l are at increased risk of arterial disease (a major cause of death in Western culture), insulin resistance (and therefore diabetes), inflammation and hypercoagulability (sticky blood). Indeed, there is a recommendation afoot in America to further reduce the threshold for prescribing to 2.5mlU/l.

What is completely illogical is that in UK the target TSH level for patients on thyroid replacement therapy is often stated as being less than 2mlU/l or even less than 1.5mlU/l. This is a ridiculous anachronism given that prescription is not recommended until levels exceed, say, 5.0mlU/l! So, someone could have a level of 4.0mlU/l and not be receiving thyroid replacement therapy (because their level is not above 5.0mlU/l), whereas if someone was on thyroid replacement therapy, a level of 4.0mlU/l would be considered much too high and would need to be brought down to below 2.0mlU/l or even 1.5mlU/l!

We should amend the threshold for prescribing thyroid hormones to 3.0mlU/L or better still 2.5mlU/l. There is a further inconsistency in BTA (British Thyroid Association) guidelines. The level of thyroid hormones in pregnancy is critical for foetal development. For pregnancy the target for TSH is a level below 2.5mlU/L. Furthermore requirements during pregnancy increase, so thyroid function should be checked every three months. What is the logic of only prescribing thyroid hormones to a non-pregnant woman with a TSH of above 5.0mlU/l but if pregnant the prescribing of thyroid hormones would start when levels exceed 2.5mlU/l?

Dr Kenneth Blanchard states that reliance on TSH to diagnose hypothyroidism is the biggest single medical error of modern times. It has resulted in millions of people missing out on this safe, life transforming, and disease preventing treatment. Population normal range versus individual normal range - they are not the same. The population normal range for levels of thyroid hormone in the blood is not the same as the individual normal range. We differ as individuals in our biochemistry as we differ in our looks, intelligence and morphology. This biochemical variation should be taken into account when it comes to prescribing thyroid hormones.

The population normal range of Free T4 is 12 - 24pmol/L. A patient, therefore, with blood levels of 12.1 would be told they were normal because they are within the population reference range. But actually that person's personal normal range may be high. They may feel much better running a high T4 of say 22, i.e. Nearly twice as much but still within the population reference range. Research done originally in the UK, and now repeated in America, clearly shows that the individual normal range of thyroid hormones is not the same as the population reference range. In order to find out who these individuals are, patients have to be assessed clinically as well as biochemically. In actual UK clinical practice this is rarely done except by a few physicians conversant with this issue.

Some people feel better on different preparations of thyroid hormones. In theory, if the patient has been shown to be hypothyroid, then all their symptoms should be improved with synthetic sodium thyroxine. In practice, this is not always the case - there is no doubt that clinically some patients feel very much better taking biologically identical hormones such as natural thyroid (a dried extract of pig thyroid gland which is a mix of T4 and T3). Indeed, before synthetic thyroid hormones became available, all patients were routinely treated with natural thyroid. The purity and stability of these preparations has been long-established, indeed much longer established than synthetic thyroxine!

Part of the reason why people feel better taking natural bio-identical hormones is that some people are not good at converting T4 (which is relatively inactive) to T3 (which is biologically active). However, this does not explain the improvement in every case. It is difficult to explain why there should be an additional effect, but for many people it is the difference between drinking cheap French plonk and good quality Spanish Rioja .The alcohol content is the same, but the experience completely different!

According to Dr A Toft, Consultant Endocrinologist, Edinburgh, “patients in whom long-term T4 therapy was substituted by the equivalent combination of T3 and T4 scored better in a variety of neuropsychological tests. It would appear that the treatment of hypothyroidism is about to come full circle”.
Ref: Endocrine Abstracts 3 S40, T3/T4 combination therapy. AD Toft, Endocrine Clinic, Royal Infirmary, Edinburgh, UK.

