Price £ 2.50 (Free to members)

Pathways

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

YOU MUST SLEEP

Humans evolved to sleep when it is dark and wake 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. Sleep is as necessary as food and water. As most of us know, with ME/CFS comes sleep disturbances and that has a fundamental effect on our recovery and well being. *See page 12*.

Leger ME Member appears in BBC Look North debate on water fluoridation.

Elizabeth McDonagh is also the National Pure Water AssociationsôChairman appeared in a recent T.V. debate. *See page 18*

Get Out Of the ME Gaol, Be Free

How a scooter liberated a member: *See page 8*

You Write

Roseanne Writes *I just wondered what you could tell me about Seacroft Clinic at Leeds? I have just read an article in "Yorkshire Post" this week and it's mentioned. I am having a relapse at moment after managing well for five years. I have also looked at the last 'Pathways' feature on Sarah Myhill's research. Where or who in this area would do me this test and what would be the cost? What are your thoughts on having it, do you know anyone who has had the test and then been prescribed treatment? What was their outcome? Could nutritional supplements really be the way forward? What's the feedback about Sheffield M.E. clinic?*

1) You cannot access the NHS Seacroft clinic unless you have been a previous patient because Doncaster PCT has a policy for sending people to Sheffield ME/CFS clinic because of border issues.
2) If you are an old patient of Dr. Myhill you can contact her directly for the test. It is about £250. You will have to have a blood sample taken locally, usually by your own GP's practice nurse, but you may have to pay for it.
3) Dr. Downing's clinic in York provides a similar service to that of Dr. Myhill. As a new patient, it would cost you just under £500 for the same thing (it is the York branch of a private Harley Street practice).
4) As you are relapsed after a stable period of five years, you really need to check that no other health problem is intervening. Sheffield would ask for your GP to run a batch of blood tests before they will see you anyway. You can jump the gun by seeing the GP yourself and if you contact me on the helpline I can give you guidance. You could attend at mentoring session at the Redmond centre, where I could be more specific and better explain your options.
5) The feedback about NHS Sheffield M.E clinic is that they are into cognitive behavioural therapy and graded exercise. Most members report that they are useful for the first 18 months or so of a case. After that, there is really very little that they can help with, practically. That may change.
6) The many group members who have had the mitochondrial function test have all had definite abnormalities except one, who without doubt has ME. What most members have received is a report from Sarah; the interventions recommended are based on her published strategies. The newer ones are carnitine and ribose, which have helped some, but not all. As to if you should have the mitochondrial function test, it depends on you personally and if you have the money and need to know for your own personal reasons. A £250 outlay would get you the test done but that same money would enable you to trial the treatments yourself and you can make your own decisions as to if they worthwhile or not. Most of the treatments are available without prescription but would be best monitored by your G.P.

Michele writes *Thought I would send you a quick e-mail to let you know I successfully passed my IAM Test this Wednesday. It was the article by Trevor in Pathways 2007 that initially made me think it would be a good thing to do, followed by a report in the Derbyshire Times in July 2007 giving the contact of Chesterfield IAM Group. I thoroughly enjoyed doing the course and I certainly think is very important when you have a chronic illness like ME/CFS to be able to show you are competent to drive - mind you I think with today's congested roads everybody would benefit from taking the course - old & young alike. It took me a long time as I did not do much last year after relapsing from the virus infection in January - ME people do thing slowly anyway but it was worth for success in the end! I am still recovering from the high levels of adrenaline that have been buzzing around my body!*

Well done Michele. I took the Advanced Driving Test about 25 years ago before ME, and it was very difficult then. Recognising that the majority of collisions are caused by driver error, the IAM's Advanced Driving Test was introduced in 1956 with the specific objective of significantly improving driving standards using the principles of Advanced Driving pioneered ï and applied with great success ï by the Metropolitan Police. To date, over 350,000 people have taken the Advanced Test, and of these over 300,000 have passed and gone on to become IAM Members. The Advanced Driving Test lasts for about 90 minutes and will usually cover between 30 and 40 miles along all types of road, town driving, motorways (if available) or dual carriageways, and even country lanes. The Examiner will hold a Police Advanced Driving certificate and will have extensive experience from working within sections of the Police Services throughout the UK.

The Test itself gives a thorough workout of driving ability, allowing the candidate to alter their drive according to the conditions and environment of the road. The types of road vary from quiet country roads, motorways to busy town centres. In each case there are hazards and situations that need to be avoided and taken care of using the methods and techniques that advanced driving gives. There may be situations where the candidate can show flair and panache on an open country road where progress can be gained at maximum safety, using optimum road positioning and excellent observation. All this combines to give a brisk smooth drive, at the legal limit on the open road. In other situations, the candidate will need to show restraint and composure to deal with tricky hazards that may become apparent throughout the drive. Such as in a town centre situation, where observation is used to pick out hazards in situations that are constantly changing. The main objective is that the candidate has to perform well in all situations rather than excel in one.

Many people often comment on the Test after taking it and, more often than not, the comments revolve around how much they enjoyed the drive. On Test the candidate gets to show the new skills that they have been tuning for the weeks during their course. The Advanced Driving Test IS NOT EASY but is within the reach of all vehicle users given the right guidance. Doncaster IAM offers members guidance into preparing for the advanced test. Anyone interested can contact Paul Tuke on 01302 886276 for further details. I will try and organise a meeting with some of the IAM members. While not everyone would be interested in the taking the test, certainly any hints and tips would be useful especially to anyone with ME.

Michele writes: *I enjoyed reading the latest Pathways Newsletter, the articles on a test for ME, and Pacing with Mark Adams. Very interesting, and a NICE photo of Mark with his dog, Could it help cope with Managing Energy Levels. Has anyone tried that ?*

To the best of my knowledge not in the same way Mark would advocate it. Managing energy levels is all about what managing ME is, and almost most of us do it, without really realising it by restricting what we do. Marks pacing strategy is used to mitigate Graded Exercise Therapy (GET) promoted by the NICE guidelines and others to get NHS service. So really it is a tactic of make do and mend. Even the private doctors like Myhill advocate pacing in some way or other, and thatôs why I included the page written by one of her patients. It looks extremely complex, and more situated to computer programme. Is there anyone out there who can help ? Members who have received GET report that what it does not do is take into account the variability of ME/CFS, and other health issues. Pacing is a keystone of ME/CFS management, but, like many other therapies, is BY NO WAY the complete answer. I find that there are two key things about getting people with ME better. Sleeping and Eating. Weôve covered eating in the past, so in this edition weôve had a go about Sleeping.

Joan Writes: *A brief note to say thank you for a very informative 'Pathways'. At last some progress in a test for this ghastly illness.*

I also started with Dr. Odes 2 years ago. In that period I have seen him twice, the rest of the doctors standing in for him were useless, admitting they didn't know anything about the illness. I got the impression he was a token specialist to cover guidelines given by the government. Unfortunately, he seems to spend a lot of time out of the country. One plus – he did arrange for a scan on my blood supply, as my major problem is muscle pain (17 years of it). The Vascular Department then sent me to Fracture/Trauma who thought it could be my spine. I had an M.R.I. scan but both were o.k. They suggested the Pain Clinic. None of them seemed to realise what an effort it is to walk anywhere, unfortunately my age doesn't help (70's). I agree with other members about the appointment system, papers lost etc., a bit of a shambles. At least I am on good terms with my G.P., at the moment he is reading 'Pathways' which I left with him yesterday. Thanks for all your good work.

Christopher writes: *I have M.E. and recently have been diagnosed with epilepsy, temporal lobe and some tonic clonic seizures (grand mal), mainly at night. Unfortunately the epilepsy drugs make my M.E. symptoms worse. While I can tolerate some drugs at low doses the dose is not high enough to control the seizures. Has anyone also experienced similar problems and have some drugs been tolerated better than others?*

You are in a difficult situation, which I have seen before. Even for normal epileptics (without ME), many choose not take their medication because of side effects - mainly sedation. This can be as high a 25% according to one member of a local epilepsy group. The main problem with epileptic fits is of course the obvious dangers, the need for supervision, and safety things like avoidance of driving and machinery etc. What people are not told about is the high risk of sudden death with epileptics who are not controlled. I've been on courses, and the figures I've seen quoted are between 5-15% over 5 years. This is why health professionals push epilepsy treatment so hard. Really, there is no point in taking an epilepsy medication unless it is effective. So, if you are going to take epilepsy medication it's got to work, and be proven to work. Most times it takes 2-3 drugs to do it, and sometimes in high doses. Also there is much chopping and changing and very often each hospital tends to have its own way of doing things. I've seen seizures of tonic clonic (grand mal) fit type in ME's who definitely are not epileptic, and when it happens it tends to be because of bad management or pacing or bad periods of illness. The absence or partial type of seizure (petite mal) quite often occurs in some people with ME, often to a point where doctors get confused and neurologists can't diagnose epilepsy Some drugs used for pain control, and other ME symptom control are used in epilepsy e.g. Epilim (valproate), Tegeretol (carbamazepine), Valium (diazepam) and gabapentin. I hope this is useful.

John writes: *Thanks for your very informative and interesting Pathways. We had read Sarah Myhill's article when it first appeared. Excellent when one considers it has been produced from private funding. But I wonder if the NHS and some of the ME/CFS bodies will take any notice. We see where our son's case fits in (and we await her next publication on the effects of treatments. He now takes T3 as suggested by S.M. some years ago and appears to be much better, but still with swings in energy and wellbeing. At his best he says he is better than he has been for more than 10 years, but there is still a long way to go.*

In a previous issue of Pathways you describe how you managed a visit to S.M. which reminded us of our visit in 2001 when our son was very ill and desperately needed hours of sleep and rest. We had to make it a two day journey with a stay at the Travel Lodge near the A49/A456 (Wooferton) junction. The staffs there were very understanding; allocating a quiet room at the back of the hotel at the end of a corridor so he could be left undisturbed until 12am. Some of your members might find this info. of value as it was hard for us to find anywhere else as suitable for him near to S.M.'s home.

