Price £ 4.00 (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 No. 60. (Summer 2019)

In many of the woods around the outskirts of Doncaster Bluebells display in late April and May.

You Write In - *Your correspondence received by Leger ME office.*

Margaret writes: I have been reading Pathways 59 and once again it is full of interest and information. Can I just add to your story about Conisbrough Castle car park. Unfortunately, this car park does not belong to the Castle and never has done. This was a FREE car park and belonged to DMBC and was used by many visitors to the Castle and other interesting areas of Conisbrough. About two years ago the DMBC sold this car park to a private company who very quickly put in a charge for parking, this did cause many people in Conisbrough to object but to no avail.

The only car parking spaces for the Castle are the few just inside the gates which does include a couple of Disabled parking areas but as you say the parking is very limited. Some visitors park in Conisborough Church car park and then walk down to the Castle, but if you are in a wheelchair it is difficult pushing a wheelchair back up the hill!

Michele writes: It was interesting to revisit Anne McIntyre's ME/CFS info for Doctors in the Spring Pathways. I will save it and take it to my GP on my next visit. Over the years I've seen different versions of Information about ME/CFS, including the NICHE guidelines and the Chief Medical Officers report. Her version of ME/CFS albeit 25+ years old is still the most accurate and realistic I've seen.

Gwen Writes: I have read the latest copy of Pathways No. 59; I look forward to reading these as I always learn something new. The section on Meares-Irlen Syndrome was interesting to read. The only thing I associate with colours is when you are tested to see if you are colour blind. On page 8 the colour I find most relaxing to read is yellow or white. The most stressful is the dark blue and the red a little bit. The text size easier to read, I would say, is the 10 point even though I can read the 8 point.

Carol Writes: I am wondering if you can help me. My daughter aged 53 has been off work recently with Flu and a Chest Infection for which she was given antibiotics, but now she has a sore throat and feels absolutely rubbish. Yesterday she felt a little better, so did some supermarket shopping, but by 7pm she started with this sore throat and is back in bed. I feel as though her immune system has taken a battering, and that she needs to take supplements to help. What would you recommend she should take? I hope you don't mind me bothering you with this, but I'm frightened in case this develops in M.E.

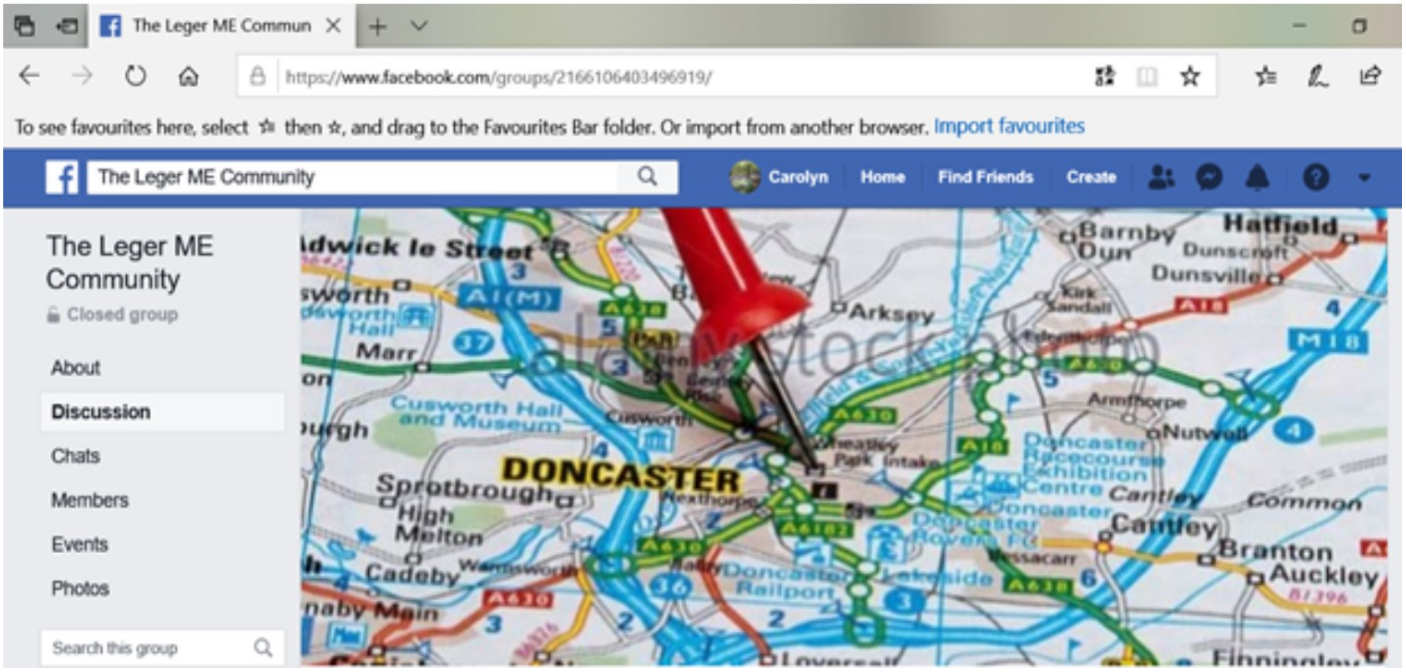
Sounds like she is trying to do something too soon. Best thing for her to do is to back off. It could be a secondary infection or a resistance to antibiotics, but it's really the GP's job to sort this out. Perhaps a general A-Z multivitamin and a high dose of vitamin D3 or of at least 800 units daily may help.

Mary Writes: I would like to warn everyone of a scam alert. I received a call from someone claiming to be from domestic insurance, who I take out my dishwasher insurance with. These people knew my name and that my policy was due for renewal. So, to begin with I believed I was speaking to a company I already used. However, they then began asking for bank/card details, which I informed them they should already have on the system, seeing as I pay via direct debit. They soon hung up on me when I refused to supply bank details. So, I then phoned domestic insurance, who have informed me it was a fraudulent call and have passed the details onto their fraud department. My worry is that as this company knew all my details and used a company name that I was familiar with. Some people could quite easily be duped in to handing over their bank details. Any idea where they got the information from?

Difficult to say, but they were definately fishing for information. There is a covert 'black supermarket' for things like personal information. Sounds to me like this was picked up from a discarded letter, either from your rubbish or Domestics or it could be from a discarded computer disk drive. In the past received letters asking for insurance payments from Domestic Insurance for items which I have never owned.

One thing that everyone should be doing these days is to shred every document with a name and address in it before disposing of it. You should have a computer or phone security App installed suck as Norton. Never give a bank account number or PIN over the telephone. Use a credit card rather than a debit card. Also, bear in mind that it is far cheaper to get a 'kitchen cover' policy rather than pay for a single appliance. I came across this issue when buying a new washer. With British Gas I could get the whole kitchen insured for the same price as Domestic insurance charge for one item.

Leger ME Community Facebook Group



The Leger ME Community Facebook page.

Come and join us in the newly launched Facebook group that is exclusively for our members. Those that have already joined are chatty and friendly and it is proving a great place to get to know new people and enjoy their humour, gossip and company. To enrol, all you need to do is search on Facebook for

The Leger ME Community

You will be asked three very short questions just to check that you are a fully paid up member. If you have any problems with Facebook then please do not hesitate to contact me, Nichola, at

njstockton@talktalk.net

Looking forward to seeing you there!

Group rules

This group is for fully paid up members of Leger ME only

1) **Be kind and courteous.** We're all in this together to create a welcoming environment. Let's treat everyone with respect. Healthy debates are natural, but kindness is required.
2) **No hate speech or bullying.** Make sure everyone feels safe. Bullying of any kind isn't allowed, and degrading comments about things such as race, religion, culture, sexual orientation, gender or identity will not be tolerated.
3) **No promotions or spam.** Give more to this group than you take. Self-promotion, spam and irrelevant links aren't allowed.
4) **Respect everyone's privacy.** Being part of this group requires mutual trust. Authentic, expressive discussions make groups great, but may also be sensitive and private. What's shared in the group should stay in the group.
5) **No memes depicting children negatively.**
6) **No blogs, surveys or selling.**
7) **No explicit sexual content.**
8) **Ask permission first Before you try to contact anyone privately.**

BDA The Association of UK Dietitians

Food Fact Sheet

Wholegrains

What are wholegrains?

A huge variety of cereal crops are grown for food throughout the world including wheat, rye, barley, oats and rice. Grains are the seeds of these cereal plants. The entire grain or 'wholegrain' is made up of three elements:

- a fibre-rich outer layer – the bran
- a nutrient-packed inner part – the germ; and
- a central starchy part – the endosperm.

During the milling process, the bran and the germ are often removed to give a 'whiter' cereal.

What nutrients do wholegrains contain?

Most of the goodness in grains is in the outer bran layer and germ of the seed so wholegrains can contain up to 75% more nutrients than refined cereals. Wholegrains provide:

- fibre
- B vitamins and folic acid
- essential fatty acids (omega 3 fats)
- protein
- antioxidants including vitamin E, selenium
- micronutrients like copper and magnesium
- other parts of the plant (phytochemicals) which may have health benefits.

Why should we choose wholegrains?

Evidence is growing that eating wholegrains regularly as part of a healthy diet and lifestyle helps to keep us healthy and may also help to reduce the risk of many common diseases. It is not only the fibre in wholegrains that has health promoting properties - it seems to be the 'complete package' of nutrients in wholegrains that work together to offer protection.

Research suggests that:

- The risk of heart disease, stroke and type 2 diabetes may be up to 30% lower in people who regularly eat wholegrains as part of a low-fat diet and healthy lifestyle.
- The risk of developing some forms of cancer of the digestive system like bowel cancer may be reduced with higher intakes of wholegrains. Some of the fibre in wholegrains moves food along more quickly and easily, reducing the time that damaging substances are in contact with the gut wall.

