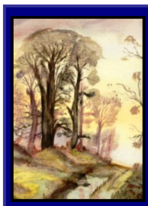

Pathways

Price £ 3.75 (Free to members)

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 44

In this edition:

ME/CFS Management: Wellbeing and getting the best out of life

So you've got ME/CFS. We all know that the only effective tool is management. In this edition we look at one aspect of ME/CFS ME/CFS management, wellbeing and getting the best out of life. It's more about changing the things that are changeable and balancing things in life in our favour. and at the same time minimizing things that work against us.

See page 8 onwards for this feature.

also featured in this edition

Medicines In Use: Z Hypnotics (Z drugs) and Sleep

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Dr Sarah Myhill: A personal profile

See page 6

Recipe Corner: Easy Gooseberry Cobbler

See page 18

Motoring and ME: The case for the hybrid car.

See page19

North of Doncaster

More on Trevor Wainwright's Adventures in the USA.

See page 21

And much more…...

You write

John Writes: I've been taking codeine phosphate 15mg tablets, prescribed by my doctor, for my IBS. I've just opened a new box, and notice that the advice on driving has changed. Is there a reason why?

Yes, there has been a change. I cover this in a recent edition of Pathways, but I think it is worth repeating.

First group	Second group
Cannabis (THC)	
MDMA (ecstasy)	Clonazepam
Ketamine	Diazepam
Methylamfetamine	Lorazepam
Cocaine	Oxazepam
(and a cocaine metabolite, BZE)	Temazepam
Lysergic acid diethylamide (LSD)	Flunitrazepam
Heroin/diamorphine metabolite	Methadone
(6-MAM)	Morphine
Amfetamine	

Currently, Section 4 of the Road Traffic Act 1988 includes an offence of driving whilst impaired through drugs, regardless of whether or not the drugs are being used legitimately. This means that if a patient's driving is found to be impaired by medicines, even if he or she is taking them as prescribed or as recommended in the product information, he or she may still be prosecuted. A new additional offence of driving with certain specified drugs in excess of specified levels came into force on 2 March 2015 in England and Wales. The legislation also provides for a statutory "medical defence" for patients taking their medicines as prescribed or in accordance with product information. Roadside drug-screening devices will use saliva to identify if a driver has taken one of the drugs listed above, or a drug that is metabolised to one of these. The first group is a list of commonly abused drugs for which low limits have been set; the second group consists mainly of licensed medicines that have a significant liability to be abused and the specified limits have been set higher than those for the first group.

Codeine is a chemical brother of morphine, and part of the way the body metabolises it is to turn it into morphine—so even though you have taken a medicine not on the list, it will show a false positive for morphine. To protect patients like yourself who may test positive for certain drugs as a result of taking medicines in accordance with advice from a healthcare professional or the patient information leaflet, the new offence has a statutory "medical defence". This may be raised at any point providing that the drug was:

- *Lawfully prescribed, supplied or purchased over-the-counter, for medical or dental purposes; and*
- *Taken in accordance with advice given by the prescriber or supplier, and in accordance with any accompanying written instructions (provided these are consistent with any advice given by the prescriber).*

As with any medicine, you must not drive if you feel sleepy, dizzy, are unable to concentrate or make decisions, have slowed thinking, or if you experience sight problems. If you need further information contact me at the next 1:1 session.

Susan writes: I was talking to my neighbour who has just finished working for the DWP. She was telling me that from time to time the DWP send letters to disability claimants advising them they may be entitled to another benefit or they may be able to claim extra money. She says it's really a ruse to see if can get any extra information to see if they can reduce the money they are paying. Have you come across this before? PS She doesn't know anything about my benefit claims.

Yes I have heard of these ruses. It's like the personalised route map to DWP medical examination. We think that this tactic will become even more common. If you have DLA as a lifetime award, and you have to fill out an ESA 50 for Employment & Support Allowance, then that will automatically trigger a review of the DLA. The DWP will most likely say that there is a material change in circumstances. They will review your DLA entitlement at the same time as your ESA. What is most likely to happen is that an early transfer over to PIP will be triggered. So, if it all goes pear-shaped you could lose everything. I warn people about this issue when dealing with DWP fill-outs. If any unexpected correspondence is received from the DWP of this nature, the best thing to do is contact me. Romans bearing gifts from the DWP always carry a Trojan horse. Please remember also that your Leger ME membership entitles you to access our welfare rights resources. PS. Never tell anyone about your own DWP benefits.

Mould Sensitivity *by Dr. S Myhill MBBS.*

Patients who are not responding to a standard allergy work-up are often suffering from mould sensitivity. This is not an easy diagnosis to make because skin-prick tests for mould allergy are unreliable. Furthermore it is uncertain whether symptoms are due to allergy to moulds or to sensitivity to mould fumes. This is a little bit like yeast overgrowth in the gut—for some people this causes a problem because they are allergic to yeast and for some because they react to the products of fermentation. The key to diagnosing mould allergy is the history and if patients are improved in a mould-free or low mould environment then this is highly suggestive that moulds are a problem. In order to survive moulds have to get their water from air, therefore they do not exist either in very dry climates (which may be hot dry or cold dry), above three thousand feet where the air is too thin to hold sufficient moisture, or on sea fronts where the prevailing winds are onshore. Since moulds do not live in oceans, their spores are constantly blown inland.

The best bet for mould allergy is neutralisation and provocation injections, but there are only a few clinics that offer these, namely: The Burghwood Clinic (Dr Shideh Pouria) the Airedale Clinic (Dr Apelles Econ) The Breakspear Clinic (Dr Munro) and Dr David Freed in Salford, Manchester.

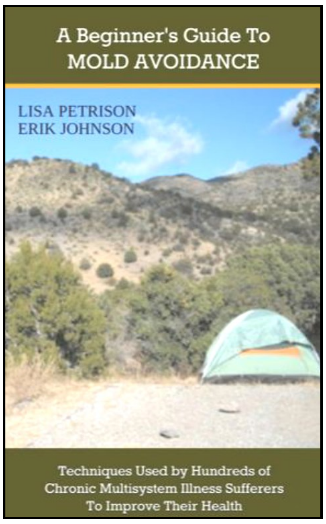
Therefore, to diagnose mould allergy I currently recommend that people have a two week holiday in such a mould-free environment. They may have already done this and not realised that their improvement was actually due to the control of their mould allergy and ascribe improvement to other factors such as freedom from stress, or sunshine, or whatever.

Being free from moulds in our temperate climate is extremely difficult. To reduce mould-counts in houses one has to take away obvious sources, such as house plants, or cure a damp problem. The next step is to reduce the humidity inside the house to less than 40% using a dehumidifier and this will kill any moulds living in the house. Reducing the humidity is helped by trying to avoid moisture-creating activities such as keeping houseplants, drying clothes, boiling pans, etc. Once the atmosphere is dried up, an air filtration system helps to get rid of the moulds in the air. Visit the website of the Healthy House, who do a range of excellent products.

Getting the relative humidity below 40% is critically important and one can now buy a little gadget from ETI Ltd called a Digital hygro-thermometer 0.1°C/F and 1% RH. This will tell you if you have got the humidity down to an acceptable level. Contact them on 01903 202151 or e-mail sales@etiltd.co.uk (quote order code 810-155). This costs £16 + VAT + £3.50 P&P at time of writing. In the early stages of mould allergy one often gets local symptoms such as rhinitis, conjunctivitis and sore throat, but as the symptoms become more systemic they can present with foggy brain and chronic fatigue. Patients who come to see me usually present with the latter symptoms.

"Mold Avoidance Manual"

I have been interested by work done in this sphere by Lisa Petrison PhD. Please see her website located at Paradigm Change. Those signing up for occasional email updates from Paradigm Change will also receive a free PDF copy of the book "Back from the Edge: How One Man's Discovery Brought Him from Desperately Sick with Chronic Fatigue Syndrome to the Top of Mt. Whitney in Six Months" (also available for Amazon Kindle. Please go to www.amazon.co.uk and search 'books' for "Back from the Edge") This book was authored by Lisa and concerned the experiences of Erik Johnson. It is a good read. Further to this, Lisa has kindly offered to make her new book, "A Beginner's Guide to Mould Avoidance" available free of charge to readers of my website. This book was co-authored by Lisa and Erik and will remain access-free and available to download from my website, subject, of course, to the authors' continuing and very kind consent. Furthermore, Lisa is currently working on putting together a preliminary report from the responses to a "mold avoidance survey" she has been conducting and it will be very interesting to see the results of this, when available. Please watch Lisa's website and mine for news of that too!. Here is the link to my website where "Beginner's Guide to Mold Avoidance" is available for download:
http://www.drmyhill.co.uk/



Medicines In Use: Z Hypnotics (Z drugs) and Sleep

The Z hypnotics are family of medicines, which in this country consists of zaleplon, zolpidem and zopiclone. They are prescription-only medicines in this country, and according to NICE are recommended for the short-term management of severe insomnia that interferes with normal daily life and should be prescribed for short periods of time only. Zolpidem and zopiclone have a short duration of action; zaleplon is very short acting. They are not licensed for long-term use as addictive-type dependence has been reported in a small number of patients. They are non-benzodiazepine hypnotics, acting at the benzodiazepine GABA receptor in the brain.

Caution about adverse effects

Generally, most hypnotics ('sedatives') will induce sleep if given at night, but also cause sedation the following day. A paradoxical increase in hostility and aggression may be reported by patients taking benzodiazepine-related medicines. Hypnotics may impair judgement and adversely affect reaction-time, and so affect ability to drive or operate machinery. They increase the effects of alcohol. There is an additional problem that a night dose may impair driving on the following day. They also can produce bizarre side effects ranging from excessive talkativeness and excitement to aggressive and antisocial acts.