Timing of dosing

I have learned much more from consultant endocrinologist Dr Kenneth Blanchard's book "The functional approach to treating hypothyroidism".

http://www.amazon.co.uk/s/ref=nb_sb_noss?url=search-alias%3Daps&field-keywords=The+Functional+Approach+to+Hypothyroidism

Dr Blanchard makes many useful clinical points:
Thyroid hormones should be taken with food - he observes that cravings can be triggered by thyroid hormones on an empty stomach. T4 (thyroxin) is slow acting and "base loads". It is the night hormone - we should split our daily dose into two. The evening dose should be taken with supper which should be at least 4 hours before bed time. By contrast T3 is the day hormone that wakes us up.

Our requirements change with the seasons - in Nature, TSH falls in winter so levels of T4 and T3 fall - this puts us into semi-hibernation and allows energy conservation by causing mild fatigue and depression with greater need for sleep. The reverse is true for the summer. In modern times. with food and warmth aplenty. the imperative to do this declines. However some people need more thyroid hormones in winter to prevent severe fatigue and depression. In this event Dr Blanchard suggests "jump starting" followed by a different maintenance dose - so for example in the autumn someone taking 100micrograms of T4 would have a jump start of 150μg for 3 days then maintenance dose of 110μg . In the spring one would do the reverse - stop T4 for 3 days then return to the usual 100μg per day. Some people only feel well using pure T3.

At present we do not have biochemical tests to predict who these people are! A reverse T3 test may help but may not. If symptoms are typical of hypothyroidism but not responding to T4 or T4/T3 mixes, then a trial of pure T3 may be in order. T3 is short acting and must be taken at least 3, possibly 5 times daily. The smallest size tablet is prescription-only tertroxin 20μg (equivalent to 100μg of T4). A starting dose would be 10μg split into 3 doses - tricky! I suggest crushing half a tablet, and using a wet fingertip to take a third of the powder three times daily. One may know within a few days if this was making a difference but a proper trial would be a few weeks. For details, see Paul Robinson's excellent book on the subject - Recovering with T3: My Journey from Hypothyroidism to Good Health Using the T3 Thyroid Hormone. http://www.amazon.co.uk/s/ref=nb_sb_noss?url=search-alias%3Dstripbooks&field-keywords=Recovering+with+T3%3A+My+Journey+from+Hypothyroidism+to+Good+Health+Using+the+T3+Thyroid+Hormone

For more detailed discussion see Thyroid Hormone Transport where the importance of pure T3 is explained in terms of transport of T3 across cell membranes.

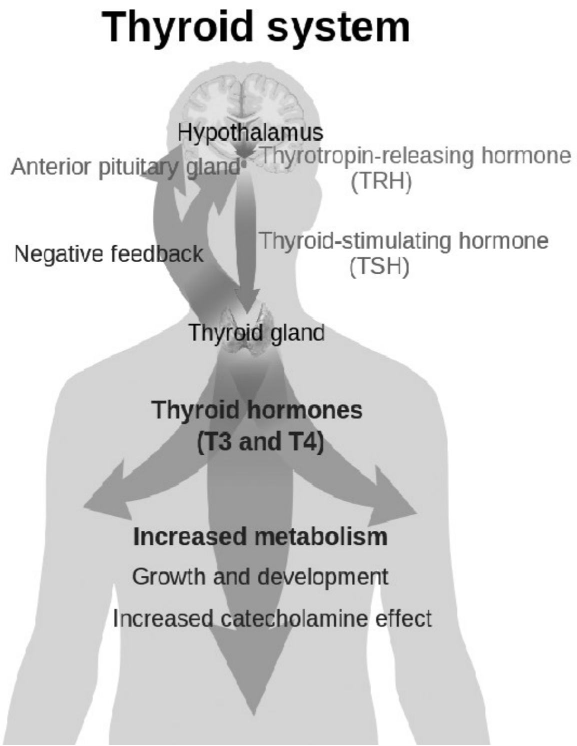
The correct proportion of T4 to T3

Dr Kenneth Blanchard maintains that the correct proportion is 98.5% T4 to 1.5% T3, for some a bit more, others less. Achieving this is difficult because armour thyroid is 80% T4 and 20% T3. He uses slow release T3 - not available in UK. However transdermal T3 could be an option - watch this space! The timing of dosing with T3 may be critical