- Some of the fibre provides a food source for 'friendly' gut bacteria helping them to increase and produce substances which are thought to protect the gut wall, such as short-chain fatty acids.
- Wholegrains may help in maintaining a healthy body weight over time as part of a healthy diet and lifestyle.
- Wholegrains are usually low in fat but rich in fibre and starchy carbohydrate and often have a low glycaemic index (GI). This means they provide a slow release of carbohydrate into the blood which, together with fibre content, may help keep you feeling fuller for longer - aiding to control snacking and appetite.
- Most cereal foods eaten in the UK are refined and our intake of wholegrains is very low. Surveys show that 95% of adults don't eat enough wholegrains and nearly one in three of us get none at all.

How can I increase my intake of wholegrains?

When choosing foods from the starchy food group, replace refined cereal foods such as white bread and rice with wholegrain varieties such as wholemeal bread and brown rice.

Wheat, oats, barley, rye and rice are the most commonly available cereals which can be eaten in the wholegrain form. To find them, look for the word 'whole' before the name of the cereal e.g. whole-wheat pasta, whole oats and make sure they are high up/ first in the ingredients list.

Multigrain is not the same as wholegrain – it means that the product contains more than one different type of grain. There is currently no advice on what amount of wholegrains to eat in the UK but many experts in other countries say to aim for three servings a day *(see table overleaf for portion size)*.

List of wholegrains

Cereals:

- wheats, including spelt and durums
- rice
- barley including hull-less or naked barley but not pearled
- maize (corn)
- rye
- millets
- oats, including hull-less or naked oats
- wild rice.

Other grains:

- buckwheat
- quinoa
- 'ancient grains' e.g. kamut, freekah, amaranth.

Summary

Most of us eat too few wholegrains to get the health benefits from the whole range of nutrients they contain as we tend to eat more refined cereals. However, given the wide variety of wholegrain foods now available, it is easier than ever to make them the tasty staples of a healthy diet.

Further Information

Food Fact Sheets on topics including *Weight Loss and Allergies* can be downloaded at www.bda.uk.com/foodfacts

Wholegrain foods and ideas for use

Type of Food	Wholegrain varieties	Portion Size = 1 serving	Ideas for use
Breakfast cereal	Whole oats including rolled oats and oatmeal*; wholewheat cereals such as Weetabix, Shredded Wheat, bran flakes, puffed wholegrains, wholegrain muesli*; and wholegrain cereal bars.	One tablespoon uncooked oats three tbsp wholegrain cereal.	With milk or yoghurt and fruit for breakfast or as a snack, as a topping for crumbles, as a snack. Avoid those with added sugar and salt.
Bread and crackers	Wholemeal, granary, wheatgerm, wholegrain with multi-grain*, seeded*, mixed-grain*, soya* linseed*, rye (pumpernickel)*, pitta, wholewheat crackers, and rye crispbread*.	One medium slice bread ½ wholemeal tortilla ½ wholemeal pitta two rye crisp bread two oatcakes.	In place of white bread, cream crackers and sweet biscuits.
Flour	Wholemeal, wheat germ, buckwheat, unrefined rye*, barley*, oatmeal* and oat flour*.	n/a	In baking or recipes in place of white flour or mixed half and half.
Meals	Brown rice, wholewheat pasta*, whole barley*, bulgur (cracked) wheat*, quinoa*, and barley (not pearl)*.	Two-three heaped tbsp cooked brown rice Two-three tbsp wholegrain pasta.	With casseroles, curries, sauces, in soups, and in salads.
Snacks	Wholegrain cereal bars, oats cakes, wholegrain rice cakes, popcorn (plain), wholemeal scone, and wholegrain breakfast cereals.	½ scone two oatcakes two to three cups/ individual bag plain popcorn.	In place of sweets, crisps and savoury snacks, cream crackers and sweet biscuits.

** Low GI varieties of wholegrains*

Written by Sian Porter, Dietitian.

The information sources used to develop this fact sheet are available at www.bda.uk.com/foodfacts

Sleep is vital for good health - Especially in ME/CFS

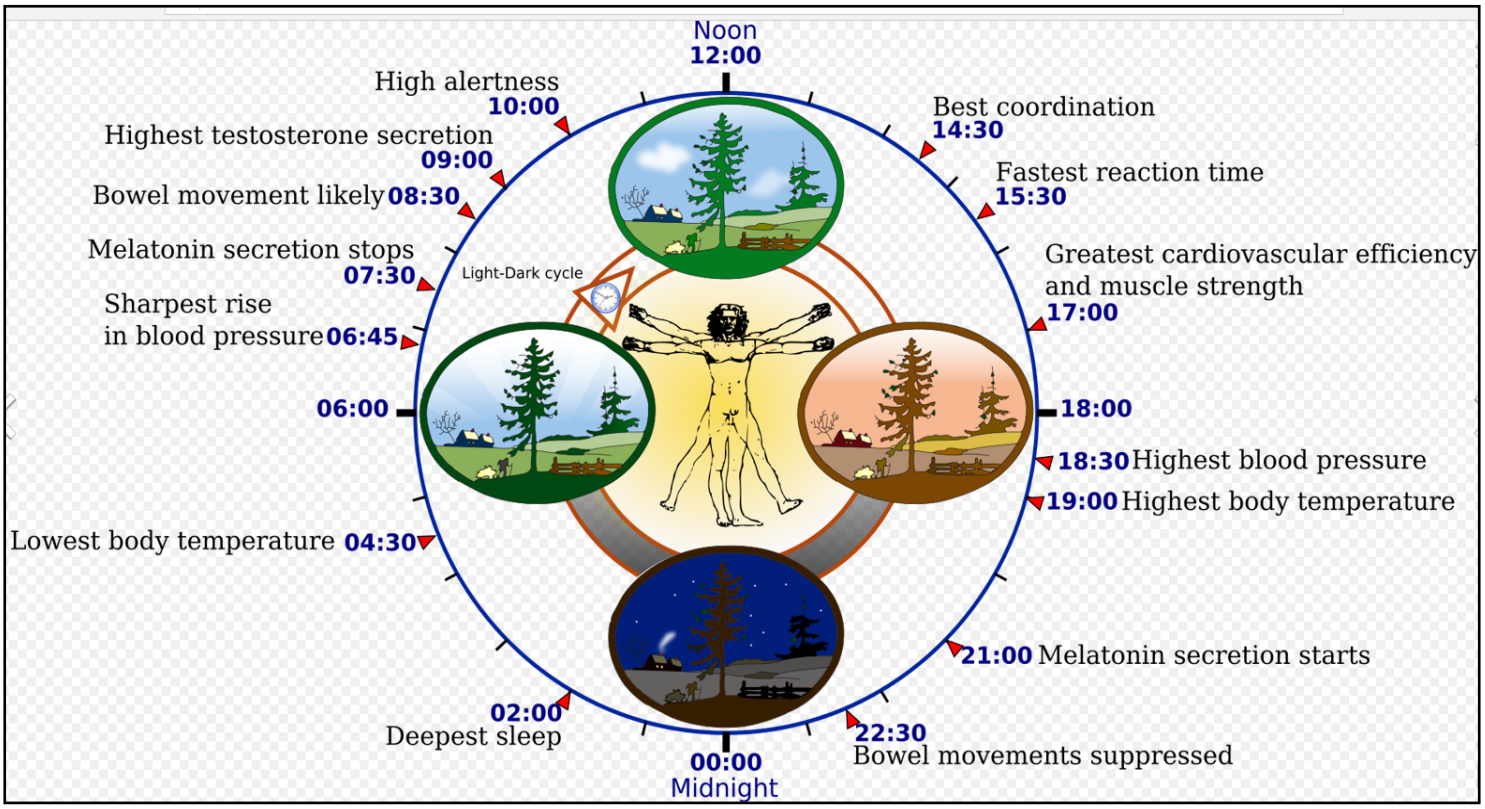
Adapted from Dr S Myhill's website

Humans evolved to be asleep when it is dark and be awake when it is light. Sleep is a form of hibernation when the body shuts down in order to repair damage done through use, to conserve energy and hide from predators. The normal sleep pattern that evolved in hot climates is to sleep, keep warm and conserve energy during the cold nights and then sleep again in the afternoons when it is too hot to work and hide away from the midday sun. As humans migrated away from the Equator, the sleep pattern had to change with the seasons and as the lengths of the days changed.

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. Get the physical essentials for a good night's sleep sorted We are all creatures of habit and the first essential is to get the physical essentials in place: -

- A regular pre-bedtime routine - your "alarm" should go off at 9pm at which point you drop all activity and move into your bedtime routine.
- A regular bed time - 9.30pm latest! Perhaps earlier in winter.
- Learn to recognize the sleep wave - one comes every 90 minutes
- Learn a "sleep dream" to train the subconscious to switch on the sleep button!
- Your day needs the right balance of mental and physical activity.
- Do not allow a bed fellow who snores - you need different rooms!
- A high fat low carbohydrate snack just before bedtime (e.g. nuts, seeds) helps prevent nocturnal hypoglycaemia which often manifests with vivid dreams or sweating or waking in night. Hypoglycaemia - the full story is the commonest reason for disturbed sleep. However some people find any food disturbs sleep and they sleep best if they do not eat after 6pm.
- Perhaps restrict fluids in the evening if your night is disturbed by the need to pee.
- No stimulants such as caffeine or adrenaline inducing TV, arguments, phone calls, family matters or whatever before bed time! Caffeine has a long half life - none after 4pm.
- Dark room - the slightest chink of light landing on your skin will disturb your own production of melatonin (the body's natural sleep hormone) - have thick curtains or blackouts to keep the bedroom dark - this is particularly important for children! Do not switch the light on or clock watch should you wake.
- A source of fresh, preferably cool, air.
- A warm comfortable bed - we have been brainwashed into believing a hard bed is good for us and so many people end up with sleepless nights on an uncomfortable bed. It is the shape of the bed that is important (see section on posture Poor posture - a common cause of low back pain. How to correct it). It should be shaped to fit you approximately and then very soft to distribute your weight evenly and avoid pressure points.