The controversy re GET (and CBT) goes on and on. What Mark Adams describes in his article headed Pacing but which he then calls GET may just be a more intelligent and sensitively applied treatment for recovery for some people who probably involve much input and control from the patient. I will write to him. Recently we met an ME/CFS sufferer who got glandular fever at the same time as Michael did 20 years ago. Michael's GP was insistent on exercise as a way of getting him over his fatigue with the result that he became so ill he had to give up his job. In contrast her GP insisted on many weeks of complete rest followed by a very gradual return to work (years) with the result that she now has a near normal life. So even 20 years ago some GPs understood what was needed). Keep up the good work! Your publication is much more informative than others in the ME/CFS world.

Janet writes: *The Doncaster Disability Cluster is made up of independent people, local groups, organisations and services who support the inclusion of disabled people in our community, ensuring everyone can achieve their potential in life. We will be holding a Disability Awareness Day on 11th JULY 10.00 am - 3.00 pm at The Doncaster Deaf Trust, Leger Way Doncaster. The content of the day is yet to be decided but we will be looking to engage with a variety of activities linked to disability so any suggestions / offers at this stage which highlight the achievements of disabled people will be greatly appreciated.*

News from Fairlawns.

(The South Yorkshire and North Derbyshire Chronic Fatigue Syndrome/ME Service)

I attended a meeting of the CFS/ME Local Patient Involvement Group (LPIG) at Fairlawns on the 15/5/2009. The purpose of the meeting is for ôusô(user groups) to give feedback to the clinic administration. I represent the Doncaster Area.
Along with patients and other local group leaders, I came back from this meeting feeling a little more positive. The following is, for Pathways readers, my digest of some of issues raised.

CFS/ME - A challenge for schools?
This will be a meeting on Wednesday 8th July 2009 1.00 pm - 4.00 pm at St Mary's, Bramall Lane, Sheffield, S2 4QZ . This free training event is suitable for teachers, SENCOs, Learning Mentors, pastoral care staff, EWOs, Hospital and Home Education Tutors within the region of South Yorkshire and North Derbyshire. The aim is to give an overview of CFS/ME and its effects of education, provide a framework for the management of children and young people with CFS/ME in schools, provide a young person's perspective and provide networking opportunities. The afternoon will be interactive with a mixture of activities. There will be plenty of opportunities for participants to explore and discuss questions they have. For further information please contact: Julia Openshaw, Administrator on 01142292937 julia.openshaw@sheffieldpct.nhs.uk

Just how well are they Doing ?
The biggest blockage to people being seen is lack of information sent in by referring G.P.ôs, BUT they are treating more patients with the same resources as their expertise develops.

Referrals	**2005**	**2006**	**2007**	**2008**
Received	236	234	233	262
Accepted	200	190	126	192
Assessments	171	174	192	212
New Patients	77	116	127	186
Treatment strategies				
Occupational Therapy	223	328	440	604
Physiotherapy	53	165	303	228
Clinical Psychology	100	198	215	201
Groups	0	7	9	6
Total treated	376	691	958	1033

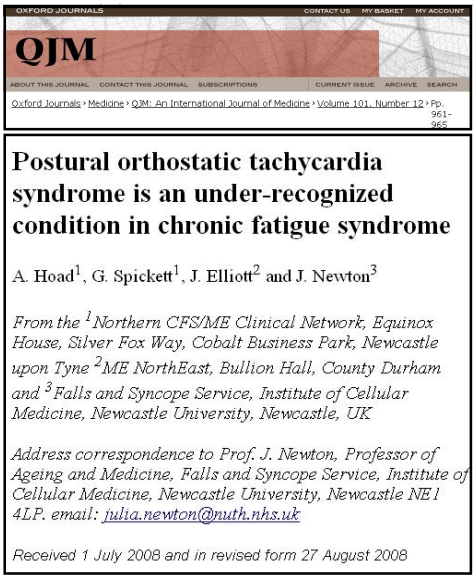
User Consultation Event Held Wednesday 4th February. Although the weather was atrocious, the event was well supported and 35 evaluation forms were returned. The main complaint seemed to be the food, otherwise feedback is fairly positive. There is plenty of paperwork from the meeting, but here are some brief comments. The user event was organised to explore ideas for change regarding the main problems that had been identified about the service from people who had received therapy.

Waiting times - the main issues were about helping GPs (and possibly others) to refer more effectively into the service as well as reducing waiting times for therapies once referred. Possible solutions include more training for practitioners and providing information packs for staff as well as for newly diagnosed patients.
Discharge - the main issues were about feeling abandoned once contact with the service had ended. Possible solutions include developing links for further support via a discharge pack; possibly offering a help-line; drop-ins; and/or information on a website.
Accessibility - A major issue revolved around the service being based in Sheffield yet covering a wide geographical area. Possible solutions include developing satellite clinics; developing training so more practitioners are able to offer support more locally; considering whether community or volunteer transport is a possibility.
Mike.

ME & Autonomic Nervous System dysfunction: A 2 year investigation.

From the spring issue of 'Breakthrough' 2009, courtesy of ME Research UK.

The autonomic nervous system controls cardiovascular, digestive and respiratory functions, and has a range of other important roles. When it goes wrong, the consequences can be severe. One of the key difficulties faced by ME/CFS patients is standing, especially standing still, without experiencing symptoms such as dizziness, altered vision, nausea, fatigue, etc. The possibility therefore exists that there could be a problem with the autonomic nervous system in the condition. In 2007, Professor Julia Newton of the School of Clinical Medical Sciences, University of Newcastle received a grant from ME Research UK and the regional Clinical Service to examine a large group of patients using a battery of tests of heart rate and blood pressure. The Cardiovascular Laboratory in which the tests were done is one of the largest autonomic testing labs in Europe. With all the necessary equipment and expertise for comprehensive autonomic testing.



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Postural orthostatic tachycardia syndrome is an under-recognized condition in chronic fatigue syndrome

A. Hoad[1], G. Spickett[1], J. Elliott[2] and J. Newton[3]

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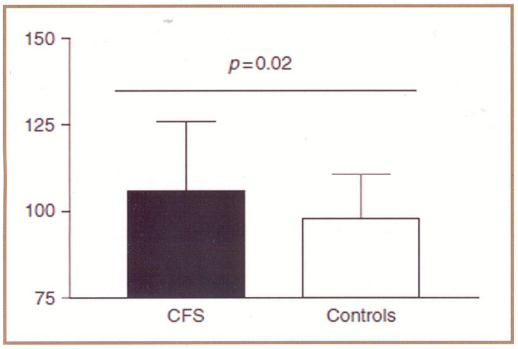
Professor Newton's results - published in the Quarterly Journal of Medicine (August 2007) - showed that autonomic dysfunction was present in three-quarters of the patients studied, a much unexpected finding. Furthermore, in a separate study (see the opposite page), she has reported that a simple- to-measure assessment of the heart rate response to standing was abnormal in a significant proportion of patients. ME Research UK, the John Richardson Research Group and the Irish ME Trust have provided funding for the next phase of the work - a two-year project exploring some of the mechanisms behind these autonomic problems in ME/CFS patients. The investigation has two broad aims. The first is to examine fully those individuals attending the Newcastle CFS/ME Clinical Service and to develop a database of patients who can be followed up over the long-term. The second aim is to begin to answer the following question: 'Does the autonomic dysfunction in people with ME/CFS arise in association with abnormalities of the brain, muscle and liver, as has already been shown in patients with other illnesses?' For this investigation, a series of linked studies will examine muscle bioenergetics, and structural and functional abnormalities of the brain and liver. These investigations will use state-of-the-art magnetic resonance techniques, including assessment of liver fibrosis and percentage fat

Prof. Julia Newton (centre) with Nurses Katherine Wilton and Jessie Pairman

The most recent scientific paper from Professor Newton's group at the University of Newcastle (Quarterly Journal of Medicine, December 2008) described the prevalence of one simple-to-measure aspect of autonomic dysfunction, namely postural orthostatic tachycardia syndrome (POTS), in a group of patients recruited via the specialist CFS/ME service in Newcastle. POTS is defined as symptoms of orthostatic intolerance associated with an increase in heart rate on moving from lying to standing. Importantly, the major finding was that significant POTS could be measured in a high proportion (27%) of the patients but in only 9% of healthy control subjects. Moreover, the POTS observed in the ME/CFS group was characterised mainly by an increase in heart rate to more than 120 beats per minute on standing (see graph on next page). This increase in heart rate was significantly associated with increasing fatigue.

The central finding is important: POTS is a frequent finding in patients attending the clinic, suggesting that the clinical evaluation of patients presenting with ME/CFS should include heart rate responses to standing, an obvious and easily measurable clinical sign. It remains unclear, however, whether the observed POTS should be viewed as a clinical entity distinct from ME/CFS, or whether patients with

POTS represent a particular subset of ME/CFS patients with the most marked symptoms. Whatever the case, the authors remark that the diagnosis of POTS (a potentially treatable condition) may currently be missed in ME/CFS patients attending clinical services. And they suggest that, at the very least, a haemodynamic assessment of the response to standing should be included in the clinical assessment of patients attending ME/CFS clinical services. POTS is the most common form of orthostatic intolerance without orthostatic hypotension, and can produce substantial disability among otherwise healthy people. One large series of the reported symptom burden to be significant and to include weakness, and muscle aches and pains suggested a neuropathic basis for at least half the cases of POTS, and an autoimmune component for a substantial percentage of cases.