Paul Robinson, in his excellent book on T3, hypothyroidism and the Circadian rhythm The Ct3m Handbook:
http://www.amazon.com/The-Ct3m-Handbook-Paul-Robinson/dp/0957099320
has made the interesting observation that our circadian rhythms, essential to health, are determined by when hormones are produced. Since hormones work synergistically we need them to be produced at the same time. Timing is triggered by the pituitary gland, the conductor of the endocrine orchestra! It starts with TSH levels rising sharply at midnight and is followed by increases in T4, T3 and cortisol later in the night. As they come together they trigger wakefulness. Paul found out for himself, and proved it to his satisfaction through blood tests, that his health was further improved by taking his morning dose of T3 at 5.30am. See his website *Recovering with T3* for his account of this.

Initial improvement followed by decline

Dr Blanchard observed that some patients improved on thyroxin and then worsened. He describes a "sweet spot" of optimal levels of T4. He believes the reason for this is that TSH is partly responsible for converting T4 to T3 - so, if levels of these hormones are too high, TSH is switched off and with that comes a switching off of T4 to T3 conversion. T3 is the day hormone that fires us up and because T4 is slow acting there may be a delay in noticing this "switch off" of T4 converting to T3 and this can be clinically very confusing.

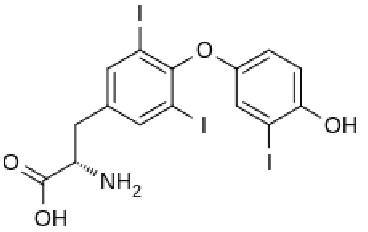


Monitoring treatment just by using a TSH test can be misleading. In his article (follow the link below in External Links) Peter Warmingham cogently explains how just TSH is not a good way to monitor replacement therapy. It is vital to measure levels of free T4, ideally free T3 as well, and assess the patient clinically - i.e. how do they feel? Are there any clinical symptoms of under or over dosing? Finally anyone who is hypothyroid for reasons other than autoimmunity is likely to be iodine deficient. See Iodine - what is the correct daily dose?

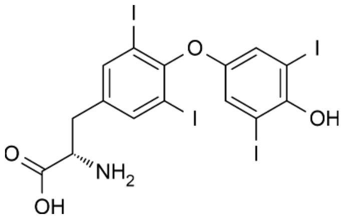
Why are we seeing an epidemic of thyroid disease?

A whole range of chemicals has been shown to be goitrogenic (substances that suppress the function of the thyroid gland by interfering with iodine uptake) and/or suppressors of the HPA axis and/or suppressors of thyroid hormones uptake and/or suppressors of T3 uptake. These include perchlorates (washing powder), phthalates (added to plastics to increase their flexibility, transparency, durability, and longevity) and bisphenol A (in plastic wrappings), pyridines (cigarette smoke), PCBs and PBBS (fire retardants in soft furnishing), UV screens (sun blocks and cosmetics), and many others. For a full list see Oxford Medicine Chapter 3.2.2 Environmental Factors. A recent study showed that hypothyroidism was 30% more common in areas of fluoridated water - that makes perfect biological sense - fluoride is a smaller molecule which fits and blocks the iodide receptor.

More on Thyroid Hormone & ME/CFS *by Mike*



T3



T4

The thyroid hormones, triiodothyronine (T3) and its prohormone, thyroxine (T4), are tyrosine-based hormones produced by the thyroid gland that are primarily responsible for regulation of metabolism. Iodine is necessary for the production of T3 and T4. A deficiency of iodine leads to decreased production of T3 and T4, enlarges the thyroid tissue and will cause the disease known as simple goitre.