Disturbed Sleep. If your sleep is disturbed by heat and sweating then this is likely to be a symptom of low blood sugar. Another common cause of disturbed sleep is hyperventilation which often causes vivid dreams or nightmares. I suspect much hyperventilation is adrenalin driven from nutritional stress (hypoglycaemia) or psychological stress. If sleep is disturbed by pain, try to find the cause of the Pain. If this is not possible, then one must just take whatever pain killers are necessary to control this. Lack of sleep simply worsens pain. If one wakes in the nights with symptoms such as asthma, chest pain, shortness of breath, indigestion etc. then this may point to food allergy being the problem with these withdrawal symptoms occurring during the small hours. If you do wake in the night do not switch the light on, do not get up and potter round the house or you will have no chance of dropping off to sleep. Use again your sleep dream.

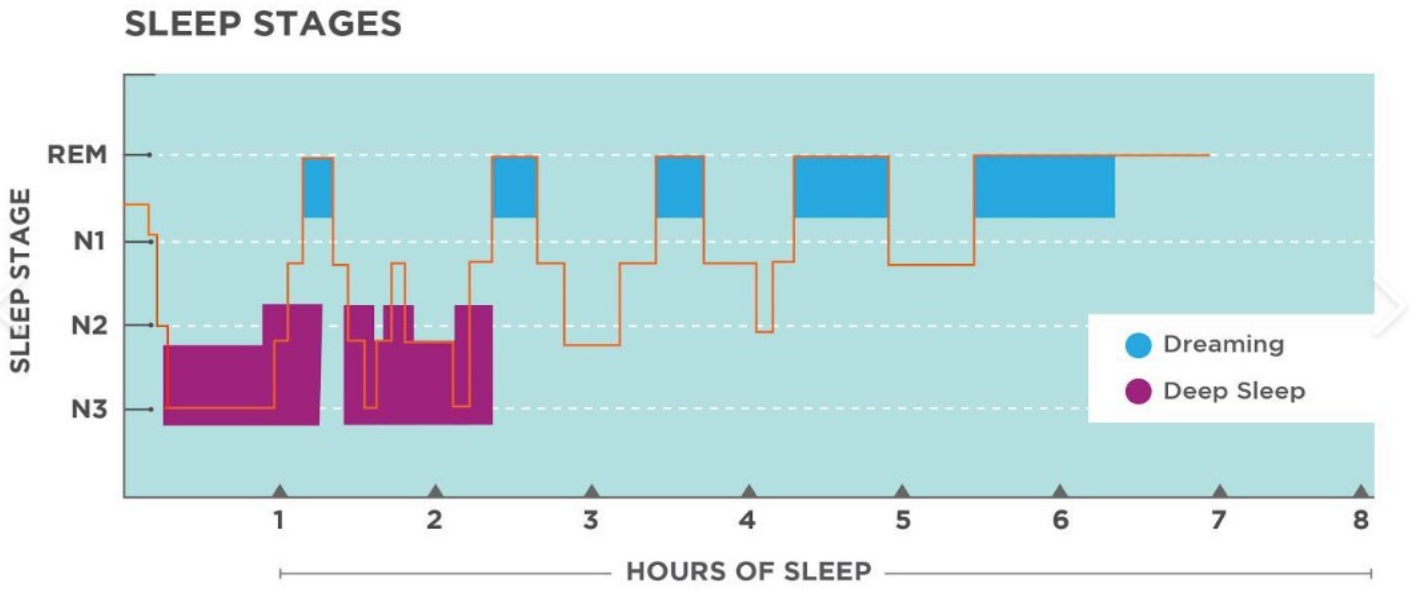


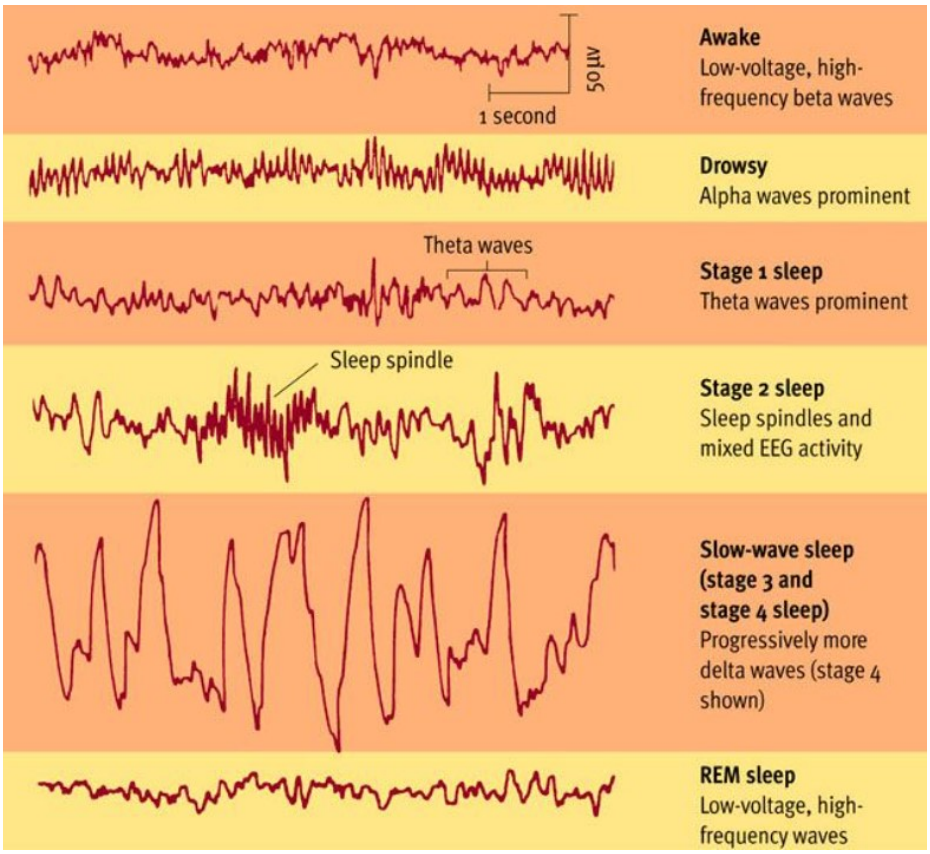
The human biological clock with thanks to Creative Commons

Get the hours of sleep. People needed more sleep during the winter than in the summer in order to conserve energy and fat resources. Furthermore during the summer, humans had to work long hours to store food for the winter and so dropped the afternoon siesta. But the need for a rest (if not a sleep) in the middle of the day is still there. Therefore it is no surprise that young children, elderly and people who become ill often have an extra sleep in the afternoon and for these people that is totally desirable. Others have learned to "power nap", as it is called, during the day and this allows them to feel more energetic later. If you can do it then this is an excellent habit to get into - it can be learned! The average daily sleep requirement is nine hours, ideally taken between 9.30pm and 6.30am, i.e. during hours of darkness, but allow for more in the winter and less in the summer. An hour of sleep before midnight is worth two after - this is because human growth hormone is produced during the hours of sleep before midnight. To show how important the balance of hours of sleep and rest are, divide the day into 12 hours of activity and 12 hours of rest. If you have one extra hour of activity (13 hours), you lose an hour of rest and sleep (11 hours). The difference is two hours!

Sleep when it is dark. Light on the skin prevents the production of melatonin, which is the sleep hormone essential for a good night's sleep. Therefore, the bedroom should be completely blacked out and quiet in order to give the best chance of quality sleep. Even people who are born blind still have a day night rhythm - it is light landing on the skin which has the effect - just closing your eyes will not do it! A study done in 1907 before electricity was available showed that people went to bed when it got dark and rose when it got light. On average through the year they got 9 hours sleep, more in winter, less in summer. Nowadays we average 7 and a half hours of sleep - we are losing on average 550 hours of sleep a year! Loss of sleep is a major risk factor for heart disease, cancer and degenerative conditions! We damage our cells during wakening hours, and heal and repair during sleep - get the balance wrong and one ratchets downhill with time with not enough time to heal and repair the damage created during wakeful hours!

Recognise the sleep wave. Actually sleep does not gradually creep up on us during the evening - it comes in waves. There is a sleep wave about every 90 minutes and you will get to sleep most efficiently if you learn to recognise and ride the sleep wave. Often there is a lesser one earlier in the evening when people drop off to sleep in front of the TV, or they jump and make a cup of tea to wake themselves up because "they are not ready to go to bed" - actually they are! My sleep wave comes at 9.20 and I like to be in bed reading well before this - it is immediately recognisable now and I have learnt to expect it!