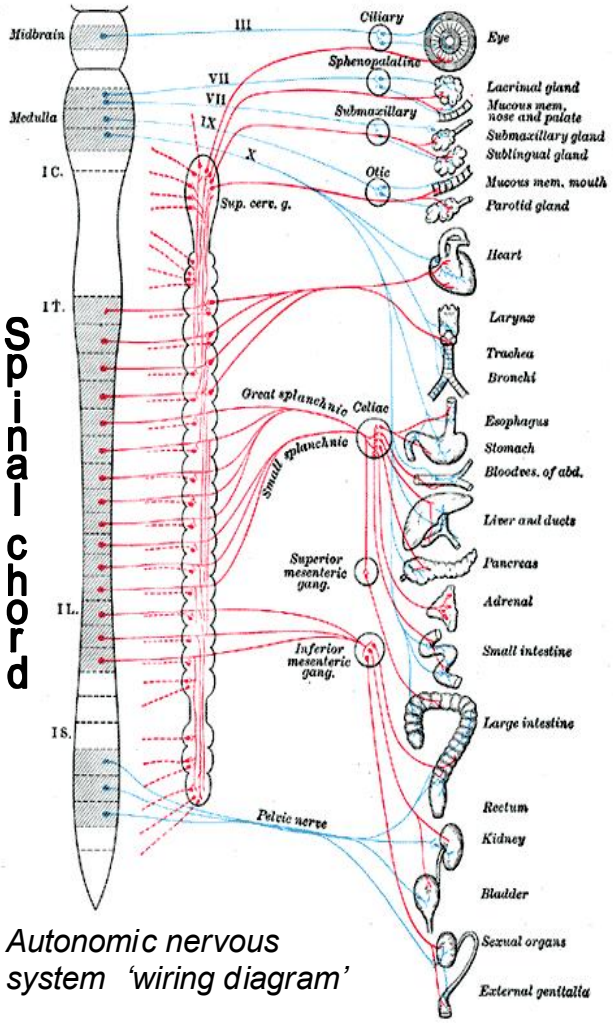


Graph of maximum heart rate (in beats per minute) after standing, showing the difference between ME/CFS patients and matched controls

Other studies have shown POTS to be accompanied by a range of autonomic nervous system abnormalities, including vagal nerve withdrawal and enhanced sympathetic modulation, and that it can be associated with findings consistent with pooling in the lower limbs, similar to pathophysiological, mechanisms occurring in a proportion of people diagnosed with ME/CFS. Given these associations, it is important that POTS be recognised and managed, whether in ME/CFS or in other groups of patients. Professor Newton's findings suggest that current treatment regimes (which can include a range of pharmacological and non-pharmacological strategies) for the management of orthostatic hypotension and POTS should be incorporated into ME/CFS management programs.

Jargon Buster

The 'doing' side of the nervous system is in two parts, the voluntary (which controls muscles for example) and the involuntary, that which controls the inner organs. The involuntary systems job is the 'body management unit' that blood, food and other functions take place. etc. It is known as the Autonomic nervous system. There are two parts.
a) Sympathetic nervous system. (red) This promotes a "fight or flight" response, corresponds with arousal and energy generation, and inhibits digestion. 'Running away'
b) Parasympathetic nervous system. (Blue) This promotes a "rest and digest" response, promotes calming of the nerves return to regular function, and enhances digestion.
The HPA axis is part of the sympathetic system, and is dysfunctional in ME/CFS. There is evidence to suggest that the parasympathetic is affected in some way in ME.
Postural orthostatic tachycardia syndrome (POTS) refers to abnormalities in the control of the speed of the heartbeat, and blood pressure. The 10th (x) nerve (vagus) controls the heart and internal organs, thus one single nerve problem may explain why most of the body organs are affected, and may go some way into explaining the variety and sometimes bizarre section of problems experienced by people with ME/CFS. Without getting technical, the autonomic side has to ensure that blood is diverted to the right place as the right time. Many people with ME suffer from a version of early morning stiffness (dysfunction), and this is usually because the sympathetic nervous system is late in activating. It's like a shop selling Christmas cards as Easter.



Autonomic nervous system 'wiring diagram'

Get Out Of the ME Gaol, Be Free *by Ann Fisher*

Today I feel like I have got my óget out of jail freeôcard. Unfortunately it isnôt free in fact quite expensive, but I feel I am now back in the game and raring to go. But first a brief history, I have suffered or endured ME for 19 years, starting off moderately to severe, I gradually improved over a number of years to having mild symptoms, never quite shaking it off but able to lead a life close to ónormalô I ran around after children /teenagers, worked part time and enjoyed my hobbies of walking and dancing. So it was a bit of a shock , óto say the leastô when 18 months ago I had a severe relapse ï no more work, walking or dancing, however the children are more or less independent now. So, when I realised a month ago that I wasnôt going to improve as quickly as I would like, and the summer months were here, then I had to do something about getting back into doing the things I missed most, one at a time, starting with walking!! Walking, I hear you say - with ME? Who are you kidding? Well not exactly walking but riding - on a mobility scooter.

Finding a mobility scooter to do the things I want it to do isnôt easy. I want it to go over foot/cycle paths, to take a little rough ground and collapse down into the boot of the car. No offence to any pensioners reading this but I didnôt want to look like a pensioner going round the shops as I am still in my 40ôs, so I needed a different style and something a little rugged to fit the landscape. I was of course asking too much. After hours on the internet and visiting shops we came up with what we hope will be a good compromise with the óRascal Liteway 4ô And to suit my sense of fun and need to be a little different from the crowd they have provided it in burnt orange not the usual blue or red. Just in case anyone else is looking for a scooter, I did have to really shop around. I was first offered the one I bought for £1400 by a shop in Mexborough, and then found it to be £1200 - also in Mexborough. I eventually bought it for £850 from Sheffield with a recommendation from a friend I met at the Sheffield ME clinic.

While researching a scooter I was also onto tourist information centres trying to find suitable paths and tracks in Derbyshire, Yorkshire and Nottinghamshire, which once again, in my naivety, I thought would be easy. But the Peak District National Park came up trumps with a booklet of paths with wheelchair access, there arenôt many but it is a good start. So we were ready for off. Batteries charged. Me rested and charged (excited). Car groaning under its new load, picnic packed, sun cream and hats, ready to explore the long awaited countryside. It didnôt disappointé ...

Questions That Can Haunt You

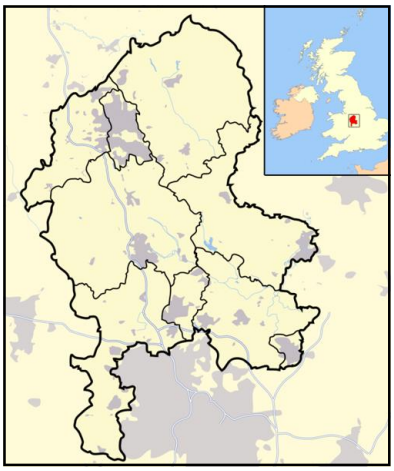
- Can you cry under water?
- Why does a round pizza come in a square box?
- How is it that we put man on the moon before we figured out it would be a good idea to put wheels on luggage?
- Why is it people say they ñslept like a babyòwhen babies wake up like every two hours?
- Why are you IN a movie, but youôre ON tv?
- Why do people pay to go up tall buildings and then put money in binoculars to look at things on the ground?
- Why do toasters always have a setting that burns the toast to a horrible crisp which no decent human being would eat?
- If corn is made from corn, and vegetable oil is made from vegetables, what is baby oil made from?
- Did you ever notice that when you blow in your dogôs face he gets mad with you, but when you take him for a car ride, he sticks his head out of the window?

Thanks to Sutton ME/CFS Support Group

Thoughts for the Day

If you put ñeat chocolateò at the top of your list of things to do today, youôre certain to get at least one thing accomplished.
Man walks into Doctorôs surgery with a strawberry on his head. The doctor says ñIôll give you some cream for thatò
Mummy, Mummy, thereôs a man at the door with a bald head.
Tell him your dadôs got one!!!

Thanks to Central Lancashire ME/CFS Support Group



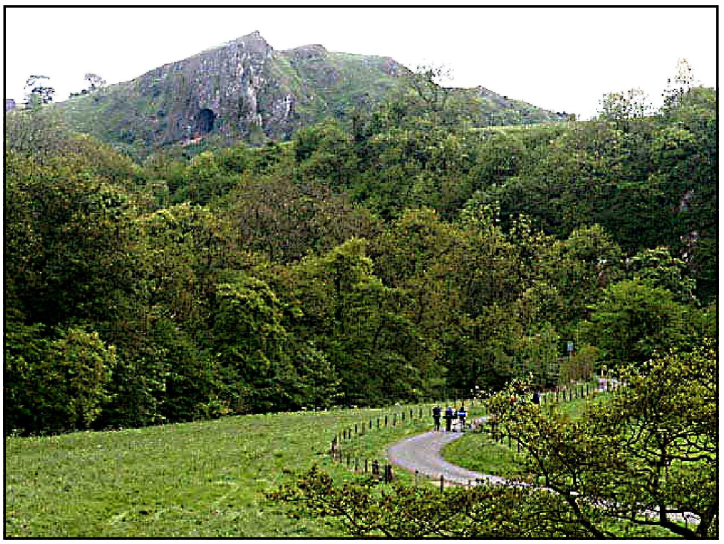
Wetton village, situated in the Peak District National Park and is pleasant stone built village standing high above Wetton Mill in the Manifold valley about 8 miles from Ashbourne.