The major form of thyroid hormone in the blood is thyroxine (T4), which has a longer half-life than T3. The ratio of T4 to T3 released into the blood is roughly 20 to 1. T4 is converted to the active T3 (three to four times more potent than T4) within cells by deiodinases (5'-iodinase). These are further processed by decarboxylation and deiodination to produce iodothyronamine (T1a) and thyronamine (T0a). All three isoforms of the deiodinases are selenium-containing enzymes, thus dietary selenium is essential for T3 production. Peripheral thyroxine is believed to be a prohormone and a reservoir for the most active and main thyroid hormone T3. T4 is converted in the tissues (as required) by iodothyronine deiodinase. Deficiency of iodothyronine deiodinase can mimic an iodine deficiency. T3 is more active than T4 and is the final form of the hormone, though it is present in less quantity than T4.

Both T3 and T4 are used to treat thyroid hormone deficiency (hypothyroidism). They are both absorbed well by the gut, so can be given orally. Levothyroxine is the pharmaceutical name (INN) of levothyroxine sodium (T4), which is metabolised more slowly than T3 and hence usually only needs once-daily administration. Natural desiccated thyroid hormones are derived from pig thyroid glands, and are a "natural" hypothyroid treatment containing 20% T3 and traces of T2, T1 and calcitonin. Also available are synthetic combinations of T3/T4 in different ratios (such as liotrix) and pure-T3 medications (liothyronine). Levothyroxine Sodium is usually the first course of treatment tried. Some patients feel they do better on desiccated thyroid hormones; however, this is based on anecdotal evidence and clinical trials have not shown any benefit over the biosynthetic forms. Thyronamines have no medical usages yet, though their use has been proposed for controlled induction of hypothermia, which causes the brain to enter a protective cycle, useful in preventing damage during ischemic shock.

Today most patients are treated with levothyroxine, or a similar synthetic thyroid hormone. However, natural thyroid hormone supplements from the dried thyroids of animals are still available. Natural thyroid hormones have become less popular, due to evidence that varying hormone concentrations in the thyroids of animals before they are slaughtered leads to inconsistent potency and stability. Levothyroxine contains T4 only and is therefore largely ineffective for patients unable to convert T4 to T3. These patients may choose to take natural thyroid hormone as it contains a mixture of T4 and/or alternatively to supplement with a synthetic T3 treatment. In these cases, synthetic liothyronine is preferred due to the potential differences between drug-lots of natural thyroid products. Thyroid hormones are generally well tolerated. One exception is that thyroid hormones may aggravate heart conditions, especially in older patients; therefore, doctors may start these patients on a lower dose & work up to avoid risk of heart attack. This happened to one Leger ME member.

What are thyroid function tests?

The usual blood tests done for thyroid function are TSH, T4 and sometimes T3. A blood sample is taken from a vein in the arm and sent off to the laboratory for analysis. Usually the 'free' or active portion of T4 and T3 is measured (i.e., FT4 and FT3). Laboratories use reference ranges to compare blood test results with results in the normal healthy population. The reference ranges used in the different manufacturers' testing kits do vary. These ranges are only a guide. The reference range for FT4 in particular does currently vary between methods and so any 'typical' reference range quoted will be subject to method and local interpretation, especially within private practice.

Test	From	To	Units
TSH	0.4	4.5	mU/L (milliunits per litre)
FT4*	9.0	25.0	pmol/L (picomoles per litre)
FT3	3.5	7.8	pmol/L (picomoles per litre)

North of Doncaster *Personal Experience from Trevor Wainwright*

Austin Wildlife Rescue

On a dirt road of Martin Luther King Jnr Boulevard, Austin, Texas, is a sign “Please drive carefully our squirrels don’t know one nut from another”. Sadly neither do other animals as a result they end up at the end of the dirt road as guests of Austin Wildlife Rescue (AWR). Founded in 1977 Wildlife Rescue started as a small group of concerned individuals from diverse backgrounds with a common interest in providing experienced care for the wildlife of the Austin and Central Texas area. Believing all life is precious; Wildlife Rescue rehabilitates and releases orphaned, sick, or injured wild animals and educates the public to coexist with wildlife.