What doctors are advised they should do?

Before a hypnotic medicine is prescribed, the cause of the insomnia should be investigated. Where possible, if a cause is found e.g. pain, that is part of the syndrome and should be treated first. However before a hypnotic medicine is prescribed other medicines may be tried first. The most popular one I see is amitriptyline.

Doctors are advised not to prescribe Z drugs indiscriminately and as routine. They should only be reserved for short courses in the acutely distressed. Typically, tolerance to their effects develops within 3 to 14 days of continuous use and long-term efficacy cannot be guaranteed. There is a tendency to need an increased dose to get the same effect, and there can be withdrawal-rebound on withdrawal after long term use. Broken sleep with vivid dreams may persist for several weeks. It is considered better that more sustainable sleep hygiene strategies should be implemented rather than Z-drugs. Doctors are also reluctant to prescribe Z drugs because they are liable to abuse and the supply is strictly restricted as with heroin and cocaine. There is more recent research linking heavy use of hypnotics with early onset dementia.

Historical aspect

Going back 30-40 years, there was a prescribing fashion to prescribe benzodiazepine medicines for sleeping and anxiety problems.

Medicines like Librium (chlordiazepoxide), Mogadon (nitrazepam) and Valium (diazepalm) we heavily prescribed, and they cost the NHS a lot of money especially when prescribed by brand name,.

This practice was suddenly curtailed when Mrs Thatcher became Prime Minister, and she brought 'The Black List' into existence. Brand names were barred and only the generic version allowed. Furthermore the NHS took the view that patients should buy their own sedatives and sleeping medicines. At the same time many other proprietary medicines, including cough medicines, were axed from NHS prescriptions.

Before any hypnotic medicines are prescribed, the causes of sleep difficulties are explored. These are general and not ME/CFS specific. Here are some sleep hygiene tips from the Patient UK website.

- Reduce caffeine - do not have any food, medicines, or drinks that contain caffeine or other stimulants for six hours before bedtime. Some people have found that cutting out caffeine completely through the day has helped.
- Do not smoke within six hours before bedtime.
- Do not drink alcohol within six hours before bedtime.
- Do not have a heavy meal just before bedtime (although a light snack may be helpful).
- Do not do any strenuous exercise within four hours of bedtime (but exercising earlier in the day is helpful).
- Body rhythms - try to get into a routine of wakefulness during the day and sleepiness at night. The body becomes used to rhythms or routines . If you keep to a pattern, you are more likely to sleep
- It is best to go to bed only when sleepy or tired in the late evening.
- Switch the light out as soon as you get into bed.
- Always get up at the same time each day, seven days a week, however short the time asleep. Use an alarm to help with this. Resist the temptation to lie in - even after a poor night's sleep. Do not use weekends to catch up on sleep, as this may upset the natural body rhythm that you have got used to in the week.
- The bedroom should be a quiet, relaxing place to sleep. It should not be too hot, cold, or noisy.
- Earplugs and eye shades may be useful if you are sleeping with a snoring or wakeful partner.
- Make sure the bedroom is dark with good curtains to stop early morning sunlight.
- Don't use the bedroom for activities such as work, eating or television.
- Consider changing your bed if it is old, or not comfortable.
- Hide your alarm clock under your bed. Many people will block-watch and this does not help you to get off to sleep.
- Mood and atmosphere - try to relax and wind down with a routine before going to bed. A stroll followed by a bath, some reading, and a warm drink (without caffeine) may be relaxing in the late evening.
- Do not do anything mentally demanding within 90 minutes of going to bed - such as studying.
- Some people find playing soft music is helpful at bedtime. Try a player with a time switch that turns the music off after about 30 minutes.
- If you cannot get off to sleep after 20-30 minutes - then get up. If you can, go into another room, and do something else such as reading or watching TV rather than brooding in bed. Go back to bed when sleepy. You can repeat this as often as necessary until you are asleep.

There is one particular piece of advice I do not to agree with and that is

'No matter how tired you are, do not sleep or nap during the day'

If people with ME/CFS need to sleep during the day they should, otherwise stress increases and is detrimental to fatigue, pacing strategies, and things like brain fog or absences start to occur. I often come across people who tell me this time after time. 'Taking a short nap in the afternoon enables me to sleep better at night. Here is a clue from Dr. Myhills website:

Sleep is essential for life:

After the First World War a strain of Spanish 'flu swept through Europe killing 50 million people worldwide. Some people sustained neurological damage and for some this virus wiped out their sleep centre in the brain. This meant they were unable to sleep at all. All these poor people were dead within 2 weeks and this was the first solid scientific evidence that sleep is more essential for life than food and water. Indeed all living creatures require a regular "sleep" (or period of quiescence) during which time healing and repair takes place. You must put as much work into your sleep as your diet. Without a good night's sleep on a regular basis all other interventions are undermined.

Dr Sarah Myhill: A personal profile

When confronted with the complexity of a condition like Chronic Fatigue Syndrome, conventional medicine struggles to come up with the right answers. Simply treating and suppressing the symptoms fails to address the root causes and individuality of each client.

Dr Sarah Myhill realised this 15 years ago when she was practising as a GP. Instead she chose to explore a different kind of medicine, one which would empower people to heal themselves through addressing the root causes of their diseases.

Dr Myhill states, ‘Five years at medical school followed by one year in hospital jobs does little to prepare a doctor for the real world. I had no answers to the early questions thrown up by NHS General Practice –

“Why do I have high blood pressure?”
“Why do I get such awful headaches?”
“Why am I depressed?”

Correct conventional answers to these questions are deficiency of, respectively, anti-hypertensive drugs, painkillers and SSRIs. But this is not the ‘why’ of the matter. Indeed it is hardly even the ‘what’ of the matter. Masking the symptoms does not explain them. The clues, which the symptoms represent, have been missed and the investigative detective work, which should have resulted from those clues, has been left undone.

'Doctors routinely confuse the making of diagnoses with merely the descriptions of symptoms and clinical pictures, neither of which constitutes a diagnosis. Examples include hypertension, asthma, irritable bowel syndrome or arthritis, all of which are descriptions of symptoms and none of which is an actual diagnosis. Clinical pictures include Parkinson’s disease, heart failure or Crohn’s disease. But these are convenient titles simply to slot patients into symptom-relieving categories which do little to reverse the disease process or afford a permanent cure. Symptom-relieving medication postpones the day when major organ failures result. I call this ‘unsustainable medicine’.

‘My early days in NHS General Practice were exciting! I learned to expect miracles as the norm! I watched a child’s “congenital” deafness resolve on a dairy free diet, I saw patients with years of headaches see relief from cutting out gluten grains, I saw women with chronic cystitis gain relief from cutting yeast and sugar from their diets. A proper diagnosis establishing causation has obvious implications for management and potential for cure. What was so astonishing to me was that when I tried to communicate my excitement and experiences to fellow doctors they could not have been less interested and dismissed me as a “flaky quack”!

‘However the greatest challenge came from seeing and treating patients with ME/Chronic Fatigue Syndrome. This was the elephant in the room! There was absolutely no doubt that these patients were seriously physically unwell. I saw Olympic athletes, England footballers and cricketers, university lecturers, airline pilots, tough farmers, fire fighters and Gulf War veterans reduced to a life of dependency by debilitating pathological fatigue. What has been so unexpected is that the answers to treating ME/Chronic Fatigue Syndrome have shed a whole new light on other common medical problems such as cancer, heart disease, dementia and other such degenerative conditions.’

Problems arising if your ME friendly Doctor if not longer around?

From time to time this problem arises and I receive desperate enquiries. Most people with ME/CFS tend to latch onto a particular doctor and suddenly that doctor is not around. For example Dr Skinner has recently died. Sarah Myhill is restricting her patients and at the time of writing taking no new patients. The Nutritional Associates formerly in York is no longer there. The most common other example is if a GP moves away or retires. The two main problem areas that I come across are regarding unconventional use of common medicines or DWP matters.

DWP matters — When this happens, very often the usual outcome is a benefit refusal for ESA ,DLA or PIP. When a benefit claim is made, enquires are always made to the patient's GP. If your friendly GP is not around, a refusal very often occurs due to a new doctor or partner not knowing enough about your case. Also it is very often the case that no recent evidence is available. There is not one single fix except to start a new claim from scratch. Recently some long-term ME/CFS patients were referred to the Sheffield ME/CFS clinic by their new doctor. Generally all they will do is issue a standard letter which I find is a waste of time as it contains no patient-specific assessment. This I see as a problem. There are however workarounds which vary according to the case.

Medicines - The main problems I come across are related to B12 injections and thyroxine. Both these two medicines are widely available to treat common health conditions, but not for ME/CFS. Thyroid problems occur because only TSH is checked by many GP practices, and not T3 & T4 which are the factors which matter for ME/CFS. Thyroid medicines and B12 injections are all prescription-only medicines and needing a doctor's prescription. There is no simple quick fix. The NICE guidelines advise against the use of these medicines. I know of no younger doctors around that will use B12 & thyroid drugs for ME/CFS treatment. Again there are workarounds which vary from case to case.

How can you avoid these 'doctor not around' problems?