We drove to the Manifold Valley Track in South Derbyshire, and parked south of Wetton Mill in a lay-by, this meant there would be no walking/ scooting on a road (as some of the trail is on small single track roads). From here we went south; the foot path is flat and covered with tarmac all the way, but a little rough in places. We went as far as a café at Lee House Farm, had a delicious ice cream, (far too many calories it was a very hot day though) before returning the same way. We travelled a distance of approximately 6.5 miles my husband had a good long walk and I had my day in the countryside. This part of the walk is central on the trail, there are, I believe, larger car parks and toilets at both ends of the trail. There are toilet facilities at both Wetton Mill Tea rooms and Lee House Tea rooms but they are not really designed for wheelchairs.

Bluebells, thanks to Pathways reader Rob

It was a delight to see the things I have been missing such as the spring flowers; forget me not, campion, bluebells, buttercups and so many more of which I don't know the names. Trees were coming into full fresh green leaves, giving us shade from the sun. Birds were darting for cover as children on bikes passed with their parents and there were butterflies - orange tipped and a sulphur yellow one – I must start to learn their names. The river Manifold in places was bubbling over the rocks and the cliffs and caves were spectacular. Even the sickly sweet smell of the garlic flowers was wonderful. I didn't notice that I was invisible to others as some say they are in wheelchairs (that may have something to do with the burnt orange colour) but I said hello to walkers and cyclists as they passed as I normally would when walking and everyone responded, I even made some of the children jealous as their parents made them keep cycling, one said "I want one of them" as his aching legs had to propel him on down the path.
It was a perfect day.

A flash of orange, photo thanks to Carolyn



A local landmark, Thors cave, rising 360ft above the river Manifold has a 60ft entrance. The disused Leek and Manifold Valley railway track bed now forms the Manifold Way, giving a flat path like many disused railways in Derbyshire ideal for disabled access

Off course the day was exhausting and I know I will suffer for it over the next few days, but I travelled in reasonable comfort for a long time and over a long distance. So I have got out of my jail and passed GO, I am now looking forward to exploring more trails and paths and pestering information providers for more guides.
Who knows, I may even start to write my own.

Details of my walk may be found in the Peak District National Park Authority's booklet 'Your Welcome' Access for all to the moors project, Aldern House, Baslow Road, Bakewell, Derbyshire, DE45 1AE

More on the Judicial Review of the NICE Guideline

From spring 2009 *Breakthrough* ME Research UK

For the Judicial Review of the NICE Guideline on CFS/ME on the 11th and 12th of February 2009, at the High Court in London, Dr Neil Abbot provided an Expert Witness statement on the evidence base underpinning the main treatment recommendations. In this article, he summarises his conclusions, mainly with reference to cognitive behavioural therapy (CBT), though many points also apply to graded exercise therapy (GET).

Summary of randomised controlled trials in adults

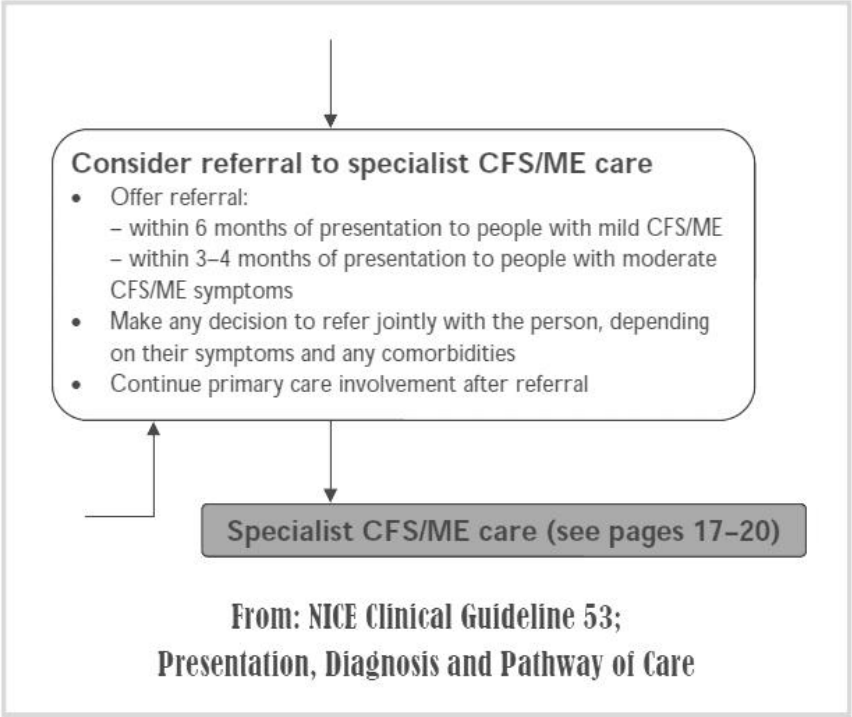
(source: Appendix 1, NICE Guideline; and Bagnall et al, 2007)

Author and year	Case definition	Treatment	Patient numbers	Comparison group	Overall effect of "treatment"
Lloyd, 1993	Australian	**CBT** (+ DLE injection)	90	Placebo injection only	None
Deale, 1997 & 2001	Oxford	**CBT**	60	"Relaxation"	Positive
Sharpe, 1996	Oxford	**CBT**	60	Standard medical care	Positive
Prins, 2001	CDC, 1994	**CBT**	270	"Guided support" and "natural course"	Positive
Whitehead, 2002	CDC, 1994	**CBT** by GP	65	"No intervention" control	None
Wearden, 1998	Oxford	**GET** & fluoxetine	136 (4 groups)	Review of activity diaries/placebo capsule	None
Fulcher, 1997	Oxford	**GET**	66	Flexibility exercises and relaxation therapy	Positive
Powell, 2001 & 2004	Oxford	**GET**	148 (4 groups)	Standardised medical care	Positive
Moss Morris, 2005	CDC, 1994	**GET**	49	Standard medical care	Positive
Wallman, 2004	CDC, 1994	**GET**	61	Relaxation/flexibility therapy	Positive

The National Institute for Clinical Excellence (NICE) is rightly respected for basing its treatment recommendations on evidence. In the case of the illness ME/CFS, its principal recommendations were cognitive behavioural approaches for the specialist management of the illness because currently these are the interventions for which there is the clearest research evidence of benefit. However, cognitive-behavioural approaches are widely recognised, including by the NICE Guideline itself (section 6.3.8, page 252), to be non curative for ME/CFS; and in other physical illnesses these approaches are used as adjuncts to but not substitutes for mainstream treatment. So, what was the evidence base for the central role of these approaches in the clinical management of the illness? The table opposite shows that the evidence base for these cognitive behavioural approaches consists of a small group of randomised controlled trials on adults (ten trials in all; seven with mild-to-moderately positive results and three with negative results). Focusing in on CBT (a form of psychotherapy used to treat a variety of psychological impairments) the first thing to note is that two out of five trials have a negative overall result (Whitehead, 2002; Lloyd, 1993). The remaining three trials have overall positive effects, and moreover have high validity scores, indicating that they are likely to have been well-designed and conducted. Nevertheless, the gold standard evidence-base consisted of three mild-to-moderately positive randomised controlled trials only. It is instructive to compare this with the evidence base available for NICE Guideline 8 on multiple sclerosis, with many hundreds of trials. Other key points to note are the following:

Patient numbers. The trials of CBT have relatively small numbers of patients; in four of the trials, analysis was performed on no more than 30 patients in the CBT groups, while the largest trial (Prins, 2001) analysed 92 patients in the CBT arm. Since only two of the trials (Deale, 1997; Prins, 2001) reported making a power calculation to determine the adequacy of sample size to determine a treatment effect, it is entirely possible that some samples were too small to determine a true effect.

Different kinds and duration of treatment. There is a difference between trials in the type and content of CBT delivered, as well as in the number, frequency and length of intervention sessions given. This makes it impossible to say that like was being compared with like as far as type and delivery of treatment was concerned.



From: NICE Clinical Guideline 53;
Presentation, Diagnosis and Pathway of Care

Diagnostic definitions. Case definitions of CFS differ, raising the question of whether homogeneous groups of patients are being compared between trials. Two of the positive trials recruited patients using the Oxford criteria (1991) which focuses on unexplained chronic fatigue and does not require additional symptoms. Given that the NICE Guideline itself recommends that post-exertional malaise and other symptoms such as cognitive difficulties, sleep disturbance and chronic pain be present for a diagnosis to be made, it is entirely possible that new patients diagnosed by their GPs using NICE guidance constitute a different - most probably more sick - clinical group than those who took part in the original trials.

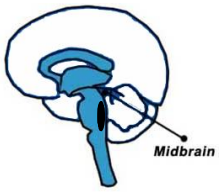
Comparison groups differ. As each trial employed a different comparison group (placebo injection, relaxation, standard medical care, guided support/natural course and no intervention) it is impossible to say that the CBT delivered was having a specific treatment effect. For example, some people (including the authors of the Canadian Consensus document of 2003) wonder whether a programme of formal CBT or GET adds anything to what is available in the ordinary medical setting under a good and concerned medical practitioner.

Long term effects. In four out of five trials, follow-up was relatively short, and so the relevance of the findings over the longer term remains unknown. This is particularly important in an illness which is a long-term condition, and tends to be chronic with serious debility in some; a moderate treatment effect in the short term might not show treatment-specific gains in the longer term. For example, the one trial (Deale, 1997) in which five-year follow-up results were reported revealed no significant difference in physical functioning and fatigue between CBT and a relaxation control group after five years, though other parameters were improved. Serious commentators might consider that the conclusions about efficacy one could draw from this small group of trials are suggestive and tentative only. A recent Cochrane review (Price, 2008) found fifteen studies of CBT (including controlled clinical trials) for CFS/ME, and took a far more measured, cautious view of the evidence and its limitations than the authors of the NICE Guideline, as did a second recent review (Malouff, 2008).