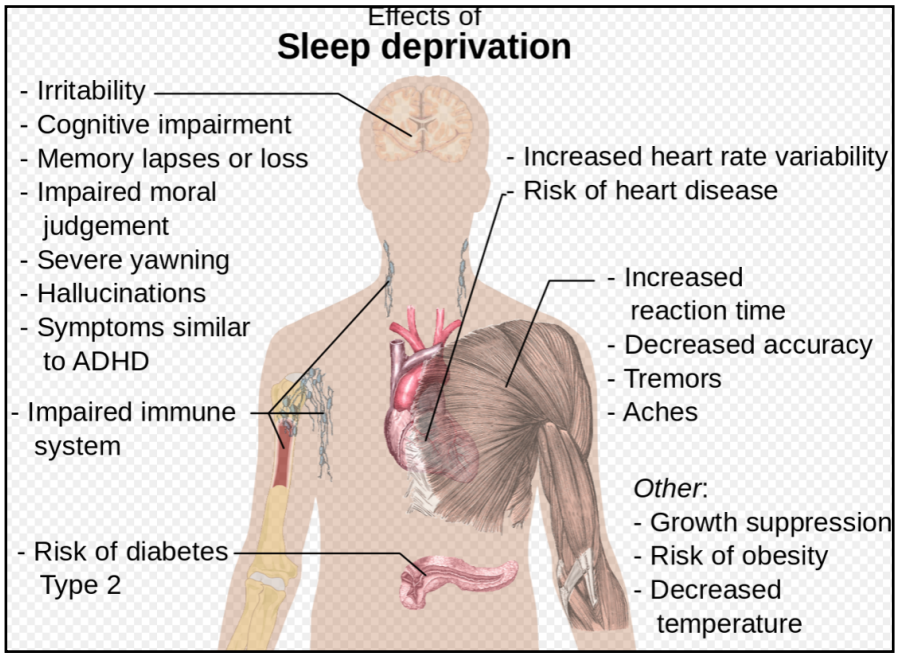




Get the brain off to sleep. Getting the physical things in place is the easy bit. The hard bit is getting your brain off to sleep. I learned an astonishing statistic recently which is that throughout life, the brain makes a million new connections every second!! This means it has a fantastic ability to learn new things. This means it is perfectly possibly to teach your brain to go off to sleep, it is simply a case of pressing the right buttons. Getting off to sleep is all about developing a conditioned reflex. The first historical example of this is Pavlov's dogs. Pavlov was a Russian physiologist who showed that when dogs eat food, they produce stomach acid. He then "conditioned" them by ringing a bell whilst they ate food. After two weeks of conditioning, he could make them produce stomach acid simply by ringing a bell. This of course is a completely useless conditioned response, but it shows us that the brain can be trained to do anything.

Applying this to the insomniac, firstly, he has to get into a mind-set which does not involve the immediate past or immediate future. That is to say if he is thinking about reality then there is no chance of getting off to sleep - more of this in a moment. Then he uses a hypnotic (see below) which will get him off to sleep. He applies the two together for a period of "conditioning". This may be a few days or a few weeks. The brain then learns that when it gets into that particular mindset, it will go off to sleep. Then the drug becomes irrelevant. However, things can break down during times of stress and a few days of drug may be required to reinforce the conditioned response. But it is vital to use the correct "mind-set" every time the drug is used, or the conditioning will weaken.

I do not pretend this is easy, but to allow one's mind to wander into reality when one is trying to sleep must be considered a complete self-indulgence. Treat your brain like a naughty child! It is simply not allowed to free-wheel.



Find a sleep dream that suits you
Everyone has to work out their best mind-set. It could be a childhood dream, or recalling details of a journey or walk, or whatever. It is actually a sort of self hypnosis. What you are trying to do is to "talk" to your subconscious. This can only be done with the imagination, not with the spoken language.

We know that the hypnotic state is characterised by extreme responsiveness to suggestion. You can use this information for conditioning yourself in self hypnosis. Here is a standard procedure to follow. Lie down in bed, ready for sleep initially with your eyes open (the room needs to be dark). Mentally give yourself the suggestion that your eyes are becoming heavy and tired. Give yourself the suggestion that as you count to ten, your eyes will become very heavy and watery and that you will find it impossible to keep your eyelids open by the time you reach ten. If you find that you cannot keep them open and have to close them, then you are probably under self-hypnosis. At this point deepen the state by again slowly counting to ten. Between each count mentally give yourself suggestions that you are falling into a deep hypnotic state. Give yourself suggestions of relaxation. Try to reach a state where you feel you are about to fall asleep. Give yourself the suggestion that you are falling more deeply down into sleep. Some may get a very light feeling throughout the body; others may get a heavy feeling.

Let us assume that your eyes did not become heavy. Then repeat the procedure. You can count to one hundred if you need this period of time to assure an eye closure. The closing of the eyes is the first sign you are in a receptive frame of mind. Let us assume that you get the eye closure. Take a longer count to get yourself in the very relaxed state. Once you achieve this, you should be able to respond properly. The difficult bit is not allowing your brain to wander off into other areas. You must work hard at concentrating on the counting and the responses that achieves. If you respond properly, give yourself the "post-hypnotic suggestion" that you will be able to put yourself under later by counting to three, or using any specific phrase you desire. Continue using it every day and give yourself the post hypnotic suggestion every time you work with it, that at each succeeding session you will fall into a deeper state and that the suggestions will work more forcefully with each repetition.

Each time that you work towards acquiring the self-hypnotic state, regardless of the depth that you have achieved and whether or not you have responded to any of the tests, give yourself the following suggestions: "The next time I hypnotise myself, I shall fall into a deeper and sounder state." You should also give yourself whatever suggestions you desire as though you were in a very deep state of hypnosis. You may ask "If I'm not under hypnosis, why give myself the suggestions?" You do this so that you will begin to form the conditioned reflex pattern. Keep at it. One of the times that you work at achieving self-hypnosis the conditioned response will take hold.....you will have self hypnosis from that time on. It is like learning to drive a car with a clutch. At first you must consciously go through the process of putting your foot on the clutch and shifting gears. Usually there is a grinding of the gears and you feel quite conspicuous about this, but gradually you learn to do this almost automatically and you gain confidence in your driving ability. The same is true of hypnosis. As you work at you task, you gradually get the feel of it and you achieve proficiency in it.

Use medication to reinforce the sleep dream. I instinctively do not like prescribing drugs. However, I do use them for sleep, in order to establish the above conditioning and to restore a normal pattern of sleep, after which they can be tailed off or kept for occasional use. Indeed, viruses can cause neurological damage (for example polio) and this could involve damage to the sleep centre. So often CFS patients get into a bad rhythm of poor sleep at night, which means they feel ill for the day, which

means they get another bad night. They are half asleep by night and half awake by day. Furthermore, their natural time for sleep gets later and later. They go to bed late and if they have to get up at the usual time, chronic lack of sleep ensues. Indeed there is now evidence that the biological clock is dependent on normal adrenal function - and we know this is suppressed in CFS.

So often some medication is needed to facilitate sleep. Most CFS patients react badly to drugs in normal doses. I like to use combinations of low dose herbals, natural remedies and prescribed drugs to get the desired effect. Everybody works out his or her own cocktail which suits.

I am always asked about addiction. My experience is that this is rare, especially if drugs are used as above to develop a conditioned reflex. One has to distinguish between addiction and dependence. We are all dependent on food, but that does not mean we are addicted to it. We are all dependent on a good night's sleep for good health and may therefore become dependent on something to achieve that. This does not inevitably lead to addiction. Addiction is a condition of taking a drug excessively and being unable to cease doing so without other adverse effects. Stopping your hypnotic may result in a poor night's sleep but no more than that. This is not addiction but dependence.

Sleep Problems and Fatigue syndromes

By Mike Valentine FRPharmS

As we have seen from Dr Myhills feature, sleep is a vital biological process that is necessary to restore both the body and mind. Insomnia (sleeplessness) is the most common sleep problem. Insomnia is a prolonged inability to obtain adequate or uninterrupted sleep. Types of insomnia are-

- **Transient insomnia** – lasts a few days and is usually a result of a stressful situation e.g. a DWP visit, an exam or as a result of an altered sleep routine.
- **Short-term insomnia** – lasts 1-4 weeks. It is typically due to emotional trauma or physical illness.
- **Chronic insomnia** – affects most people with ME/CFS/FMS, and is usually a result of ingrained poor sleep hygiene and other factors.

After sleep hygiene, as per Dr. Myhills pages, usually the first step is to try and identify if there is any identifiable cause, and treat that first. For example some with asthma may awake coughing or short of breath. Treating that problem may improve things. However in most cases in most these are multifactorial:-

- **Mental health problems** Depression, anxiety, mania/hypomania, dementia
- **Physical illness** Pain, arthritis, hypothyroidism, acid-reflux, heartburn, headache, menopause
- **Environmental factors** Temperature, noise, light, new environment
- **Social or Psychological factors** Bereavement, divorce, unemployment, loneliness, less physical activity
- **Dietary factors** Alcohol, caffeine, nicotine, heavy meal, rich or spicy foods
- **Factors affecting sleep cycle** Jet lag, shift work sleep-wake cycle
- **Medicines** – direct effect diuretics, CNS stimulants e.g. speed, SSRIs like fluoxetine, duloxetine.
- **Medications – chronic use** β-blockers, theophylline, some antidepressants (SSRIs, MAOIs, flupentixol), cholinesterase inhibitors
- **Withdrawal from medicines** Opiates (pain killers), benzodiazepines e.g. diazepam.

In many cases of ME/CFS doctors to use a tricyclic antidepressant like amitriptyline or nortriptyline in a low dose e.g. 10mg. Any higher dose is likely to cause side effects in ME/CFS patients. These medicines have multiple effects, which include sedation, reduction of pain. There are more powerful versions likes trimipramine (which is very sedating) or mirtazapine. Medicines like Z-hypnotics, temazepam and diazepam are really only for short term use as they become less effective over time. Melatonin may cause depression in the long term. There are over the counter medicines. There are well known brands like Nytol (diphenhydramine) or herbal products like valerian.