Firstly you need to keep in touch with your doctor's practice and create a track record. ME/CFS is a chronic long term condition, which does not exempt someone from other ill health or long term problems. I believe that ME/CFS patients should have a case-review at least once a year by their GP, as most people with ME/CFS have other long terms conditions. The common ones I come across are diabetes, osteoarthritis, asthma and breast cancer. These chronic conditions will need frequent specific checks usually from a practice nurse. This is an opportunity to update your track-record independently of your doctor for example. Again, each case depends on its merits. During a 1:1 mentoring session I can usually find a way forward.

THERE'S A RUMOUR GOING ROUND THAT YOU WERE KIND TO SOMEONE WITH M.E.

ME/CFS Management: Wellbeing and getting the best out of life.

What gives you fulfilment?

So you've got ME/CFS. This does not stop you thinking about the good things in life, and sharing them with others. If you make routine all the positive things in life, you can increase your ability to have an optimistic outlook on life. It is important to pause and step back step back and reflect. Are you only half fulfilled and also half unfulfilled? Fulfillment has a major impact your health and wellbeing. With an optimistic outlook you will improve quicker and look after yourself better, so can, more importantly, cope with your ME/CFS problems better. How positive are you? Psychologists believe that we need around three times more positive emotion than negative emotion to improve. Negative emotions tend to persist longer than positive ones so it is important to maximize the positive aspects of life and minimize the negative ones. Being positive will enable you to cope with your ME/CFS, have a new outlook, handle rebounds (setbacks) better and recover more quickly. Hopefully this should enable you to network better with others, and develop a more optimistic outlook on life. Hopefully the negative experience of ME/CFS will be turned positive and make you a better, more balanced person.

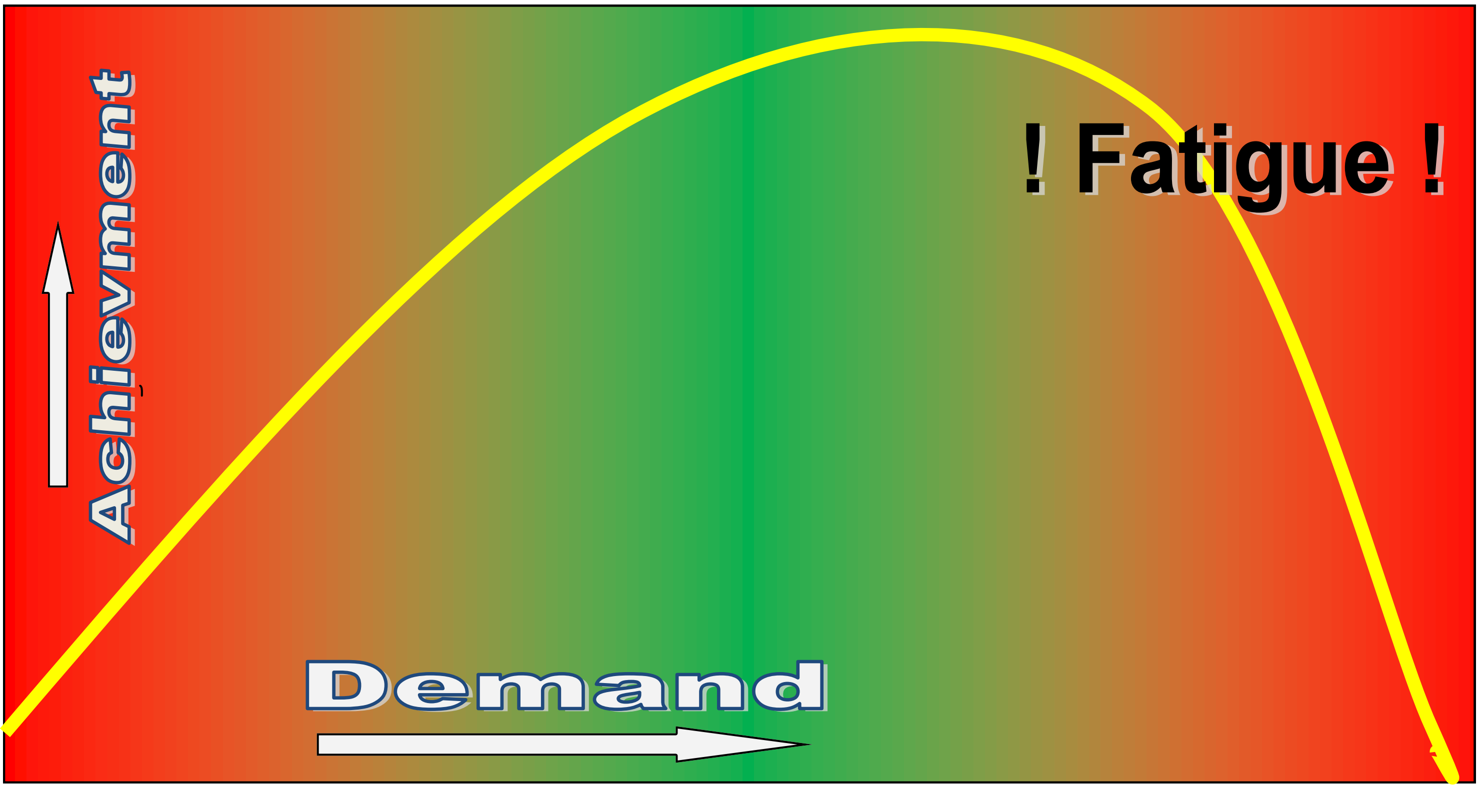
The Concept of Wellbeing

Wellbeing may be thought as something positive. If means different things to different people. In its simplest interpretation it can the thought of something functioning well and feeling good. This also has to include things like .a sense of meaning, a fair share of material things, to have control over your place in life, and have the ability to deal with life's changes and problems. The concept of wellbeing is a bit like ME/CFS. It means different things to different people. Although you may have a mental and/ or physical aspect to your health problem you can still consider yourself to have good wellbeing. You can still have a mental health problem or a physical disability and consider yourself to have good wellbeing.
Wellbeing is there to make sure your life and needs are balanced to manage your ME/CFS and prevent deterioration or complications of health problems. That has physical, social, lifestyle, time management, financial, emotional and mental implications. This is why during a case review I look at these issues. There are six major components to Wellbeing in ME/CFS.

i) **Health.** Maintain your health as far as possible, and follow the appropriate advice, but only within the context of ME/CFS. There are many anomalies with ME/CFS compared to the general population. For example specific caution needs to be taken with statins, vaccinations and graded exercise, while for an individual without ME/CFS they would be strongly recommended.
ii) **Network**. Be friendly and project a positive image. Do nice things for your friends & others. Give your time for the benefit of others. Join a community group and give your time. Look at yourself as giving something positive to the wider community. Be nice and pleasant to people and don't be grumpy.
iii) **Explore & Challenge.** Keep learning - try something new or rediscover an old interest. Set yourself a realistic achievable goal. This will do wonders for your confidence and increase your personal satisfaction.
iv) Keep physically active. While being active may make you feel good, do it within your limits and learn to pace yourself. Treat with extreme caution well-meaning advice like go to a gym or graded exercise, except from those specifically trained for example in a ME/CFS clinic.
v) **Be aware and research.** Enjoy what you do. Work out what matters to you. Be aware of your place in life, Explore new aspects of your life,
vi) **Communicate.** Connect with the people around you. Remember that ME/CFs can be socially isolating. Keep up your relationships with family, friends, colleagues and neighbours, at home, work, and school or in your local community to promote your wellbeing.

It is best from time to time to take stock and reflect on your wellbeing. Think of wellbeing as money, which is something that has to be earned managed and budgeted. It is all too easy to lose or spend. It is also unrealistic to set yourself targets or expectations relating to how you were before ME/CFS.

Pacing, Peak Performance Pressure & Stress



Undesirable zone **Ideal zone** **Danger Zone**

The diagram represents a typical demand and achievement situation that we often come across. It could apply to a wheat crop for example. The more fertilizer that is applied the bigger the crop. However there is a level of which can be applied when the increase flattens off (diminishing returns). Very shortly after this point increasing amounts of fertilizer reduces the yield and it becomes poisonous. Similarly this could apply to learning and exam performance or stress applied in a workplace. On reflection many people will realise that the demand pressure or stress was the main factor that triggered symptoms.

It is all too easy to compare ourselves with how we were before ME/CFS, and this can be wrong. We need to learn to expect less now than in pre ME/CFS days. It is easy to get caught up with all the activity that is going on, especially when everyone around us seems to be doing more and more. In reality, what happen is that we become overwhelmed by simple tasks and our performance is impaired. Even making simple decisions or tasks becomes massive. The risk is then that we push ourselves into a relapse and the ME/CFS intensifies. The fatigue (rebound) point is different for each person and changes according to the severity of ME/CFS. In fact, for many it changes at many points during the day. It should be obvious that there is a link between our wellbeing and health problems.

This is where pacing comes in. With pacing we learn to read our bodies, and know what can be achieved. We have to learn to stop when the fatigue point is reached. The actual fatigue point for everyone is different, and for many has to be learnt by trial and error. Many people with ME/CFS for example when reading too much find that they can't read any more until the following day. This is because the muscles that image onto the retina of the eye fatigue and stop working. Some people start to itch, others may get tinnitus or acute visual problems.

The only strategy that works to deal with this is pacing. 'Adaptive Pacing' is the Sheffield ME/CFS clinic's angle on fatigue -control. This is a skill to be learned and practised rather than knowledge acquired.