The practical consequences of NICE's recommendations can be seen in the Quick Reference Guide to the NICE Guideline, which (unfortunately) is the only part read by most healthcare professionals and GPs. On page 6, the Pathway of Care ends at a category called Specialist CFS/ME care (see figure above) inside which CBT and/or GET are the principal treatments alongside activity management. Whatever the merits of these therapies in them for psychological illnesses, can it be reasonable for them to be enshrined in established national guidelines which feed into clinical care and government policy (at a potential cost to the country of £45.2 million over a five-year period) on the evidence available?

Sleep Disorders, Insomnia and ME/CFS

All parts of the human body seem to work 24 hours a day, 7 days a week without rest, with the exception of the brain. The most obvious example is the heart, which can never take a rest during a lifetime. The brain seems to need cycles of activity & rest in order to work properly and maintain itself.
Humans evolved to sleep when it is dark and wake 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 a vital biological process that is necessary to restore both body and mind. It is usually taken for granted, unless it is disturbed. Sleep disorders are something which almost all ME/CFS sufferers experience; they have a profound effect on recovery, quality of life, relationships, employment and personal safety.



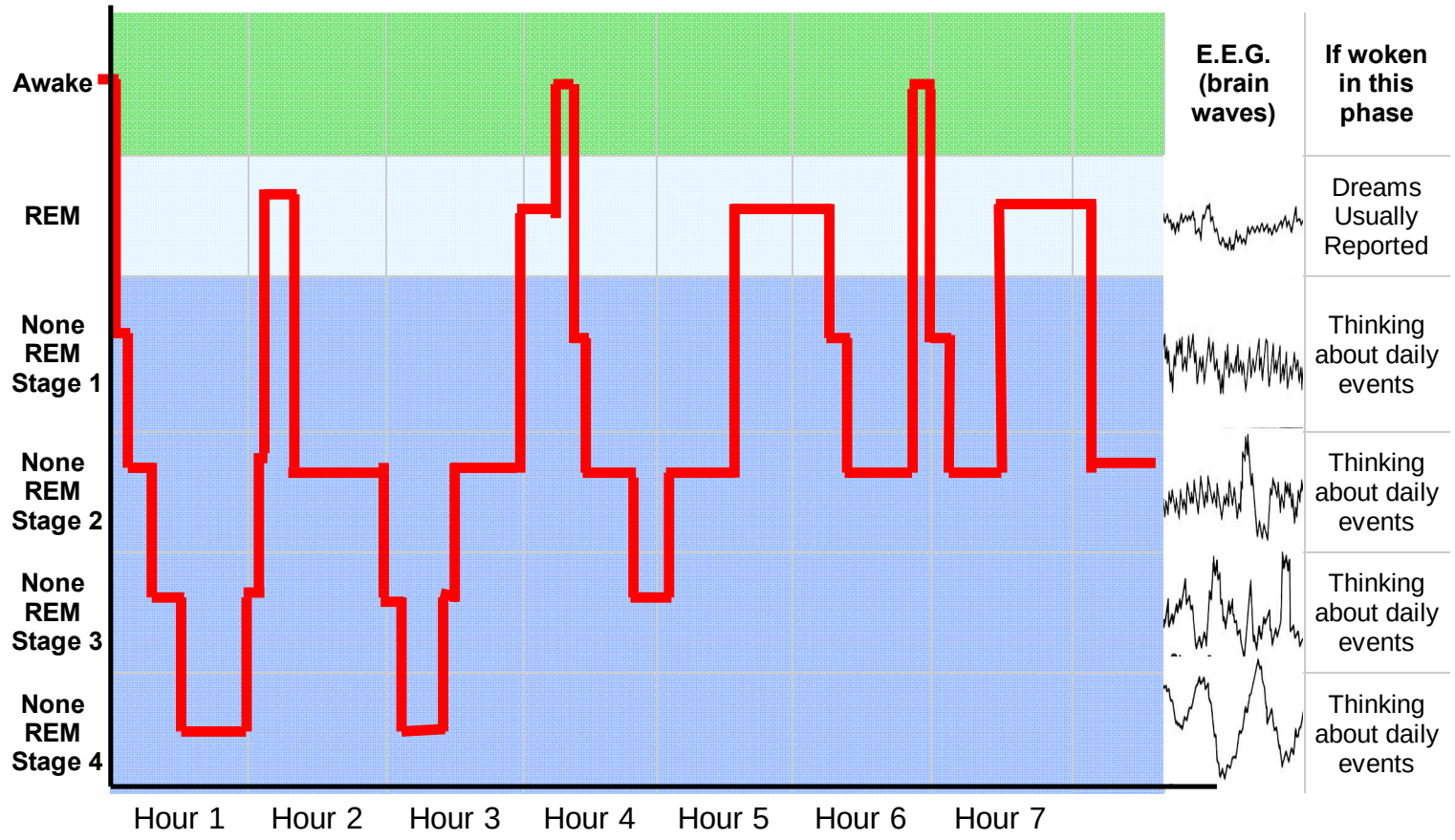
The sleep cycle is controlled by specific areas of the mid and hind-brain. The neurotransmitters serotonin (5-HT), noradrenaline, acetylcholine and GABA are implicated, and drugs which modify these processes are used in sleep treatments. Sensory stimuli stimulate the Reticular Activating System (RAS), especially if they are intense, varying or meaningful. Sleep is facilitated by the absence of stimulation, of the RAS. There are five different stages of sleep which can be divided into two sorts known as rapid eye movement (REM) and non-rapid eye movement (non-REM) sleep. REM sleep is characterised by rapid sweeping of the eyes under the eyelids. During this phase blood circulation to the brain is increased, dreaming is common and the brain shows a high level of activity. A person in REM sleep is in the deepest stage of sleep and difficult to wake. REM sleep is thought to be associated with the restoration of memory, the repair of brain tissue and the laying down of memories. Non-REM sleep can be divided into four stages characterised by a gradual slowing of electrical activity within the brain, progressive relaxation of the muscles and slower more regular heart beat.

Sleep disorders
Insomnia is rarely a diagnosis in its own right, usually a symptom of some other condition. It can happen in a variety of ways:
Difficulty in falling asleep ï problems with sleep latency
Waking during the night several times
Prolonged periods of wakefulness during the night
Early morning waking
Waking in the morning not feeling refreshed.

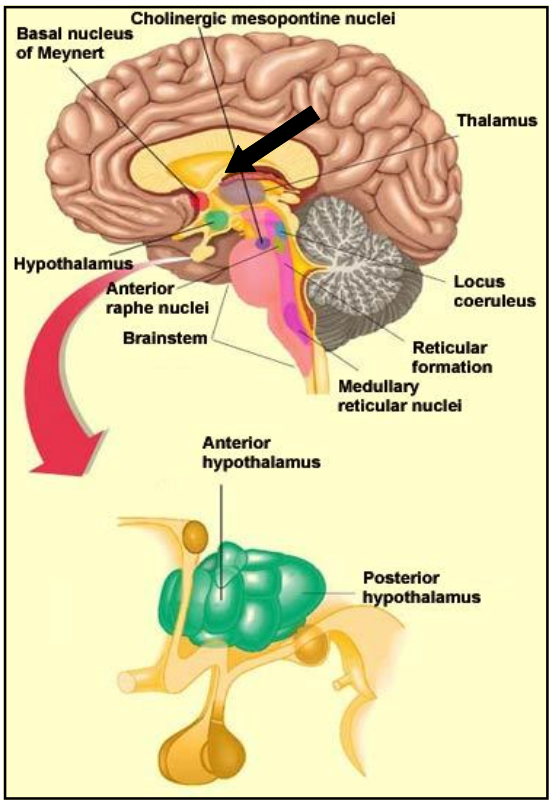
Type	Length	Cause	Treatment	Problems
Transient	only a few days	Jet-lag, short-term hospitalisation or minor stress drug withdrawal	Sort term hypnotic medicines to relieve symptoms	Usually resolves by itself
Short term	1-4 weeks	Shift work, serious illness or bereavement.	Sort term medicines to relieve symptoms	Patient usually stops or misses doses
Chronic or long term	more than a month.	Poor sleep hygiene. Chronic disease	The cause needs treating where possible. Sleep hygiene helps.	Rebound on withdrawal, and reduced effectiveness.

About one third of all adults will report one or more of the above sleep problems and, in addition to those who suffer from the above temporary bouts of sleeplessness, there are those people who suffer from chronic or prolonged insomnia lasting many months or years. This can be severe and disabling.
Insomnia. Although sleeplessness is common, it is by no means trivial. Difficulty in sleeping can be extremely distressing to the individual, as can the consequences of a lack of sleep. Sometimes merely the fear of not being able to get to sleep is enough to prevent the onset of sleep
Insomnia can be divided into two types ï
Primary insomnia is insomnia that is not caused by a physical or mental illness, or because of a side effect of medication or substances (such as alcohol or street drugs).
Secondary insomnia is caused by ill health or as a result of medication or substances. Pain, anxiety or depression can also lead to secondary insomnia. So can ME/CFS.