I had been watching Houston Animal Cops on TV and wondered if they have something similar in Austin. Research led me to AWR an expression of interest was sent resulting in my being invited to volunteer. I was going to be there in April for Texas National Poetry Month, one of the events had been moved leaving me more spare time. Prior to starting I had visited the centre and been impressed with what I had seen, so on April 12th I began as a volunteer I would be there for 10 days; it was hands on from the start.

The season usually dictates which animals are brought in. At the time I was there it was birds, squirrels possums and racoons. My daily tasks consisted of cleaning out cages, ensuring there was ample food and water before getting the animals down to it and checking on their progress i.e. how active they were. Baby birds were fed every 20 minutes, whoever was nearest did it, as they got older the intervals got longer, as they became able to pick up their own food they were considered for release back into the wild. The phone and doorbell ring continuously as animals are brought in. Not all are accepted; some are found to be capable of living on their own so are sent back out, or, if meeting certain criteria, the same advice is given over the phone. The advice is given by specially trained workers, something for others to aspire to.

On arrival animals are checked as to their chances of survival, those that are going to be looked after are first put in a holding area till accommodation can be made ready. Once this is done, rehabilitation begins, progress is measured and as the animals grow their diet is changed. Eventually those that make it are placed in outside cages to give them more space and get them ready for life back in the wild. Sadly not all get this chance. Some are past help and are painlessly put to sleep. This happened on my first day and I could feel tears welling in my eyes as it was being done. On a brighter note, I also watched squirrels in an outside cage being captured and taken for release.

The Centre also has a medical room with x-ray machine and operating theatre for emergencies, always kept in a state of readiness. Certain inspections can also be carried out there. As one can imagine the Centre can get too many animals. To ease this certain trained volunteers look after the animals at home; others are fostered out to experts as in the case of a baby vulture, an armadillo and a baby deer among others. AWR is funded entirely by voluntary contributions many left by those who bring in the sick and injured animals. I was able to help in this by asking for donations at certain poetry events where I was the featured poet and read poems about my time there. I wrote twelve in total.

During my time there I attended to possums, squirrels, baby birds and small racoons. The possums will bare their teeth at you but normally once in your hand will relax and appear to wink at you. I say normally because one bit me twice. The standard treatment is to allow the wound to bleed, then apply peroxide, that solves the problem. Raccoons are different, babies and small ones reared in captivity are OK, but wild ones carry a risk of rabies so only volunteers who have been inoculated against it are allowed to attend to them. Volunteers must pay for their own inoculations, which they say is worth it for the pleasure of working with them. Squirrels are perhaps the most vibrant as they will happily run up and down your arms while being fed and their cages changed. Visiting wild life is also catered for with feeding stations, even a nectar station for humming birds. It was good to see some of the animals improve; one adult possum when brought into the centre had lost the use of its back legs, but with care and attention was slowly regaining it. As it was able to walk more it was moved to an outside cage and I had the privilege of putting it in there.

Sadly though some appear to be getting well but take a turn for the worse. Some are beyond help as in the case of a deer brought in by a group of deaf people following a road collision. They had come across a group of people debating what to do with it and taken the best action they thought possible. They brought it to the centre, at great risk to themselves as had it become agitated it could well have “kicked off” endangering the lives of those trying to help it. Sadly its injuries were too much and it was put to sleep, allowed to go with dignity and in caring hands. Thankfully due to the dedication and commitment of booth staff and volunteers many more animals live to tell the tale and are returned to the wild and for ten days I had been part of it. Ten days in which I met some wonderful caring people.

There is much more I could write. This article has only covered a small part of what was a very rewarding experience. Did I enjoy it? Would I do it again? Yes, actually they have said I would always be welcome, and yes, I am going again this year, and having the rabies shots so I can do more, this time with racoons and skunks. As long as I keep on the right end of the latter. – *Trev*

Approaching the entrance

Sign you are there

Polite but true request

Hayley Centre Manager & Kelsey (a volunteer) outside the centre

Baby Armadillo

Baby Rabbit

Baby Vulture - the one I attended to last year was quite friendly

Baby Squirrel, also very friendly

Baby Opossums can look vicious but can be very affectionate