Anxiety & Stress

Stress is the body's response to too much pressure and too much anxiety. We can learn to recover from its effects but, if we ignore it, it can cause long term harm especially if you have ME/CFS. As part of the overall management plan it is important to be aware of our early warning signs of stress, and also if your are a carer to be able to recognise the changes in behavior of those around us to alert us to the fact that they may be under pressure and starting to exhibit signs of stress. People express stress in different ways and if we perceive that others are behaving in a way that is different from the expected norm it is worth considering how we can support them. Many of these problems may be preventable if the signs are recognised early on, something is done about it. Here are the signs and symptoms of stress which vary considerably between different people.

What is stress ?

'The adverse reaction people have to excessive pressures. Expectations or other types of demands placed.

Stress is a mental or emotional strain or tension that we all experience from time to time.

Emotional Symptoms	Behavioral changes	Physical Sensations
Irritable, bad tempered	Irritability, unable to settle	Heart racing (Tachycardia)
Anxious	Irrational movements, tics & tremors	Breathing faster
Impatient	Sleep difficulties	Tense muscles/headaches
Angry	Eating more or less	Hot and sweaty
Depressed	Drinking more	Relapsing/Recurring illness
Hopeless	Using drugs/cigarettes/alcohol	Difficulty concentrating

The problem is that once these symptoms become chronic there will be more pronounced abnormal physical, emotional or behavioral problems, negative emotions and then physical problems like ME/CFS, stroke heart attack etc..

What is Anxiety?

"A feeling of worry, nervousness, or unease about something with an uncertain outcome".

Anxiety. The burst of adrenaline and nerve impulses which we have in response to stressful situations can encourage a 'fight or flight' response. However, some people are more prone to normal anxieties. For example, some people are more anxious than others before examinations particularly of the DWP sort..
However anxiety is abnormal if it is out of proportion to the stressful situation, and still continues once the stressful situation has resolved and also when there is minor stress with no apparent reason.

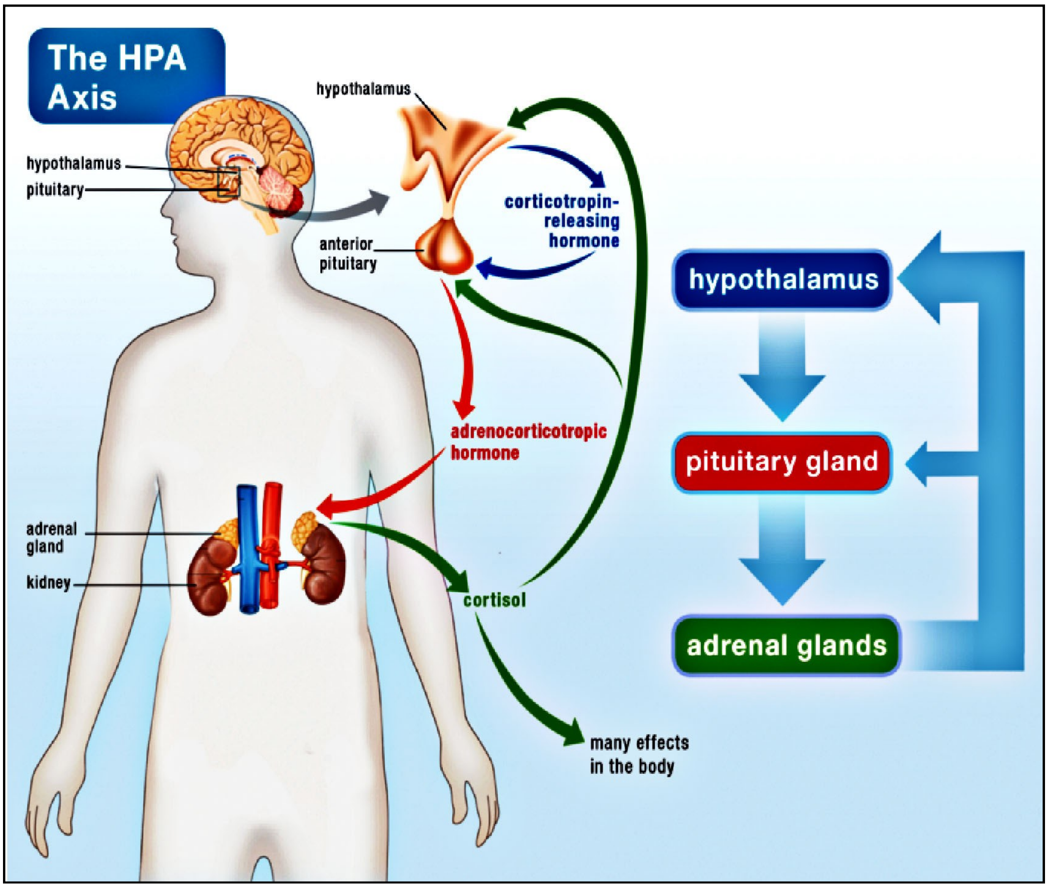
Anxiety differs from stress in that it persists after the triggering event has passed. The constant feeling of being stressed is anxiety. These feelings sit just under the surface and manifest themselves in you as a continuous daily uneasiness, apprehension, or fearful feeling in the pit of your stomach or chest, particularly when you're placed constantly in similar situations or have the fear of being so. Ultimately this can lead to unexpected panic attacks which are often seem in ME/CFS.

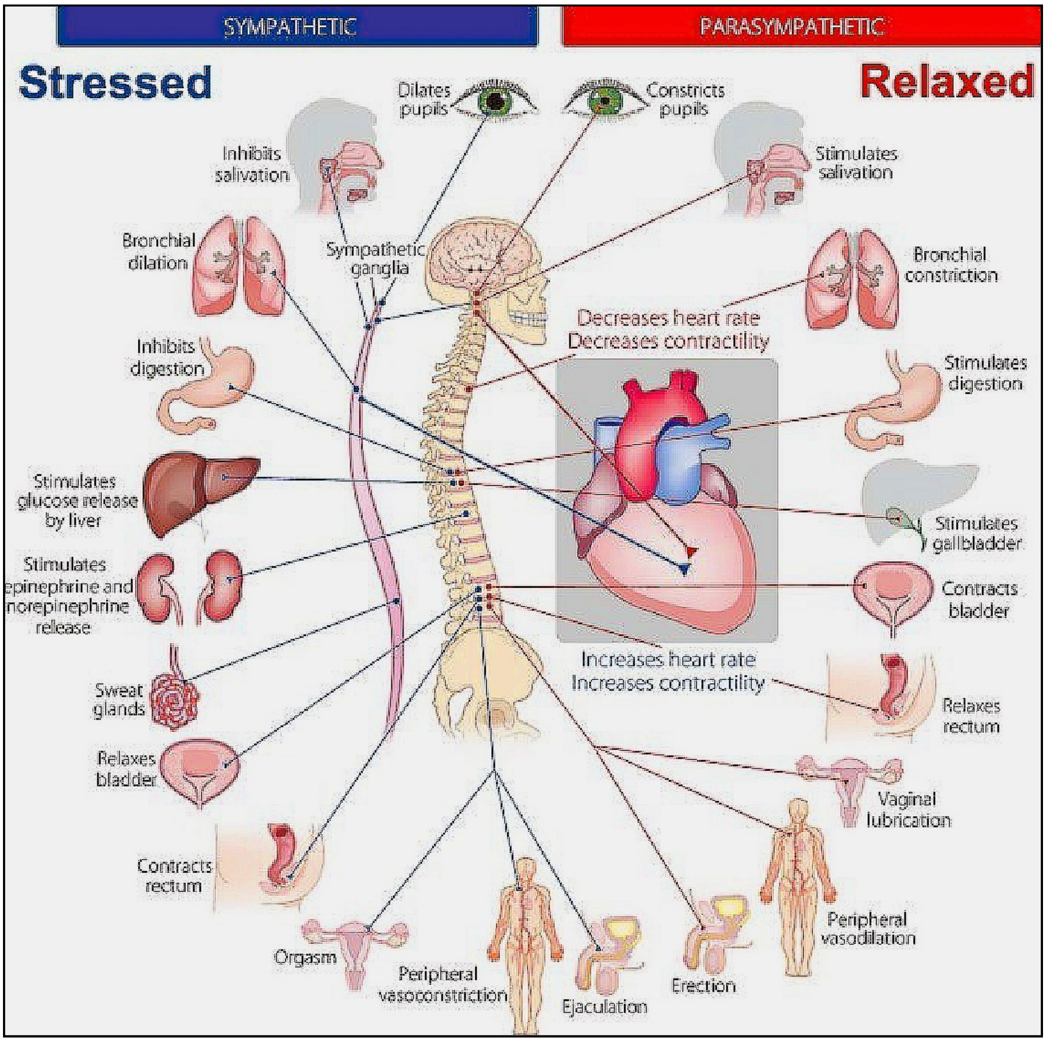
If is normal to feel anxious. feel tense, nervous and perhaps fearful if something is going to have a big life changing impact. As a result there may be difficulties with sleeping, eating or concentration. Some of the common causes of this are:

Attending an interview, starting a new job, moving house, having a baby, being diagnosed with an illness, going into hospital, deciding to get married or divorced, sitting an exam, a DWP form or particularly for those with ME/CFS DWP medical examination

The HPA axis and the body's reaction to stress.

Suppose a native in darkest Africa comes face to face with a lion. His body will react to this stress via the HPA axis to prepare him to run, climb a tree or choose some other way to survive by evading the lion. The HPA activation triggers the production and release of steroid hormones the primary stress hormone being cortisol. Cortisol is very important in organizing systems throughout the body to run including the heart, lungs, circulation, metabolism, immune systems and skin to deal quickly with the lion threat. It also increases blood sugar levels so there is plenty of energy available. The following adaptions occur:-





Catecholamines i.e. dopamine, noradrenalin and adrenaline stimulate the area of the brain called the amygdala, which triggers an emotional response to a stressful event, that is fear.