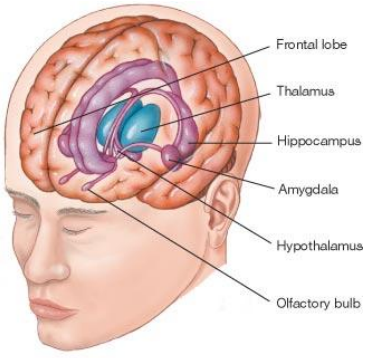
Sleep Patterns or Sleep Architecture

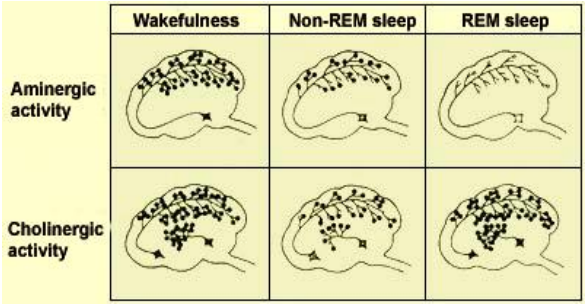


Stage 1 - which starts with yawning and the eyes beginning to feel heavy, represents the transition from wakefulness to sleep
Stage 2 - represents the first real stage of deep sleep
Stages 3 and 4- initially occur about an hour after falling asleep and are collectively known as 'slow wave sleep' or 'deep sleep'.
A normal sleep pattern Cycling between REM and non-REM sleep continues during a normal night in periods of approximately ninety minutes. This pattern is referred to as 'sleep architecture'. Progressively shorter and shorter cycles of non-REM sleep are interspersed with lengthening periods of REM sleep, which ensures that both body and mind are rested and refreshed on waking. During sleep deprivation, non-REM sleep outweighs REM sleep. This disturbs the sleep architecture, leaving the sufferer feeling tired and unrefreshed on waking.



After the First World War a strain of Pandemic Spanish 'flu swept through Europe killing 50 million people worldwide. Some people sustained neurological damage; it wiped out their sleep centre in the brain. They were unable to sleep at all. All these people died within 2 weeks. Similar things happen when stroke, disease or injury damage the sleep centre, proving that sleep is a essential for life as food and water. In ME/CFS The hypothalamus is dysfunctional





Brain activity varies according to the sleep/wake state and different systems

The reticular activating system (RAS) is the name given to the part of the brain (the reticular formation and its connections), and is believed to be the centre of arousal and motivation in humans. Stimuli from this area keep people awake, and lack of stimuli facilitate sleep. The RAS affects the thalamus, then the hypothalamus, and finally the pituitary. We know that there are disturbances to all these parts of the brain in ME/CFS.

What can you do to sleep better?

Although hypnotic medicines can help with sleep, most doctor prefer to recommend sleep hygiene before medicines. Many medicines used to control sleep cause tolerance (more you take, the less well they work), and reduce the amount of deep sleep. Her e are some simple steps that doctor s recommend but they ar e not always appropriate to ME/CFS.

General Advice	Justification or Reasons	Issues with ME/CFS
Don't sleep late	Even if you've had a bad night or use the weekends to catch up on sleep as this can upset your body clock	Bad advice, goes against pacing rules, and does do take into account early morning stiffness experience by many ME's. Sleeping to later in the day gives many people with ME/ CFS a better quality day.
Get up at the same time each day	This to reinforce your body clock no matter how you feel; this will help your sleep patterns	Although it has some foundation, most people with ME/CFS will have a bad day is woken too early and active too early.
Avoid daytime naps	If your goal is to sleep more during the night but napping can help with short-term alertness if you keep your naps to no more than 20 to 30 minutes.	ME's derived of sleep during the day become stressed and can't sleep. Sleep during the day when needed usually results is a better nights sleep.
Go to bed when sleepy and not before.	Psychological association of bedrooms with sleeping	Most M.E.s don't get the normal craving to sleep
If you are awake in bed for more than 20 minutes, get up and leave the bedroom.	Force sleep. Do something you find relaxing until you feel tired enough to go back to bed	If you wake in the night don't switch in the light, as this will disturb your sleep cycle.
Make sure your bedroom is not too hot, cold or noisy	Try wearing earplugs to block out any or snoring from your partner and an eye mask to shut out light or external noise.	Sometimes works, pain, parasthesia, neuropathic pain ,things like tinnitus and visual disturbances need medicines to control.
Try to only use the bedroom for sleep.	Avoid watching TV or working in your bedroom.	In some families the bedroom is the only private space.
Ensure your bed is comfortable and big enough for you and your sleep partner.	Your mattress should support you well. Generally mattresses should be replaced every ten years or so.	Bed clothes and mattresses can cause irritation or discomfort. It is important to ensure you are comfortable. Sleep in a separate bed if necessary.
Hide the alarm clock.	Do not clock-watch as this does not help with getting to sleep.	Some ME's find a ticking clock irriitating.
Relax and wind down before bedtime.	Relaxing activities like a bath or playing soft music helps facilitate sleep.	Sometimes it helps, but this also cause stress in higher grade cases.
Do not do anything mentally or physically	Studying or difficult reading within 90 minutes of bedtime delays sleep onset.	ME tend to have issues winding down.
Put the day to rest.	Don't worry about the day's events or tomorrow and don't worry about the chance you won't sleep. Remember people cope even after a sleepless night.	Does not apply to people with ME. A sleepless night can cause a relapse or rebound.
Avoid caffeine or stimulants for six hours before bedtime.	Avoid simulating foods/drinks This includes tea, coffee, cocoa, chocolate caffeinated soft drinks and any food containing caffeine	Most people with ME find this out for themselves, and avoid these things during the evening as they seem more sensitive.
Avoid smoking before bedtime.	Nicotine in cigarettes is a stimulant which can keep you awake.	Anyone who smokes is damaging their health and making ME worse. Seek health advice.
Avoid alcohol in large quantities or using it to help you drop off.	Alcohol helps sleep, but it disrupts sleep later in the night and causes early morning wakening.	Many Me's are sensitive to alcohol, and it makes them feel ill or causes insomnia. It may potentiate some medicines
Avoid a heavy meal just before bedtime.	Try eating earlier in the evening or keeping to a light meal.	Depends if IBS is a prominent symptom. A meal is usually facilitates sleep
Try exercising late in the evening.	Regular exercise in the day or early evening such as a brisk walk or run will actually help sleep but not too close to bedtime.	Nice if we could. Exercising usually stresses high grade ME's past the point where they can sleep.

Specific ME-related Sleep issues

(Thanks to Dr. Sarah Myhill)

Sleep Phase delay. This is integral to the ME disease process and is typically delay by 4-6 hours. HPA axis problems cause the body clock to run late. In children, it may be twelve hours delayed, quite often sleeping all days and active at night. The quickest fix is sleep hygiene and hypnotic drugs, but is an indication of increased disease activity. Getting pacing right and doing what needs to be done to back off the ME is the only long term solution.

Pain. If sleep is disturbed by pain, just take whatever pain-killers are necessary to control this. Lack of sleep simply worsens pain. Pain can take many forms, and things like fibromyalgia foci, burning, itching restlessness and odd sensations are also forms of pain. The NHS first line choice is paracetamol, followed by opiates (codeine), and if necessary strong opiates like morphine or Butrans patches may be needed. TCADS like amitriptyline at a low dose very often help. Really this should be overseen by a pain control clinic.

Hypoglycaemia. If your sleep is disturbed by sweating or tremor then this is likely to be a symptom of low blood sugar, which is fairly common. Very often a hangover headache is present. However some people find any food disturbs sleep and they sleep best if they do not eat after 6pm.

Hyperventilation is a common cause of disturbed sleep which often causes vivid dreams or nightmares. Dr Myhill tells me that she often use a benzodiazepine such as diazepam 2-5mgs at night which reduces the sensitivity of the respiratory centre.

Your Sleep			
How was your sleep last night? (scale of 1-5)			
What time did you wake up this morning?			
What time did you go to bed last night?			
How long did it take you to fall asleep?			
How many times did you wake up during the night?			
Did anything cause you to wake up during the night?			
How many hours do you think you slept in total?			
How good did you feel your sleep was? (scale of 1–5)			
Your activity in the day			
How many cups of caffeine drinks did you have after 5pm?			
What time did you have your evening meal?			
How many units of alcohol did you have this evening?			
Did you exercise after 8pm?			
How you feel in the day			
How refreshed did you feel in the morning? (scale of 1–5)			
How alert did you feel throughout the day? (scale of 1–5)			
How sleepy did you feel today? (scale of 1–5)			
What time of the day did you feel the most sleepy?			
How generally well did you feel today? (scale of 1–5)			
How energetic did you feel today? (scale of 1–5)			
Add any other details you think are relevant			

A sample page of a Sleep diary. Keeping a personal diary of how you have slept in the night is a useful way for you to record your sleeping patterns and quality of sleep over a period of time. It will help you identify if there is anything you are doing which compromises your sleep. You can also share your sleep diary with your doctor, should you decide to get further advice, so you can both talk about your sleeping problem and decide how best to manage it.

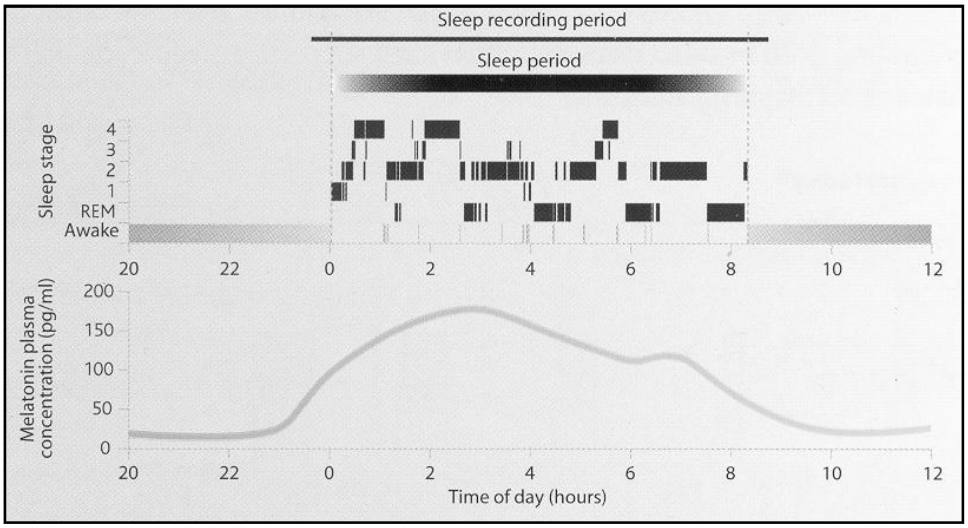
Sleep apnoea. Suspect this if your partner describes snoring and you stop breathing for a period, one or more breaths being missed. This is a specific condition which requires hospital supervision of positive pressure airways ventilation.