Whatever happens or however you do, to get on top of your health problems you must sleep.

The following should help insomnia management

DO:

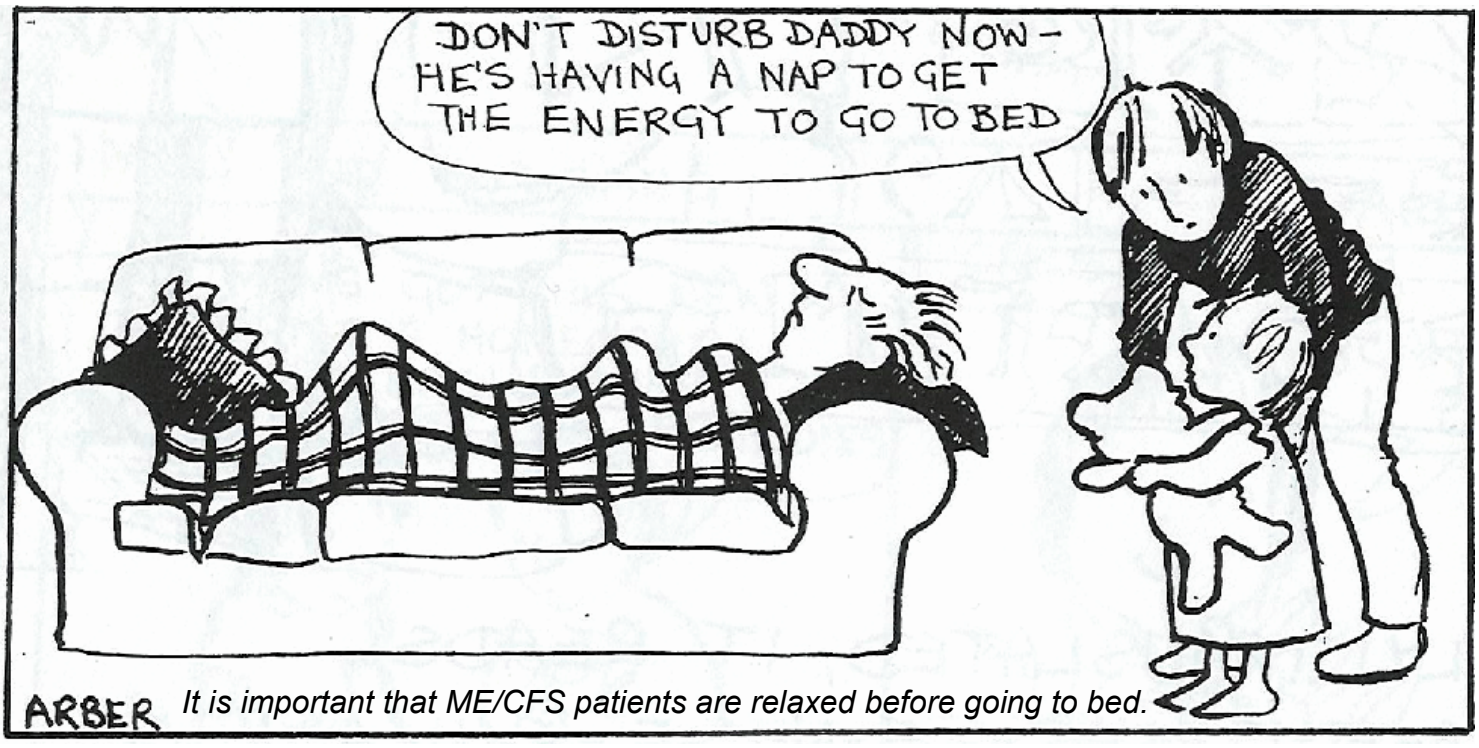
- Try to unwind and relax during the evening. Relaxation tapes /exercises may be helpful. Take light exercise, which will promote sleep. Avoid vigorous exercise close to bedtime because this can disturb sleep.
- Nothing mentally demanding for at least 90 minutes before bedtime.
- Establish a routine – retire and rise at same time every day.
- Try to go to bed before midnight; many people get a 'second wind' after this time.
- Relax when in bed. Relaxation exercises such as 'stretch and relax' or deep breathing can aid sleep. Go to bed when 'sleepy tired'; as soon as you get into bed turn the light out.
- Ensure the bedroom is a comfortable environment. Ensure it is free from noise, light and is at a comfortable temperature.
- Get up and go to another room if you are awake for more than 20 minutes, do something relaxing until you are 'sleepy tired' again.
- Consider keeping a sleep diary; it may help to identify sleep patterns and to highlight areas of poor sleep.

DON'T:

- Sleep for longer than 30-45 minutes if you feel sleepy during the day.
- Watch television or read in bed.
- Sleep too long – extra sleep can make you feel worse.

AVOID:

- Caffeinated drinks (tea, coffee, cola drinks) or eating chocolate before bedtime.
- Alcohol to aid sleep. Alcohol may induce sleep initially but its diuretic action will cause waking later in the night.
- Rich or spicy food, red meat, sugar rich food, cheese and a heavy meal too close to bedtime. A small snack can be helpful for sleep, such as dairy products, peanut butter, whole meal foods or bananas.



It is important that ME/CFS patients are relaxed before going to bed.

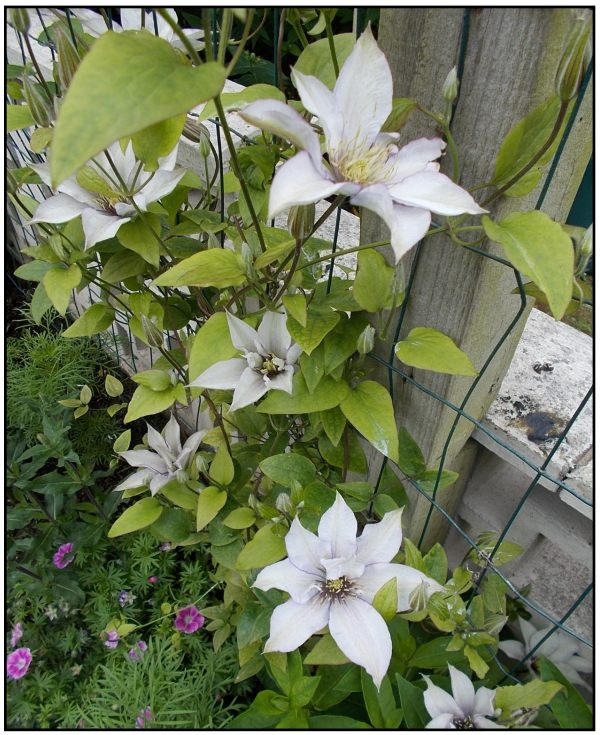
Garden Watch late Spring to early Summer

By Carolyn

Well, the odd weather patterns have continued, it went warm, then chilly, then cold, and is still very variable except in one very noticeable way, we still have had hardly any rain for things to grow in the garden.

The late Spring brought out the very best of the Laburnum tree this year and the bees just loved it. Along with the Clematis `Crystal Fountain` which is now beginning to grow happily up the tree itself.

The Violas (above) have been giving a lovely show, along with the hedging plants, And the new Clematis, `Samaritan Jo` is flowering well with many buds appearing now



A surprise Aquilegia clothed in Red and White appeared (don`t know why it reminds me of my favourite football team !!). And also a more unusual more `bell shaped` white one with yellow centres is new this year..

Bedding plants are now in pots and containers and new varieties of `Salvia` along with `Cosmos` , `Phlox` and various other plants both large and small are all growing nicely. Have been working on planting up a very shady and dry area under hedging and am hoping to buy a Silver Birch tree to add to a corner of the front garden but more of this later in the year. There is one new regular visitor to the garden and she is one we are so happy to have with us, a beautiful Mistle Thrush. Whether you are gardening on a window sill, a balcony, containers, or in the ground `Happy Summer Gardening`.

ME/CFS, DLA and Personal Independent Payment.: An Update.

With thanks to Benefit and work

Personal Independence Payment (PIP) can help you with some of the extra costs if you have long term ill-health or disability. At the time of writing, a claimant could get between £23.20 and £148.85 a week if of working age. The amount you get depends on *'how your condition affects you'*, and not the condition itself. So this means that a diagnosis of ME/CFS is not an automatic right to entitlement. Claimants are assessed by a so called '*health professional'* to work out the level of help needed. This is the most contentious issue with ME/CFS.
Any award will be regularly reviewed to ensure the level of is right.

PIP vs. DLA – similarities and difference.

Personal Independence Payment (PIP) began replacing Disability Living Allowance (DLA) for working age claimants from 8th April 2013. The assessment for PIP of all current working age DLA claimants was due to be completed by mid 2019. However, the redeployment of Department for Work and Pensions (DWP) staff to the correction of existing PIP awards has led to a delay in the migration of existing DLA claims. At the time of writing , this is now due to be completed in 2020-21. The government initially claimed that the introduction of PIP would ensure that resources are targeted where they are most needed. They also clearly stated, however, that one of the intentions behind the introduction of PIP was to reduce the cost of the current benefit by around 20%. The DWP's initial estimates were that, once all current working age DLA recipients have been reassessed for PIP:

29% will have had their award increased
15% will remain unchanged
29% will have had their award decreased
26% will have no award at all

Official Statistics

According to official DWP statistics, by the end of October 2018, 1,227,000 DLA reassessment claims to PIP had been processed. Of these:

- 482,000 (39%) had their benefit increased
- 169,000 (14%) had their benefit left unchanged
- 268,000 (22%) had their benefit decreased, but not stopped altogether
- 253,000 (21%) were disallowed after the assessment
- 49,000 (4%) were disallowed before the assessment
- 8,000 (1%) withdrew their claim.