Neuropeptide is a small protein that decreases sleep and increases alertness and anxiety.

Memory Effects, both long & short term. During the stressful event, catechol amines also suppress activity in areas at the front of the brain concerned with short-term memory, concentration, inhibition and rational thought. This allows a person to react quickly, either to fight the lion or to flee from it. Also it suppresses the ability to handle difficult social or intellectual tasks and behaviors during that time. At the same time the brain is signaled to store the emotionally loaded experience in long-term memory by neurotransmitters. This is thought to be because in primitive times, this brain action would have been essential for survival. Long term memories of dangerous situations such the lion would be critical for handling these threats in the future. Recent research findings also show that during times of stress, nerve cells in the brain interpret chemical signals abnormally. Instead of switching "off" these nerve cells interpret the signals as telling them to switch "on." This is a bit like car brakes fading, due to heating after descending a steep hill/

Action by the heart, lungs, and circulation. As the lion comes closer, the heartbeat rate and blood pressure increase instantaneously. As the lungs take in more oxygen, breathing becomes rapid. Red and white blood cells are discharged from the spleen, enabling the blood to transport more oxygen throughout the body. Blood flow may actually increase to 3- 4 times that of the resting rate or higher. This equips muscles, lungs and brain for the anticipated extra needs.

The immune system's response. The effect of stress of the lion encounter on the immune system causes mobilization of resources into potentially critical areas; the bodies' front lines such as the skin and the lymph nodes, where injury or infection is most likely to occur. This is effected by steroid hormones which reduce activity in parts of the immune system, so that specific infection fighters (including important white blood cells or other immune molecules can be repositioned.

Mouth and throat. There is dryness and difficulty in talking. Also the stress can cause spasms of the throat muscles, making it difficult to swallow and speak. This is because fluids are diverted from nonessential locations.

The skin: The effect moves blood flow away from the skin to support the heart and muscle tissues so that in the case of a wound, bleeding and blood loss is reduced. Hair seems to stand erect, and the scalp tightens. The skin becomes cool clammy and sweaty.

Metabolic response: Digestive activity, a non-essential body function is shut down during short-term periods of hard physical work or crisis. Blood sugars are raised to ensure there is sufficient fuel to handle the stress (lion).

The bladder and bowels. Intestines and bowel activity are inhibited and also that of the bladder. via adrenalin-like hormones and the sympathetic nervous system. The sympathetic nervous system activates along with the HPA axis. However the opposite applies if severely stressed enough.

For the relaxation response, once the threat has passed stress hormones return to normal. The body's systems then return to normal.

HPA problems & ME/CFS

In the early 1990s research in America revealed that ME/CFS patients have impaired HPA activation. When happens is that the HPA system does not activate or come in when it should, and can be thought of being reluctant to kick in. This means physically when the resources are needed to deal with stress they are just not there. Eventually if stimulated sufficiently the HPA axis over activates. More seriously I've seen people with ME/CFS, when stressed, over react, particularly with respect to anger.

Following this discovery there was a flurry of follow-up research papers in the hope that it might lead to some treatment or treatment intervention. Some looked at cortisol level. Some looked at ACTH. What they found was that there was too much variation between individuals to draw any significant and valid conclusions. I think this is because the selection of subjects for the research didn't take into account subtyping. Dr. Kerr more recently found seven subtypes in gene expression studies. It is most likely that the different subtypes are effectively different conditions with the same symptoms, and need different treatments. Along with this came clinical trials with cortisol but again no definite conclusion could be reached. On average I find only about 30% of patients benefit from any given intervention.

Change and Control of your thoughts.

In the world everything has some level of controllability. It can be put into three levels

- Things over which we have direct control. e.g. how we spend money and lifestyle.
- Things over which we have partial control e.g. health, and politics
- Things over which we have no direct control e.g. Aging and sex

Research suggests that we have sixty to eighty thousand thoughts a day. We have not control over them but we can control how we act on them. The thoughts can be weird; can be irreverent nothing to do with what we are doing. They can also be negative or positive. All of us have an inner voice (conscience) talking away to us telling us what we should and should not do. This can be right or wrong and we have to interpret it in a conscious way. The classic example of the inner voice is schizophrenia where the inner voice is negative and out of control and distant from reality.

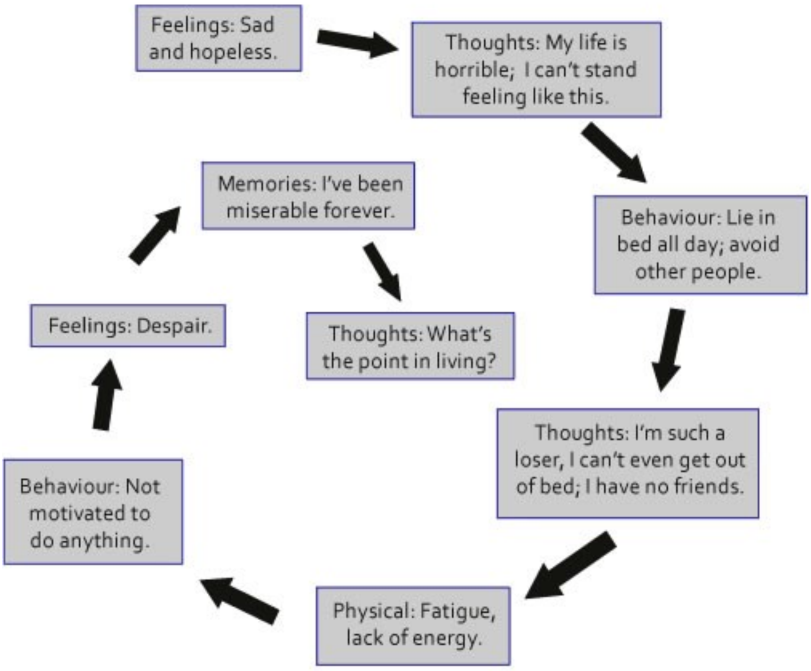
Cognitive Behavioral Therapy (CBT)

CBT is a type of counselling treatment that helps people to understand the thoughts and feelings that influence behavior. CBT is advocated by NICE and commonly used to treat a wide range of disorders to help people cope with ME/CFS as well as addiction, depression and anxiety. It focuses on teaching patients how to identify and change destructive or disturbing thought patterns that have a negative influence on behavior. CBT aims to break negative vicious cycles by identifying unhelpful thought processes and challenges your reaction to them. The principle deals with our current way of thinking rather than delving into past experiences. Hopefully, once we understand the power of these negative thoughts it is possible to change the way we think and learn to think in a more rational and positive way. Sometimes too much emphasis is placed on CBT in ME/CFS and a significant proportion of ME/CFS patients believe CBT is harmful. There are some branded versions of CBT commonly used in ME/CFS e.g. the lightning process and reverse therapy. While CBT does have its place in rehabilitation in ME/CFS, it does not affect the disease process, it is only a management tool.

CBT tries to correct some common errors in thinking style that can lead to this negative or potentially harmful thinking:

- emotional reasoning - I feel guilty so I must be guilty
- jumping to conclusions - I'm no fun, nobody would want me around
- all-or-nothing thinking - if I don't do it perfectly, there is no point in doing it at all
- over generalising - nothing ever goes well in my life
- Multiplication - this situation is awful, there is nothing I can do about it.
- Personalisation/blaming - the evening didn't go well, it was my fault, I 'should' have been more entertaining.

CBT attempts to tries to substitute these negative thinking styles with more positive thoughts appropriate to reality. How you judge a situation depends on the kind of thinker you are. On the right is a negative spiral of thoughts which CBT is designed to control.



The ABC process:

Think about when your partner comes home

Stage	Unhealthy way	Healthy way
A) Triggering Event	Partner comes home and does not speak	Partner comes home and does not speak
B) Beliefs about the event	What have it done, I must have upset her	Somethings gone wrong ?
C) Your assessment	I worry that this will put stress on our partnership	How can I be positive & help ?

This is an example of the ABC process after Albert Ellis, a well know psychotherapist. If we apply the process to this scenario, the way we think can have a major effect in how we interpret situation. This is what CBT is all about.

How to manage your time.

Most of us reading Pathways will have ME/CFS. There will be better days and worse days. Everyone is different. Of the 168 (7x24) hours in a week there may only be 10% of these where we get quality time to do what we have to. You have to prioritse you time to make best use of it. The following table illustrates the issues.

Priority	Urgent	Non urgent
Important	My medicines have run out. I need to get a supply ASAP as I am running out.	I need to set up my repeat prescriptions so that my pharmacy can deliver them
Not important	I need to get a supply of my vitamin and mineral supplements as they are running out	I need to get my vitamin and mineral supplements from the pharmacy.

This method can be applied to prioritizing many things. Like you are short of money—do you pay your electric bill or sky subscription ?

One thing you have to do with ME/CFS if to managing your time effectively. While it can be dull to plan ahead, by organising, planning and prioritizing you can decide what you want to do, how to deal with things and how to fit everything in that needs to be achieved. This will also help reduce stress as and conserve your energy levels. Pacing is a skill that is learned and not inherent so it is possible to improve. Many people choose to do the easiest things first whereas it takes a conscious effort to learn to do the thing first that you want to do least. It reduces stress as it frees up the mind from the nagging knowledge that action is needed to take away some of the personal angst for you. You become clear what the short term priorities are. In our case the not important tasks are lifestyle choices and are more a comforting ‘leaning post’ rather than being something you really need.