Depression and Anxiety. This is a common problem experienced by many chronically ill people including ME sufferers. Difficulties with sleeping and early morning waking are signs of depression. Treating the depression with sedating medicines like clomipramine or mirtazapine prescribed will also help to promote sleep if taken at night.

Other disturbances Night coughs often occur in asthmatics with ME. This usually means that asthma is not properly controlled. Any chest pain, shortness of breath or indigestion needs to be investigated by a doctor, as other medical conditions could be implied.

Sleep Medications and ME

(by Dr. S. Myhill)



Melatonin levels rise prior to sleep and drop after - so it would seem logical to prescribe melatonin. Melatonin 3mgs (one tablet) 1-3 tablets at night. Some people just need 1mg. CFS patients have a poor output of hormones from all their glands namely the hypothalamus, pituitary, adrenals, thyroid and also the pineal gland. The latter is responsible for producing melatonin, the natural sleep hormone. It seems logical to me therefore to try this first. It is available on the NHS. One or two of my patients have become depressed with melatonin, so be aware of this.

Valerian root 400 mg 1-4 capsules at night. This is an herbal preparation which is shorter acting and can be taken in the middle of the night.

Nytol (diphenhydramine 50mg). This is a sedating antihistamine available over the counter. This is longer acting - don't take in the middle of the night or you will wake feeling hung over.

If there is no improvement with a combination of the above, or if there are intolerable side effects, then I would go on to a prescribed drug. I usually start with one of the sedating antidepressants such as:

Amitriptyline 10mgs - 25mgs. I would start with 5mg initially. Most CFS patients are made worse and feel hungover with "normal doses", or Surmontil 10-30mgs at night.

Short acting temazepam 10mgs. This is useful but recently has been made a controlled drug so doctors are understandably twitchy about prescribing it. It is controlled because some drug addicts were taking the gel and injecting it into themselves. Nowadays I tend to use instead zaleplon (Sonata) or medium acting zopiclone (Zimovane)7.5mg.

Diazepam is helpful if sleep is disturbed either because of hyperventilation (it reduces the respiratory drive) or for muscle spasms (it is a good muscle relaxant).

Different people will respond to different combinations of hypnotics. For example, one person may take a melatonin and two valerian at night, plus a zaleplon when they wake at 3.00am. So mebody else may be best suited by 10 mg amitriptyline at night with a Nytol. Don't be afraid to try combinations - there are no serious side effects that I am aware of with any of these used in combination. However, don't change more than one thing at any time otherwise you (and I) will get confused!

When your normal sleep pattern has been restored you can begin to reduce or tail off completely your hypnotic medication but only if good quality sleep can be maintained. Use the hypnosis techniques every time you try to go to sleep, even when your sleep is disturbed by the need to pee - eventually your brain will learn! If your sleep begins to suffer, you must go back on the medication that worked before because the need to sleep is of paramount importance in CFS patients.

If you are a patient of a private doctor like Dr. Myhill, she can supply you with these medicines at cost. Some NHS areas, particularly Barnsley are ME-unfriendly. They have policies of prescribing only small amounts of hypnotics like zopiclone, which many patient report are like gold to obtain...

Anger in Hampshire as South Central SHA ignores consultation results to order fluoridation against the wishes of local people *by Elizabeth McDonagh*

South Central Strategic Health Authority SCSHA) and Southampton City PCT blatantly promoted fluoridation throughout their September 8th to December 19th 2008 consultation into their proposed fluoridation of 195,000 people in parts of Southampton and Hampshire. In spite of that, a clear majority of local people have responded that they are opposed to fluoridation. The SHA had 10,065 written responses in total. 72% of all local written responses to the consultation were opposed to fluoridation. In spite of 72% of local residents opposing fluoridation, SCSHA, on February 26th, voted unanimously to instruct Southern Water to fluoridate the water supply.

The Strategic Health Authority also ran a telephone poll of 2060 people which was designed to be representative of the gender, ethnic, economic and work status mix in the area. The results fell roughly into thirds with just less than a 1/3 (32%) FOR fluoridation, about 6% more (38%) AGAINST. The final third consisted of 19% who neither supported nor opposed and the rest (10%) who ódidnôt knowô In the face of majority opposition, the unanimous vote of the SCSHA Board on 26th February to instruct Southern Water to fluoridate is a disgrace which shows that, from the beginning, the consultation was a sham and a huge waste of public money. £178,000 was allocated for the Consultation and we estimate that, if staff time is taken into account, something close to £500,000 was spent.

Under the 2003 regulations, ***"the Authority is satisfied that the health arguments in favour of proceeding with the proposal outweigh all arguments against proceeding."***

Fluoride is known to cause harm to humans and animals, even at 1 ppm. Fluoridation gives no control of any individualôs dose because some people drink more than others. Also some people are more susceptible to fluorideôs toxic effects. 1 ppm gives no adequate margin of safety to protect vulnerable subsets of the population. Every member of the SCSHA Board is now responsible for any adverse effects from fluoridation. They will not be able to shelter behind the defence that the public asked for fluoridation, nor behind the excuse that they were not informed of the harmful effects of their policy, especially on vulnerable subsets of the population.

Hampshire's Local Green Party MEP, Caroline Lucas has referred the SCSHAôs decision to the European Parliament for scrutiny. Meanwhile, Chris Huhne, MP for Eastleigh, has appealed to Lord Chris Smith, head of the Environment Agency, to order a full assessment of what impact 100 tonnes of extra fluoride per year could have on watercourse eco-systems. And Julian Lewis, MP for New Forest East, who has described the consultation process as ñhopelessly biasedò, has lodged a complaint with the Local Government Ombudsman. NPWA has produced a comprehensive critique of SCSHAôs óConsultation Documentô We have also made a submission to the European Commissionôs Scientific Committee on Health and Environmental Risks which is currently taking a second look at water fluoridation as a public health measure.

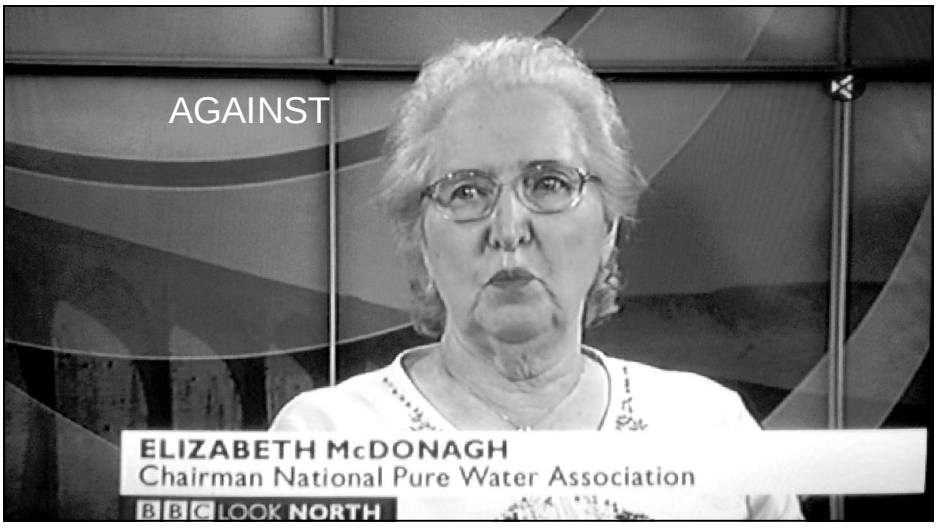
On Tuesday June 9th, Hampshire Against Fluoridation presented a 15,300 signature petition to the Prime Minister. Later in the day, the group met Hampshire MPs at the House of Commons. The MPs pledged to try to óput a holdôon the fluoridation proposal. One, who supported fluoridation agreed because he felt the consultation process was flawed and it was important that the public had confidence in the SHAôs decision-making. The present Government is in favour of fluoridation, as evidenced by the former health Minister, Alan Johnson, allocating £42 million (over three years) to SHAs who planned to óconsult the publicô The fluoride pushers are keen to get their plans approved before any change of government and we are now witnessing moves towards fluoridation in many areas of the country. The whole of Yorkshire is at threat because Kirklees PCT and Bradford PCT have asked the Strategic Health Authority to initiate the process by commissioning a technical feasibility study. Yorkshire Water says that fluoridation of small areas would be a problem because the water pipes do not coincide with political or health authority boundaries. As a member of the British Alliance for Equity in Dental Health, Kirklees Metropolitan Borough Council has long supported fluoridation. Bradford MBC is opposed to the measure....

Could something like this happen in our area?

Programme Review: BBC 1 Yorkshire Look North, 2nd June 2009.

Sally rang and said ñLiz is on TVò ñI know, itôs showing now, and recording nowòwas my reply. The Leger ME grapevine had tipped us off that Liz (Elizabeth McDonagh), LMEôs deputy chairman was about to be on TV. She had been to Yorkshire TV studios earlier in the day in her capacity as the National Pure Water AssociationsôChairman to record their sideôs view on a planned debate about water fluoridation in Yorkshire. The angle I take as group leader is that fluoridation is mass medication of the water supply, pressured by the belief of dentists of benefit for a minor proportion of the population. There is no evidence of safety in the long term. The evidence I have seen suggests that fluoridation of the water supply would be detrimental to people with ME/CFS, and that is why I oppose it. Mass medication is not new, and has been with us for a number of years. Vitamin D is added to some milk based products to prevent rickets in breast fed children, and folic acid (a B vitamin) added to bread to reduce the incidence of neural tube defects (e.g. spina bifida) in babies. The latest idea from the USA is an anti aging polypill from the USA which everyone over 50 will take. It would contain Enalapril to reduce blood pressure, simvastin to reduce cholesterol and aspirin to reduce heart attack risks. As far as Doncaster is concerned, the water is unfluoridated, apart from naturally occurring fluoride in the water of the Balby area. I am not aware of any local statistical comparison of tooth decay rates.