Three quarters of those who registered received an award of PIP. 39% of those who registered received an increase in the level of benefit. This is higher than the 29% forecast in December 2012.
47% of those who registered received a lower level of award or no award; this includes 1% of people who chose to withdraw their claim. This is lower than the 55% forecast in December 2012.

This means that the DWP expected 55% of all current working age DLA claimants to be worse off under PIP. In reality, six years after the introduction of PIP, an Office of Budget Responsibility report in January 2019 estimated that the implementation of the new benefit had led to an increase in costs of between 15-20%. DWP's PIP disaster, costs have gone up instead of down.

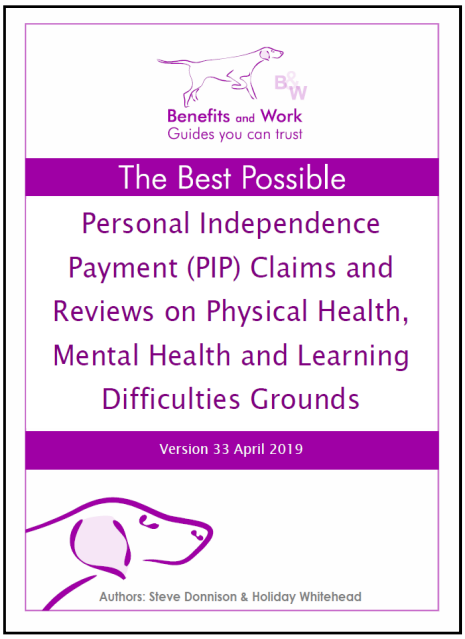
- Like DLA, PIP is not means-tested, doesn't require National Insurance contributions, can be claimed whether you are working or not, is non-taxable and acts as a passport to other benefits and premiums.
- Like DLA, PIP is divided into two components: a daily living component and a mobility component.
- Unlike DLA, each component has only two rates, a lower paying standard rate and a higher paying enhanced rate – DLA has three rates to the care component.
- Unlike DLA, PIP awards are based on a points system, meaning that the method of assessment has more in common with Employment and Support Allowance (ESA) than with DLA.
- Like DLA, there are special rules that apply to people with a life limiting illness.
- Like DLA, PIP can give some claimants access to the Motability scheme and automatic entitlement to a Blue Badge.

- Unlike DLA, the vast majority of awards are intended to be time limited – the majority will be for between two years and five years. So most PIP claimants can expect to have regular reassessments for as long as they remain on the benefit. Two exceptions to this are PIP claimants of State Pension age and those with the most severe, lifelong conditions who receive the highest level of support. Recent changes will mean that these groups will receive an ongoing award with a 'light touch' review every 10 years.
- Like DLA, people who qualify for the benefit before they reach State Pension age can continue receiving it beyond this date provided they still meet the eligibility conditions.Basic qualifying conditions
- Like DLA, PIP is a non-means tested benefit. You do not have to have paid National Insurance contributions to be awarded PIP and you can receive it whether you are in work or not.

Age limits. To qualify for PIP initially, you need to be aged between 16 and State Pension age. As state retirement age increases over time, the age at which you will be able to make a claim for PIP will also increase. For the present, children and older people will not be affected by PIP. However, guidance notes produced by the DWP make it clear that this may change in the future, once the government have had an opportunity to see how PIP performs in relation to working age claimants. People who receive PIP before they reach State Pension age will go on being able to receive it once they are over this age.
Qualifying period. For PIP, you need to have had your current level of needs for at least three months and be likely to continue having them for a further nine months. The three months test does not apply if you are transferring from DLA to PIP. Other exceptions are detailed below, in 'Linking rules' and 'Terminal illness'.
Linking rules. If you have claimed PIP in the past and then stopped because of an improvement or remission in your condition, you may be covered by the linking rules if you need to claim again. If you are under State Pension age and need to reclaim PIP within two years of a previous award ending, then you do not need to serve the 3 month qualifying period. This only applies where your claim:

- is for the same component you received before;
- is based on substantially the same health condition or conditions; or
- is based on a condition which developed from the original condition; and
- you still meet all the other qualifying criteria, such as scoring enough points in the assessment and being likely to have your needs for at least nine months. If you are over State Pension age, then the same linking rules apply, but the claim must be made within one year of your previous award ending.

Ever since Leger ME was formed in 2004, the biggest problem our members experience with DWP claims is the fill out of the form and dealing with appeals as when/if the benefit is declined. Our experience is that when a claim fails, the vast majority are due to forms being incorrectly fillout out. There are problems with supporting evidence from doctors because an increasing number of GP practices will not give the relevant information. There are problems with the quality of staff used to asses the claim mainly due to the way the way the criteria are assed, how the law stands and the interpretation of the DWP.



The way we deal with this at Leger ME is to ensure that members' claims are of the highest standard. Over the years we have found that next to experience the best source of advice are the Benefit and Work Guides. Leger ME has a professional subscription to this service, and access to these guides are part of the membership benefit.

If you are even thinking of applying for PIP, contact the office for copy of the relevant guide. Also ask for a Case Review Report, which is a statement of the relevant information for a PIP claim. These have to be booked through the office.

ME/CFS and Personal Independent Payment.: The Basic Rules and Tariff

The Personal independence payment (PIP) points scores follow. The biggest problem is that non of the criteria exactly match ME/CFS in reality, so there are problems with how these points are interpreted. Opinions differ massively with Atos (a company the DWP use for assessment locally, the DWP decision makers and the Tribunals service as to exactly how they are applied.

DAILY LIVING ACTIVITIES
To get an award of the daily living component, you need to score:

8 points for the standard rate
12 points for the enhanced rate

1. Preparing food.
a. Can prepare and cook a simple meal unaided. 0 points.
b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal. 2 points.
c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave. points. 2 points
d. Needs prompting to be able to either prepare or cook a simple meal. 2 points.
e. Needs supervision or assistance to either prepare or cook a simple meal. 4 points.
f. Cannot prepare and cook food. 8 points.

2. Taking nutrition.
a. Can take nutrition unaided. 0 points.
b. Needs –
(i) to use an aid or appliance to be able to take nutrition; or
(ii) supervision to be able to take nutrition; or
(iii) assistance to be able to cut up food. 2 points.
c. Needs a therapeutic source to be able to take nutrition. 2 points.
d. Needs prompting to be able to take nutrition. 4 points.
e. Needs assistance to be able to manage a therapeutic source to take nutrition. 6 points.
f. Cannot convey food and drink to their mouth and needs another person to do so. 10 points
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3. Managing therapy or monitoring a health condition.
a. Either –
(i) does not receive medication or therapy or need to monitor a health condition; or
(ii) can manage medication or therapy or monitor a health condition unaided. 0 points.
b. Needs either –
(i) to use an aid or appliance to be able to manage medication; or
(ii) supervision, prompting or assistance to be able to manage medication or monitor
a health condition. 1 point.
c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. 2 points.
d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week. 4 points.
e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week. 6 points.
f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. 8 points.

4. Washing and bathing.
a. Can wash and bathe unaided. 0 points.
b. Needs to use an aid or appliance to be able to wash or bathe. 2 points.
c. Needs supervision or prompting to be able to wash or bathe. 2 points.
d. Needs assistance to be able to wash either their hair or body below the waist. 2 points.
e. Needs assistance to be able to get in or out of a bath or shower. 3 points.
f. Needs assistance to be able to wash their body between the shoulders and waist. 4 points.
g. Cannot wash and bathe at all and needs another person to wash their entire body. 8 points.

5. Managing toilet needs or incontinence.
a. Can manage toilet needs or incontinence unaided. 0 points.
b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence. 2 points.
c. Needs supervision or prompting to be able to manage toilet needs. 2 points.
d. Needs assistance to be able to manage toilet needs. 4 points.
e. Needs assistance to be able to manage incontinence of either bladder or bowel. 6 points.
f. Needs assistance to be able to manage incontinence of both bladder and bowel. 8 points.

6. Dressing and undressing.
a. Can dress and undress unaided. 0 points.
b. Needs to use an aid or appliance to be able to dress or undress. 2 points.
c. Needs either -
(i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or
(ii) prompting or assistance to be able to select appropriate clothing. 2 points.
d. Needs assistance to be able to dress or undress their lower body. 2 points.
e. Needs assistance to be able to dress or undress their upper body. 4 points.
f. Cannot dress or undress at all. 8 points.

7. Communicating verbally.
a. Can express and understand verbal information unaided. 0 points.
b. Needs to use an aid or appliance to be able to speak or hear. 2 points.
c. Needs communication support to be able to express or understand complex verbal information. 4 points.
d. Needs communication support to be able to express or understand basic verbal information. 8 points.
e. Cannot express or understand verbal information at all even with communication support. 12 points.

8. Reading and understanding signs, symbols and words.
a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. 0 points.
b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. 2 points.
c. Needs prompting to be able to read or understand complex written information. 2 points.
d. Needs prompting to be able to read or understand basic written information. 4 points.
e. Cannot read or understand signs, symbols or words at all. 8 points.

9. Engaging with other people face to face.
a. Can engage with other people unaided. 0 points.
b. Needs prompting to be able to engage with other people. 2 points.
c. Needs social support to be able to engage with other people. 4 points.
d. Cannot engage with other people due to such engagement causing either –
(i) overwhelming
psychological distress to the claimant; or
(ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. 8 points.

10. Making budgeting decisions.
a. Can manage complex budgeting decisions unaided. 0 points.
b. Needs prompting or assistance to be able to make complex budgeting decisions. 2 points.
c. Needs prompting or assistance to be able to make simple budgeting decisions. 4 points.
d. Cannot make any budgeting decisions at all. 6 points.