Live as best as you can

The golden rule with ME/CFS is to avoid stress where possible. However, stressful times are unavoidable. There will be times when life becomes stressful due to things like; DWP form fill outs, DWP medical examination, moving house, bereavement, a relationship break-down or debt.

If your read the news, you will realise that 3 out of 4 reported health problems are stress related.
1 in 4 people are suffering from a mental health condition at some point in their lives and the cost of sickness absence in the workplace is rocketing due to stress. You can see that it is a common problem!
Be careful, there is a lot of fear around admitting to stress to you. Hopefully controlled stress will help

you recover.

Ways to stack the odds in your favour for recovery.

Food and diet. There are a lot of diets advocated by various people and organisations for ME/CFS. Unless you have any other chronic condition e.g. coeliac disease or diabetes that requires a specific diet, stick to a balanced diet with plenty of variation. Avoid diets that restrict your calorific intake severely, e.g. lemonade diet, citrus diet. One food source diets will lead to nutrient deficiencies. Avoid Atkins type diets which restrict carbohydrates to almost zero. Please check back in past issues of Pathways where we have included diet sheets from the British Dietetic Association which is a reliable source of advice.

Exercise: While for normal people exercise can make us feel good, it can be detrimental if not properly paced. Please remember that the fatigue rebound can occur immediately or 3-4 days later. What you really need to do is keep physically active within your limit, and this will:

- help you sleep better
- focus your thoughts and aid concentration
- improve your confidence and self-worth
- increase motivation
- Discharge negative emotions, helping you to feel less angry and frustrated.

Sleep. Typically adults need around 8 hours per night. Some people with ME/CFs have sleep difficulties whereby the sleep cycle is delayed commonly by 6 hours. Others particularly children suffer from sleep-cycle inversion, whereby they sleep all day and are active by night. It is important to get sleep, to recover. Sleep when you need to, and don’t try to force a normal sleep cycle as it will increase your fatigue levels. If you are worried or feeling stressed it is common to have difficulty sleeping. The followings strategies may be useful:

- Allocate a worry period - sort out a time in the day that you allow just for worry. Try and stick to the same time and same place. Worry can be negative, so don't select a time and a place which you associate with a pleasurable environment. Use a diary—if a stress-provoking thought or worry enters your mind, write it down and save it for your worry period.
- Challenge the thought process—worries that you are facing can be constructively explored by using tools such as the ABC model. They can help you think more rationally about the particular worry. Our emotions, however, can be powerful and in some instances it's about accepting uncertainties as a part of life.
- Come up with an action plan—Try scheduling in actions to resolve the problem.

Some ways we can help ourselves improve sleep are:

- Optimize your environment. - is it too hot, too cold, or too noisy? Keep your bedroom for a place to sleep and have sex. If possible avoid studying, watching TV, and eating in your bedroom. Associate your bedroom as a place for sleep.
- If your ME/CFS says sleep, listen to your body. Avoid advice to resist sleep as it will only stress you further.
- Avoid high caffeine drinks i.e. tea, coffee, alcohol and certain energy soft drinks before bed.
- Activity decreases symptoms of stress and anxiety. Paced physical activity naturally tires us out but also makes us feel better
- Relax, take a bath, read or try a breathing exercise like the Alexander Technique.

Commit to ME/CFS Management.

Just remember that at present ME/CFS has no magic cure—it needs to be managed and effects kept to a minimum.

Young People's Column *by Jane Colby*

Executive Director of The Young ME Sufferers Trust (TYMES Trust)
www.tymestrust.org

"My dad was an artist. Here's a selfie with some of his oils."
All the best

Hello everyone,

Some years ago I wrote a book for young people with ME, their families and teachers. It was a story about a girl called Zoe, and I included a personal message for young people with ME, to help them understand and cope with their illness. I know what it's like you see, because for a long time I was stuck in bed with ME myself.

Here is the first of a series of excerpts from the book that you might find helpful.

When Zoe gets ME, she has to find a way to save enough energy for her body to heal itself, without losing the essence of who she is. That isn't an easy challenge, and she has to change her lifestyle to meet it.

Like Zoe, people who get ME usually find that they can no longer do the things they used to do. When they try to "get back to normal" too soon, before their bodies have healed sufficiently, they just relapse – that means they get worse all over again.

This can be frightening and very depressing. It may have happened to you. Some people no longer feel like the same person they used to be. Who is this person who used to be good at maths? - or writing, or sports, or whatever, they may ask themselves.

The answer is really very simple. Someone with ME is still the same person as before—but they are also a new person at the same time.

Just like everyone else, you are a mixture of all the things that have happened to you in the past, plus the things that are happening to you now.

What's important is to accept what has happened. When people have ME, they need to change their lifestyle to help their bodies save some energy to heal and get strong again. There isn't a pill that the doctor can give you for that! But our bodies are very good at healing. If you cut your finger, it heals up all by itself. Like magic, when you think about it. It's just the same with ME except it can take a long time and you need to trust your body and look after it. It's trying its best.

GETTING ADVICE

If your mum or dad need advice about your education, or anything to do with ME, they can phone our Advice Line on 0845 003 9002 and leave us a voicemail saying what the problem is. Then we'll find the information and phone back.

COLOUR GREG'S SPRING

You might like to colour Greg's Spring picture from our latest colourful issue of Russell's Report. We have some prizes here waiting to be sent out. Just go to www.tymestrust.org and click on the Tymes Magazine button. Open up Russell's Report and print out the front page with the Spring picture. When you've finished, you can post it to us at Tymes Trust, PO Box 4347, Stock, Essex, CM4 9TE. (Let us know your name, address and age. Make sure your parents are happy for you to do this.) See you next time!

Jane

News about DLA to PIP changeover

From Benefits & Work

The DWP has brought forward the date when claimants with an ‘indefinite’ or ‘lifetime’ award of disability living allowance (DLA) will be forced to claim personal independence payment (PIP). The decision is a deliberate snub to campaigners, and to the courts, after delays in processing PIP claims were found to be unlawful just last month.

1,800 assessments a day. 3,000 claimants will now start being assessed for PIP from 13 July 2015, instead of from October, to allow the DWP to test the reassessment process, including letters and phone call scripts. The number being tested is then intended to rise massively, to an average of around 1,800 reassessments every day throughout 2016. All working age DLA claimants will have been assessed for PIP by late 2017, if things go according to plan.

Over half will lose out: More than half of all existing DLA claimants are expected to lose out under PIP, getting a lower award or nothing at all. In their original estimates made in 2012, the DWP expected:-

29% of reassessed claimants to end up with an increase in their award
16% of reassessed claimants to stay the same
29% of reassessed claimants to end up with a decreased award
26% of reassessed claimants to end up with no award at all

At present, the award rate for DLA to PIP reassessments has fallen from a high of 79% last November, down to a current low of 72%. This means that currently 28% of DLA claimants do not get an award of PIP. Even if the 2012 estimates end up being correct overall, they make a mockery of the minister for disabled people, Justin Tomlinson’s claim to the house earlier this month that:-

Benefits and Work
Guides you can trust

“. . . under the PIP system 22% of claimants will end up getting the highest rate of support, which is higher than the 16% under the DLA. We are doing more to help the most vulnerable in society. We are clear that we will protect the disabled and vulnerable. Let us remember that.”

In fact, because 22% of a smaller number of successful PIP claimants are expected to get the highest rate, it works out as almost exactly the same as 16% of the larger number of DLA claimants who get the highest rate.

So ... not doing more after all. But it has already become apparent in a few short weeks that the new minister for disabled people acts solely as a cheerleader for the DWP, with not a shred of interest in fighting for the rights of those he is supposed to champion. Meanwhile IDS (Ian Duncan Smith) has sparked incredulity and scorn following his claim last week that the Tories will “ensure that those who cannot manage and have disabilities are treated with the utmost kindness”. *More on Benefits & Work Website...*

Advice to Leger ME Members

- *The quickest will to get a benefits refusal is to fill out forms without advice from a welfare rights service. Secondly is the medical track record is inadequate.*
- *The golden bullets to deal with DWP matters are Benefit & Work Guides which are free to Leger ME members as a PDF download.*
- *For Leger ME members, there is no charge for case review and form fill out assistance at Leger ME at planned events at the Redmond Centre. There may be photocopying charges if needed.*
- *Please contact us ASAP if you received a DWP form don’t wait.*
- *Benefit Refusal inquests are free to anyone at the Redmond Centre.*

Recipe Corner *by Carolyn*

Easy Gooseberry Cobbler

Cooking time
Prep: 10 mins Cook: 30 mins
Servings 6
This low-fat and satisfying cobbler is the perfect way to end a roast lunch with friends in summer.
Additional information: Can be frozen after baking (that's handy!)

Ingredients

- 750g gooseberries, washed, topped and tailed
- 100g caster sugar (or, if you have a loved one with diabetes in the house, use fructose instead)
- 1 teaspoonful grated root ginger
- 3 tablespoonful elderflower cordial

For the topping

- 140g plain flour
- 2 teaspoonful baking powder
- 25g butter
- 25g caster sugar
- 150ml buttermilk
- 1 tablespoonful demerara sugar

Method Heat oven to 190C/170C fan/gas 5. Place the gooseberries, caster sugar, ginger and elderflower in a saucepan with 4 tbsp water and cook, covered, for 5 mins until the berries begin to pop. Put into a baking dish.

Make the topping:- Sift the flour, baking powder and a pinch of salt into a mixing bowl. Rub in the butter until the mixture looks like breadcrumbs, then stir in the caster sugar.