The presented feature opened with a caption stating that the average number of 5 year olds with 4 decayed or missing teeth is 38%, while in Bradford and Airedale it is 54.3%, Kirkless 48.3%. An 8 year old child is then showed undergoing a dental examination by Dr. David Wood, a Mirfield dentist who is also dental advisor to Kirklees Primary Care Trust. His practice is in Mirfield, halfway between Huddersfield and Dewsbury. He claimed to be able to recognise whether children came from fluoridated or unfluoridated areas just by examining their teeth. Children from Huddersfield had more healthy mouths than children from Dewsbury, which he ascribed to Huddersfield's water being fluoridated in the past. The next section introduces Liz, and a retired Leeds Dentist, Dr. Ronnie Levine who of course is pro fluoridation. The British Dental Association might discourage a practising dentist from appearing. Issues raised are that fluoride is present in some natural water supplies, fish, beer and tea. It is not an essential element for life. It is acknowledged that it is poisonous, and the safe level is much debated, the dentist saying a level of 50 ppm per day is safe and Liz saying 1ppm is not safe. Eventually the presenter intervenes and declares there is not enough evidence to prove either partiesôargument. Result, a draw. I did try to get a transcript or video copy off the BBCôs website. However mysteriously, just that feature is not available or working. Let us hope that the story has been óspikedôby the BBC for political reasons, which would lead us to question the impartiality of the BBC.



The Alexander Technique (AT)

This is a method of re-educating the way you move. It aims to help you move with the ease and tension-free grace of a child, releasing muscular tension that has built up over many years, so that you effortlessly sit, walk and stand tall. It focuses mainly on the relationship between the head, neck and spine and was developed in the 1890s by a man called PM Alexander, an actor who was having problems preventing his voice becoming hoarse during performances. He decided to observe himself acting in the mirror, and discovered that his voice was affected by the unnecessary muscular tension caused by the way he held his body. "I saw that as soon as I started to recite, I tended to pull back the head, depress the larynx and suck in breath through the mouth in such a way as to produce a gasping sound," he said. He slowly developed a technique to eliminate this tension, and started teaching it to others, which he continued to do until he died in 1955.

How is it done?
You have one-to-one sessions with an Alexander teacher, who gradually teaches you a new way of moving, sitting and standing. You're encouraged to become very aware of your body and how it moves and responds in different situations, with teachers sometimes using props such as balls to throw to you or books to rest your head on when you lie down, as the semi-supine position is used to help relax the muscles in your neck and back. An AT teacher will guide you through various movements, until the new way of moving becomes an ingrained habit.

What are its claimed benefits?
Apart from the incredible benefits in the way you hold yourself, the Alexander Technique helps you breathe more deeply and has been shown by a major, study, published in the British Medical Journal, to help with back pain. Another major benefit is the relief of tension and stress - it leaves you feeling calmer and enables you to be more in control of your stress responses

Where do people do it?
You can pay for home visits from some teachers, but most people go to their teacher's practice. This is usually just an ordinary room, as no special equipment is needed, although most teachers own a model skeleton to demonstrate the movements of the head and neck.

What do I need?
Nothing at all,-Just take yourself and your enthusiasm. The ÷Alexander Technique' is not a treatment and requires only your active participation and willingness to learn.

How many lessons will need?
This depends on your needs and goals, but people usually go for at least six.

Can I access this on the NHS? Unlikely, unless a specific local project exists. Usually individuals must pay for their Alexander Technique education out of pocket.

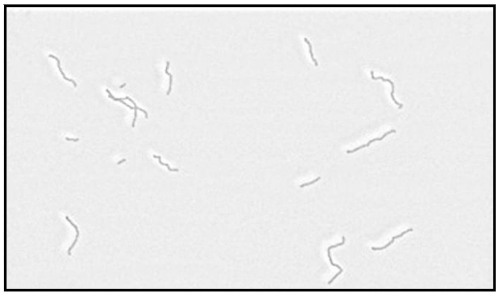
Where can I find out more? For more information and to find a teacher near you, visit The Society of Teachers of the Alexander Technique at www.stat.org.uk or call 0845 230 7828.

Is it any good for people with ME/CFS?
Having spoken to spoken to Carolyn, she reports that ñI attended a day course quite early during my ME. I found AT techniques very useful in controlling shoulder pain, and helping with relaxation in the early days, and to some extent it still helps now, years onò

The AT has not been shown to directly affect ME/CFS, but it is highly likely it can mitigate how the person copes with their difficulties, both physically and emotionally. Many local ME/CFS groups organise ME-specific yoga classes, and some are very successful and well attended but others are not appropriate for everyone. However, I suspect that AT would be most suitable for low grade (mild) cases or those in rehabilitation. I would like to see this offered by the Sheffield NHS ME/CFS clinic. It may be possible to arrange a session at the Redmond Centre if anyone is interested.
Mike.

North of Doncaster

Personal comment by Trevor Wainwright

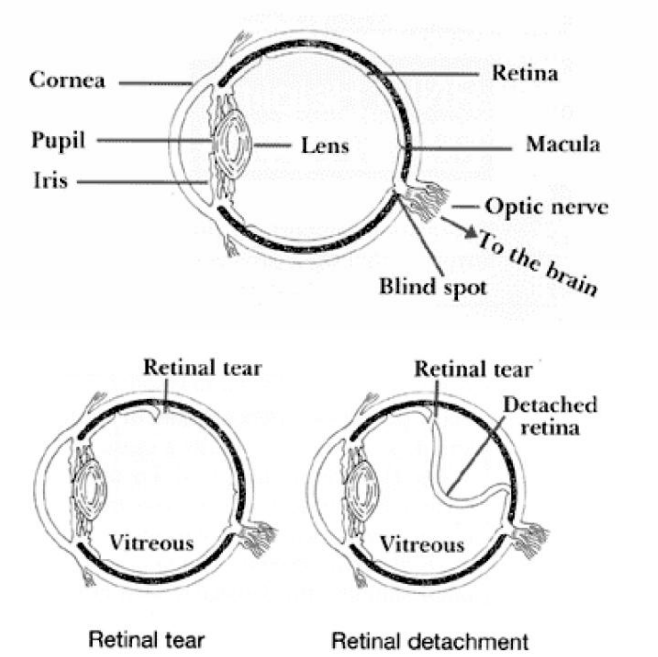


Floaters are small pieces of debris that 'float' in the vitreous humour of the eye. They occur behind the lens and cast a shadow on the retina. They appear to be in the front of the eye, and can occur in different shapes and sizes. e.g. Tiny black dots (flies), small shadowy dots, larger 'cloud-like' spots, or long, narrow strands. Floaters are harmless and will not usually interfere with vision. Many people don't notice them because the brain adapts to changes in vision, and learns to ignore them. Floaters most commonly develop as your eyes get older, as part of the natural ageing process, but any change can be significant in disease or injury.

This article was to have been HIV/ME A PAR ALLEL, part 2, but much has happened since my last article. I was to have been on the trip of a lifetime to Pakistan with some former work colleagues who are of Pakistani origin. We were to go last year on a month's cultural tour of their homeland but my wife's gall bladder op put paid to that. This year it was all systems go until April 1st which was anything but April Fools Day.

I had noticed some floaters in my eye, but a check had revealed nothing untoward. I put it down to side effects from a typhus jab as I had similar effects following a jab in 1994, prior to a foreign aid mission. Then on the afternoon of April 1st I felt something move in my right eye, causing a shadow in the inside edge covering about three quarters of the vision. A trip to the hospital revealed a detached retina and macula, had it been retina only they would have had to operate within 6 hours, as the macula was involved it was lower priority. So the first operation was carried out on April 6th, when they went into my eye, surgically re-hatched both retina and macula, and all would soon be well I thought. The first check up was on April 23rd, my eye had not begun to clear, the check revealed that the retina was attached but had bled, the blood congealing at the back of the eye, so the following day it was under the knife again to wash out the blood, at the same time revealing a fold in the retina. I did get some vision back but it was blurred and distorted, a check on May 7th revealed that the retina was re-attached and flat, but the fold still there so now it is a matter of wait, so what are these to eye components, what do they do, what happens when they go wrong?

We look first at the retina, a thin layer of light-sensitive tissue on the back wall of the eye. The optical system of the eye focuses light on the retina much like light is focused on the film in a camera. The retina translates that focused image into neural impulses and sends them to the brain via the optic nerve. Occasionally, posterior vitreous detachment, injury or trauma to the eye or head may cause a small tear in the retina. The tear allows vitreous fluid to seep through it under the retina, and peel it away like a bubble in wallpaper. A retinal detachment is commonly preceded by a posterior vitreous detachment which gives rise to these symptoms:



Flashes of light (photopsia) - very brief in the extreme peripheral (outside of centre) part of vision,
A sudden dramatic increase in the number of floaters, a ring of floaters or hairs just to the temporal side of the central vision, a slight feeling of heaviness in the eye.

Although most posterior vitreous detachments do not progress to retinal detachments, those that do produce the following symptoms:

A dense shadow that starts in the peripheral vision and slowly progresses towards the central vision, the impression that a veil or curtain was drawn over the field of vision. Straight lines (scale, edge of the wall, road, etc.) that suddenly appear curved (positive Amsler grid test), central visual loss.