MOBILITY ACTIVITIES

To get an award of the mobility component you need to score:

8 points for the standard rate
12 points for the enhanced rate

1. Planning and following journeys.
a. Can plan and follow the route of a journey unaided. 0 points.
b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. 4 points.
c. Cannot plan the route of a journey. 8 points.
d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. 10 points.
e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. 10 points.
f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. 12 points.

2. **Moving around.**
a. Can stand and then move more than 200 metres, either aided or unaided. 0 points.
b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. 4 points.
c. Can stand and then move unaided more than 20 metres but no more than 50 metres. 8 points.
d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. 10 points.
e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. 12 points.
f. Cannot, either aided or unaided, –
(i) stand; or
(ii) move more than 1 metre. 12 points.

Variable and fluctuating conditions (*This applies to ME/CFS***)**
Taking a view of ability over a longer period of time helps to iron out fluctuations and presents a more coherent picture of disabling effects. Therefore the descriptor choice should be based on consideration of a 12 month period. Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in the 12 month period. The following rules apply:

- If one descriptor in an activity applies on more than 50 per cent of the days in the period – i.e. the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen.
- If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.
- Where one single descriptor in an activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days – for example, descriptor ‘B’ is satisfied on 40 per cent of days and descriptor ‘C’ on 30 per cent of days

T he descriptor satisfied for the highest proportion of the time should be selected.

Awaiting treatment
If someone is awaiting treatment or further intervention it can be difficult to accurately predict its level of success or whether it will even occur. Descriptor choices should therefore be based on the likely continuing impact of the health condition or impairment as if any treatment or further intervention has not occurred.

Reliably, in a timely fashion, repeatedly and safely
An individual must be able to complete an activity descriptor reliably, in a timely fashion, repeatedly and safely; and where indicated, using aids and appliances or with support from another person (or, for activity 10, a support dog). Otherwise they should be considered unable to complete the activity described at that level.

- **Reliably means to a reasonable standard.**
  In a timely fashion means in less than twice the time it would take for an individual without any impairment.
- **Repeatedly** means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.
- **Safely** means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

- **Risk and Safety**
  When considering whether an activity can be undertaken safely it is important to consider the risk of a serious adverse event occurring. However, the risk that a serious adverse event may occur due to impairments is insufficient – there has to be evidence that if the activity was undertaken, the adverse event is likely to occur.

Aids and appliances
The assessment will take some account of aids and appliances which are used in everyday life. In this context:

- **Aids** are devices that help a performance of a function, for example, walking sticks or spectacles.
- **Appliances** are devices that provide or replace a missing function, for example artificial limbs, collecting devices (stomas) and wheelchairs.
- The assessment will take into account aids and appliances that individuals normally use and low cost, commonly available ones which someone with their impairment might reasonably be expected to use, even if they are not normally used.
- **Individuals** who use or could reasonably be expected to use aids to carry out an activity will generally receive a higher scoring descriptor than those who can carry out the activity unaided.

Support from other people
The assessment will take into account where individuals need the support of another person or persons to carry out an activity – including where that person has to carry out the activity for them in its entirety. The criteria refer to three types of support:-

- **Assistance** is support that requires the presence and physical intervention of another person i.e. actually doing some or all of the task in question. This specifically excludes non-physical intervention such as prompting or supervision which are defined below. To apply, this only needs to be required for part of the activity.
- **Prompting** is support provided by reminding or encouraging an individual to undertake or complete a task but not physically helping them. To apply, this only needs to be required for part of the activity.
- **Supervision** is a need for the continuous presence of another person to avoid a serious adverse event from occurring to the individual. There must be evidence that any risk would be likely to occur in the absence of such supervision. To apply, this must be required for the full duration of the activity.
- **Unaided** Within the assessment criteria, the ability to perform an activity 'unaided' means without either the use of aids or appliances or assistance/prompting/supervision from another person..

ME/CFS and Personal Independent Payment. Stacking the odds your favour.

Applying for PIP for ME/CFS is more like a lottery than a science. Furthermore, none of the descriptors directly apply to ME/CFS/FMS, so everyone involved has their own way to fit the descriptor. Outcomes of apparently similar cases are unpredictable, variable and definately NOT guaranteed. Before applying for PIP, the first thing to do is gather your evidence. The following documents are the things that provide additional evidence: -

From your GP

- A record of your last appointment with the G.P. and make sure it was less than 3 months ago.
- Copy of Summary Sheet or NHS (Patient summary Record) from G.P. Surgery (see next page)
- Copy of Repeat Prescriptions (MUR sheet, Prescription counterfoil or Surgery Printout)
- Details of all medicines (conventional and alternative) you are currently taking irrespective of supplier.
- Copy of results of any tests e.g. Blood, or other diagnosis tests at the G.P. Surgery or Hospital.

From your ME/CFS/FMS specific clinic

- Support letter from Sheffield, Leeds or other FMS/PVFS/ME/CFS clinic. This is critical – claims based on ME/CFS are often rejected without it.
- 1 week full week of the Leger ME Daily Log sheet for ME clinic sheet.
- Copy of appointment cards or letters from condition management clinic e.g. pain control clinic
- Copy of appointment cards or letters from condition management counsellor e.g. Clouds
- Copy of appointment cards or letters from community organisations e.g. SS
- Copy of appointment cards or letters from a private management clinic. e.g. chiropractor

Other Conditions (All conditions must be stated no matter how trivial or minor, as they all count)

- Support letter from Hospital or condition management clinic.
- Copy of appointment cards or letters from condition management clinic e.g. diabetic/asthma etc.
- Copy of appointment cards or letters from condition management counsellor e.g. Clouds
- Evidence of any medical devices or appliances used e.g. PFR or BM meter record sheets and charts or other records.
- Evidence of use of any dietary or lifestyle management. (Diet, substance avoidance, pacing)

Daily Living

- Copy of appointment condition assessment or statement of care needs or letters from condition management clinic (e.g. Social services or SYCIL assessment report)
- List of any things used for cooking. e.g. kettle tipper, microwave oven. trolley
- List of any things used for continence control e.g. pads, commode, ostomy bags
- List of any things used for personal care e.g. Bath or shower aids, washing aid etc.
- List of any things used for night care e.g. Bedroom adaptations, bed hoist
- List of any things used for mobility. e.g. stick, scooter, wheelchair, blue badge, mobility car

Previous Claims or Tribunals

- Copies of Past Decision Letters, points breakdown, ESA 85. PA4, RV4 or portfolio as advised
- Copies of any appeal letters or other relevant documentation

The Medical Record Summary Sheet or Summary Care Record

This document contains much of the information needed in the early pages of DWP forms and other claim forms, and is useful to include. Ask your doctors surgery to print you out a copy of your medical record summary sheet. Some GP practices allow you to access your own records e.g. via SYSTEM 1. This is at most three, to five sheets of paper, which contains the following information:-

- Your Name and Address
- Your current ongoing conditions
- The results of any tests
- Any current ongoing treatment
- Repeat prescriptions

Although many surgeries provide this information free, your doctors may charge for this information, when they do it is usually around £10-£15. It is NOT your complete medical history which some surgeries provide by mistake at great cost using many reams of paper..

Filling out the PIP Form.

As soon as you have a PIP form contact us for guidance. The PIP form itself is a computer printed document specific to yourself with a two dimensional barcode on each page. Our advice is not to touch it until you have the final draft. We have specific drafting forms, and for each Leger ME member we will do a case review and give you a draft PIP from copy. The additional thing to remember is that PIP forms in practice allow three weeks before submission is due. Getting the fillout and additional evidence often takes far longer than this. One common reason for PIP refusals are badly filled out forms especially when people get intimidated by DWP reminder letters. Most people just by phoning the DWP and explaining matter can get an extension to the required submission date.

The Medical Examination by a so called 'Health Professional'

Almost all PIP applications will involve a medical examination a some stage. The examination and questions are more akin to how the police would interview a suspect than anything else. There is an examination centre in Doncaster, however is it not accessible by car door to door. You have to walk at least 50 meters to get there from the nearest car drop-off point. The DWP know this and just by attending you will blow any chance of a mobility award. Alternatively you may be seen at home. I have heard reports that the so called health professionals receive a bonus if they provide evidence that results in the claim being declined.

If the results of the application are not acceptable

You will be sent a computer generated letter giving your result. It is based on the tariff in the previous pages. It will state how much you are entitled to and for how long, and give you a load of 'canned messages' which will be really unhelpful.

If you are declined PIP the first thing to do is contact us. We will ask you to obtain a copy of the medical examination results in a PA4 or RV4 report. This is usually where the explanation for a refusal can be found, but not always. We can usually identify the reason for a refusal. However the appeal process and the way forward is not always clear. Each case has to be dealt with on its own merits. We often find that asking for a mandatory reconsideration does not alter the outcome. Very often if the DWP decision is disputed by irrefutable evidence, or they are proven to be in default, then they will not deal with the case, and they will refer it to the tribunal system rather than back down.

Tribunals are carried by the family courts and are independent of the DWP. The best outcomes are always from a oral hearing in front of a Judge and Doctor. The are also paper tribunals, and a newer online system is being trialled. We have no experience of the latter. Always at a tribunal, you will always be given change to state your case. You don't get this with the DWP.

ME/CFS and PIP Payment. Two examples of where PIP was declined.

Here are some recent of examples from RV4/PA4 reports from so called 'Health Professionals' examinations which illustrate some common issues.

1) This example is from a members PIP application from section 3 Cooking Food.