Mix in the buttermilk to give a soft, sticky dough. Dollop **spoonfuls** on top of the gooseberries, then sprinkle with the demerara. Bake for 25 mins or until golden brown and crusty. Stand for 5 minutes, then serve with some low-fat ice cream, fromage frais or custard. I dunno about this low-fat ice cream, gotta be really nice Cornish ice-cream for me!

Nutrition per serving:
Kcalories 255; Protein 5g;Carbs 53g;Fat 4g;Saturates 2g;Fibre 4g;Sugar 34g; Salt 0.52g

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Sarah's New Routine

So I tell my man I'm working on a stand-up routine about M.E., and he goes, "Don't you mean sit-down routine? Why not a lie-down routine?"

So I say, "Very funny, now bring me some more water. It's almost noon and I've only had three litres today."

But seriously, folks, it's not easy having M.E. There's so many ways you can screw up - do too much, do too little, eat the wrong foods, get too hot or too cold and you'll be sorry. Why, the other day I got in trouble for resisting a rest!

No, it's not so bad. Actually, I'm pretty lucky to have M.E. Yes, think about it: no boring meetings, no long commute, every day a bank holiday day, and you know that wonderful feeling you have after you've been working out or shovelling snow for a couple of hours? That feeling when you're so tired you just FLOP down on your bed and your muscles go "THANK YOU THANK YOU THANK YOU!" Well, I can have that any time I want, just by unloading the dishwasher!

In fact, I'm getting so good at resting now that I'm thinking of going professional. Yep, I'm getting ready to join the 'World Resting Federation'. Picture it: Me, a Pro Rester. I'll be in my pyjamas, with my blanket for a cape, and they'll call me The Somnambulator. Every time I defeat an opponent I'll get this serious look on my face and say, "Rest in peace."

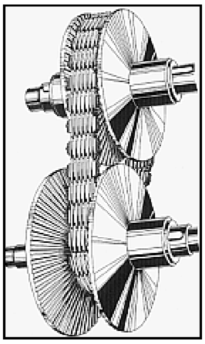
Thank you, thank you all, you've been a great audience!

Motoring and ME: The case for the hybrid car.

Many people with ME/CFS find that a car with automatic transmission enables them to drive better and further. Manual gear changing and controls co-ordination requires considerable brain power and energy, and this often distracts some people with ME/CFS from concentrating on the road. All manufacturers offer automatic transmission on their models but there is a wide variety of mechanical arrangement for the transmission. Most car showroom salesmen haven't clue how the automatic transmissions work. More recently hybrid type transmissions have become popular. In order to illustrate the difference between hybrid and conventional automatic transmissions I've used the Toyota Auris as an example. The table below is taken from the Toyota Price list May 2015 and for Auris Icon 5 door petrol hatchback. The Auris is made in many variants, and it is possible to compare the transmission type. The first line is the traditional manual gearbox version. The second line option follows the usual trend of being about £1000 more than the manual version. Interestingly the auto version is slightly more powerful and marginally more fuel efficient. The auto hybrid has a slightly bigger engine delivering the same power output but using far less fuel, saving around 16%. However there is a cost penalty of 11.5% against the manual and 11% against the automatic version. If you drivie the two auto variants, they both have the same drives, neutral, reverse, park and low gear options on the gear selector with other option buttons. So what is the difference?

Transmission type	Engine Size	Power DIN HP	Emissions g/km	Price
Manual (6 speed)	1.6l	132	138	£17,995
Auto (variomatic)	1.6l	136	136	£18,995
Auto hybrid	1.8l	136	84	£20,645

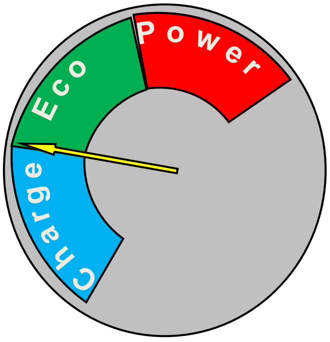
Conventional Auto gearboxes. Think about a modern bicycle. At the rear wheel there is a series of cogs. There is a mechanism whereby the chain is moved to different cogs selected by the rider. The bigger cogs are low gears, providing pulling power at low speed e.g. for hills, the smaller cogs are high gear for speed on the flat but with very little pulling power. When the derailleur changes gear, the rider has to stop peddling until the gear is engaged otherwise damage results. This is similar to the depressing of the clutch to select a gear in a conventional; manual car. Automatic transmissions come in various designs but achieve the same objective. On the left is the heart of an early variomatic gearbox manufactured by Daf. The lower cog is made of two separate tapered ridged plates. In high gear as shown, the two plates are furthest apart for starting. As a higher gear is required there are mechanical arrangements to bring the two lower plates closer together. This makes the drive belt move to ride further to the outside of the plate thus reducing the gear ratio. There are other designs of auto gearbox using hydraulic fluid. This can be thought of in terms of a fan blowing a windmill in an enclosed box of oil.



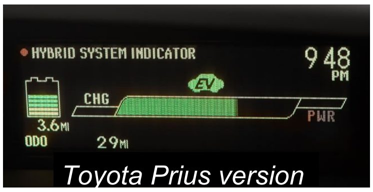
Petrol engines have to spin (idle) all the time because they require power to work the valve gear and oil pump. They idle at about 800 rpm, only producing enough power to keep themselves running. They have to be started, usually by a dedicated starter motor. The more fuel sent into the engine, the faster it goes and the more power is produced. Most petrol engines have a useable power-band between 2000-3000 rpm for economy and 3000-4000 rpm for power when accelerating through gears. They can spin only in one direction, and need a clutch or torque-convertor to take up drive from setting off and a selection of gears to cope with different road speeds. Petrol engines are good at producing power at constant speed, and have a high power-to-weight ratio. In the case of my car 55kg of petrol will give me a 450+ mile range.

Electronic motors produce the same pulling power throughout their entire speed range and furthermore they can work in reverse just by switching a few wires round. They can also be used to generate power in the case of braking or battery charging. Perhaps the best example of this is the wind up radio where the clockwork spins a small electric motor wired out as a dynamo. Electric cars can brake using this effect, and storing the recovered energy in a battery. The catch is that electric motors and their batteries have a low power-to-weight ratio which in practice limits their range. In the case of my car 50kg of battery gives me only a 10-11 mile range.

The epicyclic gearbox. While the manual and automatic box have two shafts, one for input and one for output, the epicyclic gearbox has three shafts. Going back to learner days, we learned that the drive-shaft from the engine went into a differential gearbox. This had two outputs, one for each driving wheel. Its purpose is to allow the left and right wheels to turn at different speeds when cornering. The key to the hybrid transmission is the epicyclic gearbox. If a petrol engine attached to one port, and an electric motor to the other and to a drive-shaft by a series of clutches and clever electronic wizardry is possible to create a hybrid engine running on both electricity and petrol. The first production hybrid car was the Toyota Prius which was first produced in 1997, and has since appeared in many models by major manufacturers.



Sitting in the driving seat of a hybrid car is very similar to being in one with a conventional automatic gearbox, with no clutch, and only an accelerator and brake pedal. There is however no tachometer. The tachometer measurers the speed at which the engine spins and jumps up and down with gear changes. This is replaced by a hybrid-status indicator. On the Auris hybrid the arrangement is as on the right. When parked or the needle is at the neutral point. The engine may or may not run depending on the state of charge on the hybrid battery. When you press the accelerator pedal the needle moves onto the green. The further you press the accelerator, the further the needle moves. It move into the green of the eco (energy saving) mode. On a hybrid you start on the electric motor. As then speed increases, at some point the petrol engine will come in. At that point both the electric motor and petrol engine are supplying power to the wheels. The further you press the accelerator the more power comes from the petrol engine. As the speed increases or you further depress the accelerator, the needle moves into the red. This is when the petrol engine takes over completely and is effectively like a normal petrol car in high gear. When you slow down, the needle moves into the blue charge sector. The petrol engine is off, and the electric motor then acts as a generator supplying power to charge the hybrid battery and other car electrics.



Toyota Prius version

If descending a steep hill or braking heavily then the needle will move further into the blue. Braking is achieved by both the normal brake pads and the motor acting as a generator in combination. So in effect when you brake, rather than the energy being lost as heat, it is converted to electricity, stored in the battery and used to propel the vehicle. This energy recovery system is why hybrid cars do more miles to the gallon and emit less carbon dioxide than conventional cars.

My own car is a Toyota Prius plug-in hybrid. This has the extra ability to charge the hybrid battery from the mains and is a dual-fuel vehicle, with a bigger transmission battery. It has two fuel gauges one for petrol and one for battery charge. In straight eco-mode the Prius will do 78 mpg, which is ideal for driving around Doncaster. On fast motorway runs at 70 mph it returns 60mpg. The petrol range is in excess of 450 miles. Running on all electric mode, the maximum speed is 54 mph, and it has a range of 10 miles. One battery charge will take me to most places around Doncaster and get me home. Charging is via cable which plugs into a normal domestic 13amp socket in the garage. The time taken to charge to full is about one and a half hours. Sometimes the car is charged three times a day between journeys. If the battery goes flat in a journey, the petrol engine pulls in seamlessly –so my range is not restricted by battery capacity as with all electric vehicles. The cost of 10 miles of electric-only running is about 22p. If petrol costs £5 a gallon, the equivalent cost for electric only is around £1.32 per gallon. If you choose a plug-in hybrid there is around a £4000 cost premium over the normal hybrid. The energy recovery figure for braking to stopping at 30 mph are the equivalent of 0.1 miles, at 40 mph is 0.2 miles and at 70mph is 0.6 miles. Long steep hill energy recovery can give you an extra 1-2 miles of battery capacity. That is my case for the hybrid car. *Mike*

North of Doncaster

Personal travel comment from Trever Wainwright

“Ouch” I thought trying not to wince as the needle went into my arm, the first of three rabies inoculations I needed on my return to Austin Wildlife Rescue (AWR) if I wanted to work with racoons and skunks, and I did. Knowing the pleasure I got last year I knew it would be well worth the cost but I was amazed at the difference; it cost as much in the UK for all three as it would for perhaps one in America. Mentioning my plans to a friend at church, “Skunks?” she said, “Yes” was my reply, “If they were people Jesus wouldn’t turn them away”. She had to agree. The conversation ended with her smiling when I added further, “We’re all God’s creatures, the only difference is we walk on our back legs”.