She reports she struggles with this as she cannot stand for too long, she cannot bend to the oven and has to sit and rest with pain in her back and joints. She was burning herself when using the oven. She gets tired easily. She can use the microwave as it is easier or she will order a takeaway. She will make simple quick meals for the children. She makes ready prepared, vegetables as it is quicker and makes mash potatoes that only need water adding. This is consistent with the questionnaire.

However, although she is on a moderate dose of pain relief, this patient shows no restrictions and she did not appear in discomfort at assessment. She had good memory and concentration in the MSE and did not look tired. She is waiting to attend the ME clinic but has not had an appointment through as yet. It is reasonable to suggest, she would manage this unaided and safely the majority of the days.

In this case the Atos examiner is a registered paramedic, we checked this. Paramedics are trained to deal with emergencies and have no understanding of chronic conditions, especially ME/CFS. So our member was listened to, but was not believed. No attempt was made to asses the effect of fatigue (it very rarely is) and rules regarding variable and fluctuating conditions ignored. Throughout the report the structure was the same. Rephrasing of the members statement then, **however,** then a statement to influence the decision maker decline the points. At the time of the application, our member hadn't been seen by the Sheffield ME/CFS clinic, and this appeared to be the excuse to decline the application.

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2) This example is from a members PIP application PA4 regarding the medicines list as record by a visiting examiner.

Error:
Tamsulosin is for a prostrate problems not asthma

Error:
Ezetimibe is use to treat high cholesterol not diabetes

Ignored:
Over the counter medicines don't count.

Current medication and treatment

Tamsulosin 400mcg for asthma
salbutamol 100mcg for asthma
Lansoprazole 30mg 1 x a day for stomach acid
Ibuprofen gel when required for pain
Solfecanin 5mg 1 x a day for bladder
Amitriptyline 10mg 1 x a day for pain
Nasal spray for allergies
Co- codamol 30/500 mg 2, 4 x a day for pain usually takes 4 a day
Eye drops for dry eyes
Lymecycline 480mg
Ezetimibe 10mg 1 x a day for diabetes
Metabet 500mg 2 x a day for diabetes
Ramipril 5mg 1 x a day for blood pressure
Cyclaine 50 mg for dizziness when required

Various herbal medicines bought over the counter for pain

Side effects: none reported
Efficacy : of no benefit

In this case the Atos examiner was a qualified physiotherapist and nurse (we checked this) and the examination was carried out in the patients home. It is quite clear that her knowledge of medicines is lacking, so how could she be trusted to come up with a reliable and fair report? Things like peak flow and blood sugar meters were not checked and the section on 'Managing Therapy or monitoring a health condition' ignored. Any medicines irrespective of what they are for that are bought over the counter are ignored by ATOS. In this case our member got six points, not enough to get a payment. This is happening too frequently in a number of recently declined PIP applications.

PA4 and RV4 medical reports always contain many inaccuracies, and there is no doubt that there is a strong bias against ME/CFS.

Recipe Corner *by Carolyn*

Summer Chickpea Salad

(makes a lovely side salad to go with roast chicken)

Serves 4, Cooks In10 minutes
Nutrition per serving:-
Calories 272 14%. Fat 16.5g 24%,Saturates 5.2g 26%, Sugars 3.5g 4%, Salt 1.43g 24%, Protein 11.5g 23%, Carbs 19.6g 8%, Fibre 5.6g -

Ingredients

1 small red onion peeled
1-2 fresh red chillies, deseeded
2 handfuls ripe red or yellow tomatoes
1 lemon
extra virgin olive oil
sea salt
1 freshly ground black pepper
410 g tinned chickpeas, drained, or around 4 large handfuls of soaked and cooked chickpeas
1 handful fresh mint, chopped
1 handful fresh green or purple basil, finely ripped
100 g feta cheese

Cooking Method: First of all, finely slice your red onion. Once that's done, finely slice your chillies then roughly chop your tomatoes, mixing them in with the onion and chillies. Scrape all of this, and the juice, into a bowl and dress with the juice of half a lemon and 3 tablespoons of good extra virgin olive oil. Season to taste. Heat the chickpeas in a pan, then add 90 per cent of them to the bowl. Mush up the remaining chickpeas and add these as well – they will give a nice creamy consistency. Allow to marinate for a little while and serve at room temperature. Just as you're ready to serve, give the salad a final dress with the fresh mint and basil. Taste one last time for seasoning – you may want to add the juice from your remaining lemon half at this point. Place on a nice serving dish and crumble over the feta cheese.

Date and Walnut Loaf

With many thanks to our member Ann Fisher for this recipe.

Sliced and spread with butter, Date and Walnut Loaf makes an excellent teatime treat. This recipe makes a fairly large sized loaf that keeps well – and even improves with age if stored in an airtight tin.

Imperial	Metric	Ingredient
8oz.	225g.	Stoned dates, chopped
1 teaspoonful	1 x 5ml. spoon	Bicarbonate of soda
1	1	Pinch of salt
½ pint	300ml.	Hot water
10 oz.	275g.	Self-raising flour
4 oz.	100g.	Butter or margarine
2 oz.	50g.	Shelled walnuts, chopped
4 oz.	100g.	Dark soft brown sugar
1	1	Egg, beaten

Cooking Method: Put the dates, bicarbonate of soda and salt in a bowl and pour over the hot water. Set aside until cool. Meanwhile, sift the flour into a mixing bowl. Add the butter or margarine in pieces and rub into the flour. Stir in the walnuts and sugar until thoroughly combined.
Mix the dry ingredients into the cooled date mixture and beat in the egg. Pour into a greased 1kg/2lb loaf tin and bake in a moderate oven (180°C/350° F or Gas Mark 4) for 1 to 1 ¼ hours or until a skewer inserted in the centre comes out clean. Turn out on to a wire rack and leave to cool. Store in an airtight tin.

North of Doncaster

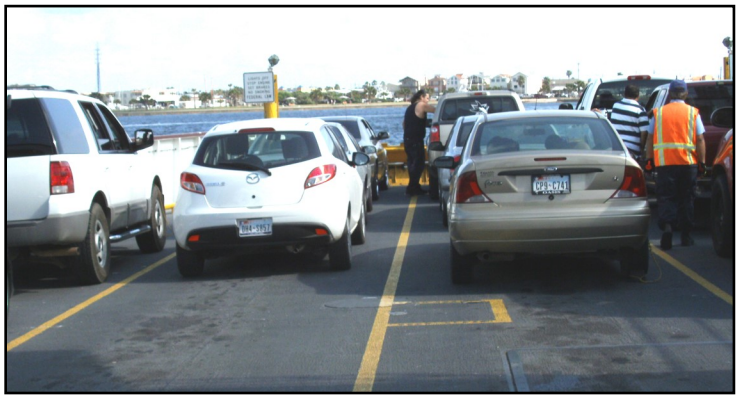
A personal travel diary in Texas by Trevor Wainwright

A wild alligator

My day had ended in Galveston with a tyre problem. It started at the Brazoria Wild Life Refuge where I had been able to photograph an alligator in the wild. It kept going down and the emergency tyre was fitted, with instructions to get the other one fixed asap. The motel staff couldn't have been better, they were an Asian couple from Halifax. He had been a postmaster for 25 years and come to work at his brother's motel. They split the profits after the bills had been paid. It was too hot for him he said and he couldn't wait till his retirement age so he could return to Yorkshire. So he helped me find a tyre fitters the tyre was changed and my tour continued.

The USS Lexington Aircraft Carrier, now a museum and community facility,

It was a pleasant ride to Corpus Christi when I realised I had left my glasses at the tyre fitters. The first thing was to get them replaced. Once done, book in at the motel. I had made decent time after lunch and after a look round Corpus Christi bay area where the aircraft carrier USS Lexington is now a tourist attraction I decided to go on the Island Drive.



On the Ferry approaching port Aransas, my hire car is the small Mazda on the left

The sister ferry: William G Burnett

Leaving Corpus Christi the way I came in, to a place called Aransas Pass, over a bridge to a small island boarding the free ferry from Port Aransas a drive down Mustang Island.

I stopped off to enjoy the beaches, and before the final drive back to the mainland island it was a great afternoon.

A Map of the area visited.

Back on the mainland, being hungry I decided to call for a cupcake, but the booth had sold out. I was making my way back into town where I saw a sign that said “Barney’s Bait Shack”. For some reason I decided to go have a look. I never got there. Seeing a guy playing a guitar I got out of my car and walked over to him. He welcomed me. We shook hands. He gave me a bottle of water. We talked for over an hour, before I had to leave, it had been great, to spend time with him.

Hugh with his dog Charlie

Back at the motel I wrote the following and read it out on more than one occasion to great aplomb. The Meet in Heaven is based on a comment from him about when we were likely to meet again, and my reply.

I saw him from my car

I saw him from my car; Sat on a camper step playing his guitar
I stopped and made my way I wanted to hear him play
I said "I'm Trevor", he said "I'm Hugh"
He shook my hand saying "sit a spell let me sing for you"
First he told me about his life, a life of pain, a life of strife
Addiction, prison, dereliction
Yet not thinking it odd, when he heard the voice of God
Saying "a task for you I bring
Play the guitar, write songs then go out and sing
On the street to those you meet
Whether they stop or walk by, go give it a try"
So learn the guitar he did, and doing as he was bid
He said "I sang to the people whether they stopped or passed through
I sang to them all saying this song is for you"
A dedication to his mother after she passed on
A song he wrote in prison about two ducks and a swan
He sang about walking alone to a future unknown
To a place called heaven where his name is carved in stone
Our time together had to end but I felt I'd found a friend
And if we meet in heaven I'll shake his hand with glee
And say "pick up your guitar Hugh and sing again for me".

Next issue: A chance remark that lead to the adaptation of a classic song from 1994 to a poem about a Yorkshire town.