Two more inoculations and a month later I was on the plane looking forward to 24 days of reading, writing, reciting poetry, and travelling across Texas doing it, but uppermost in my mind was the following day when once more I would be driving to the AWR and hopefully in addition to helping the animals there would be inspiration to write some more poems, along with dropping off the recent Pathways article about last year’s visit.

Sunday morning driving to the centre looking forward to what was to come it felt great to be there, I thought as I pulled into the driveway. I was welcomed back by Hayley. There were some new helpers to whom I was introduced. At first they seemed a bit perplexed as to why a limey guy was there; a brief explanation that I was there last year sorted it. Volunteers from last year gave me a hug, proudly I showed Hayley my inoculation card, and then it was down to business.

The one thing I did notice is that there were not many bird cages Last year they seemed to be wall to wall and feeding them a bit like painting the Forth Bridge, no sooner had they been fed and it was time to feed them again. Miller the centre’s parrot, still as cantankerous as ever, welcomed me with a screech and tried to bite me. Still it was good to be back. There appeared to be another permanent resident, a large African Spurred called Tito who had kept tunnelling out of his cage at his previous home, truly a great escaper. At certain times he would wonder round the centre reception area, often walking over the feet of staff and whenever the ridge door was opened making a beeline for it. Although initially shy he eventually didn’t mind the top of his head being gently stroked. He shared the centre reception area with a gosling called Ryan after the actor, a nice bit of Texas humour I thought, it was great having him there before he was taken to better facilities.

Even as I was arriving for my first day people were bringing animals in, it never seemed to end. One of the saddest parts was when a badly injured rabbit had been brought in, its back end gone stroking it gently I could feel tears welling in my eyes as it was decided it would have to be put to sleep. It was an emotion I would feel on a regular basis, I was not alone. Shortly after though came a rewarding moment for all when a Screech Owl and Adult Possum were taken to be released. Then a special moment for me, there was a turtle to be released in a nearby pond “perhaps Trevor would like to take it” Madeline said, I didn’t need asking twice. The sense of pride I felt as I carried it the short distance to the pond was immeasurable as I placed it in the shallows mentally willing it well before returning to the centre. Most days after, when parking up, I would look towards the pond hoping it was well.

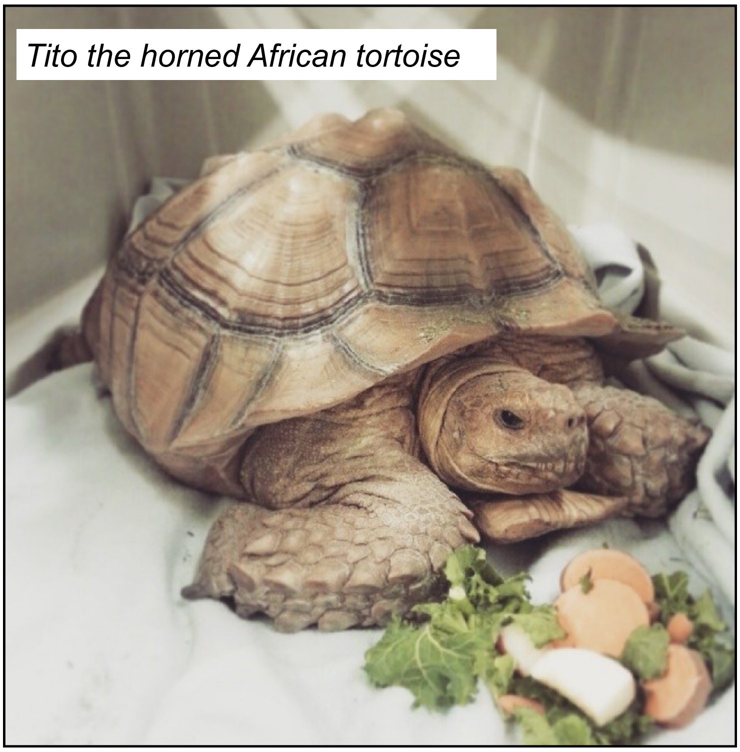
Sherlock was a large adult raccoon that had been dropped off at the centre. His previous owner had been female and he had grown too big. The first time I saw him, Madeline, one of the staff, was helping him out of a large holding cage and he clung to her like a huge teddy. It was a moment I had waited for I was able to stroke him, later I would feed him in his outside cage. On one occasion he had got stuck behind the fencing mesh, this I decided was a job best left to someone else. Later he took up residence in a pair of cut off denim shorts with the legs sewn up. Every cage had them for the animals to rest in, it was there when I was cleaning out his cage and bringing him fresh food I was able to stroke the back of his neck. There were other raccoons to be attended to; one totally laid back never moved during the day, a mum and babies, extra care was always taken there. The best was feeding the juvenile raccoons how they would hold on to the bottle and my wrist whilst being fed, yes it really had been worth the cost of the shots.

Left Eligin, Texas. 400 acres of land where well animals are released, in one day 30 opossums, 23 squirrels, and a mama raccoon were released.

A young skunk, maybe the one I saw at a few days old

The vulture

Ryan Gosling



Tito the horned African tortoise

The Hawk

The young Armadillo

Mother possum and babies in one of the outside cages

Another great moment was when Hayley asked me to hold my hands out and put a 2 day old armadillo in them, cute and fidgety like the one I saw last year. But not to forget the other equally important tasks the baby rabbits could be quite entertaining as they had to be ‘pottied’ which involved stimulation using a paper tissue, and it was always a good idea to have a towel on your lap. The squirrels too often proved testing, hard to catch hard to hold and forever fidgety with sharp claws to match but very entertaining. Just relax for a minute and they were away.

My daily routine though began in the raccoon room where I would first attend to the young possums, providing them with clean bedding paper, food, water and formula, again helping them down to the food. When they had all been attended to, I‘d watch and think there was nothing more satisfying than seeing them eating, either in groups or singly. On one occasion a small possum was chewing on a piece of carrot. It reminded me of Louie, our Boston Terrier pup back home, even more so when it looked up towards me.

There were adult possums to be fed and changed. This required taking a bit more care, particularly with the towels they used as bedding, gloves were available if needed. Once the inside animals were sorted it was then outside to what I nicknamed the parole area, where they were taken prior to release back into the wild. In the squirrel cages they would not come to you but would happily take a piece of apple from your hand. A problem here was ants, so care had to be taken to insure they did not get into the centre on any used dishes. I did get a few bites though.

There was a hawk and a vulture outside, the hawk had one wing damaged which was smaller than the other but was in good health otherwise, both it and the vulture were fed on dead rats and small dead rabbits, the hawk would flit about the cage when he saw me coming the vulture on the other hand would wait still as if weighing me up. Later I would see it being taken away to a bigger cage prior to release, and I felt proud to have been part of the team that had helped to get it ready.

Morale was great among the staff as we shared jokes and one liners. There was time for humour among staff and my comments, particularly when I said to Victoria in reply to something she had said, “And you’ve got a Limey guy for the next hour and a half, what more could you ask for, except a younger model?” At this she turned and went to the fridge, somebody mentioned blushing.

Following my return from the Lamesa Forest Fest there had been a gale while I was away and more birds had been brought in. I could have sworn they knew what the alarm was for, their little beaks opening almost as soon as it went off. More work but I didn’t mind as it made things more varied. I would be there for a further three and a half days before heading out again to another festival, during which time I would see my first live skunk, a baby one perhaps 2 inches and so cute.

My last visit wasn’t planned. It was departure day and I didn’t have to be at the airport until 3pm so rather than leave my car somewhere with a boot full of luggage I decided to put a morning in at the centre. Hayley and Madeline were surprised to see me but welcomed my offer of help, so I got straight on with the possum cages, I noticed a little deer lying in the room covered in a blanket it had been brought in cold and dehydrated, things didn’t look good but it was in the best place. I got on with my allotted tasks, it was amazing how fast time went and eventually it was time to go, so then it was a walk round wishing good bye to those animals that had for a short time been such an important part of my tour, and providing inspiration for more poems. The last animal I wished goodbye to was the little deer. It had taken some fluids, and was lying under a heat lamp gently warming its little body. “Good luck little guy” I thought wishing it well and saying a silent prayer for it to be so. Hayley said the prognosis looked good. I hoped so as I came away, with mixed emotions, sad to be leaving but glad to have been there, and cheered by the thought that in 24 hours I would see another animal that had become part of my life, our family pet Louie.

PS: I’m still in touch with the AWR and recently received the following regarding the little deer. It's with Preston and doing well! It bounced back quickly after they got fluids into it and started taking a bottle the next day. The very day after I left, fantastic. So to quote the words of Spock (with the pointy ears) *may it live long and prosper*, and may AWR do likewise in the field of wildlife conservation.-*Trev.*