Pathways

Leger ME: 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.

Leger M.E. is a new support service for ME/CFS/PVFS/FMS in Doncaster, Barnsley and the Dearne Valley. All the services that I formerly provided to other organisations will now be provided by Leger ME. The service model will be that of a professional practice, much in the same way a doctor's or solicitor's practice works. As far as the helpline on (01302) 787353 goes, it will be business as usual, but under new management.

Consistent with reframing of services the newsletter will now be called 'Pathways'. Essentially it will be from the same team that brought you the well known ME/ CFS newsletter from Doncaster. With this issue we are enclosing a sheet from the M.E. North East group. It summarises the key issues from the CMO's report on M.E. It will be useful for patients to take to their doctors on the next appointment as a checklist and information sheet. Don't give it to a receptionist or practice manager because it will get lost in the pile of junk mail doctors receive. If you require any further copies, they are available at 30p each plus 2nd class postage.

A new website is under construction at www.leger.me.uk. This will include much information and a discussion forum. By the time you receive this newsletter, it should be active.

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'Pathways' is an original watercolour painting by myself. The name 'Pathways' was suggested by one of my colleagues Margaret. It portrays the problems faced by someone with M.E., where things seem strange, out of proportion and the way ahead is not clear. I started to rough out a logo, and then for some reason turned around. There, on the wall, was the painting that I had painted in art class a number of years ago and there was my answer. Copies of the painting are available for a suitable donation to the Leger M.E. service.

North of Doncaster
&
Castleford Aid for M. E. Annual Conference
See page 12

Measuring Up ME/CFS
See page 6

How a dog could help your recovery See page 2

Left: A photograph of Justine and her friend Kirsty with their dogs, Santa and Casey. On Wednesday 7th July they did a ten mile walk around Doncaster, to raise funds for local M.E services.

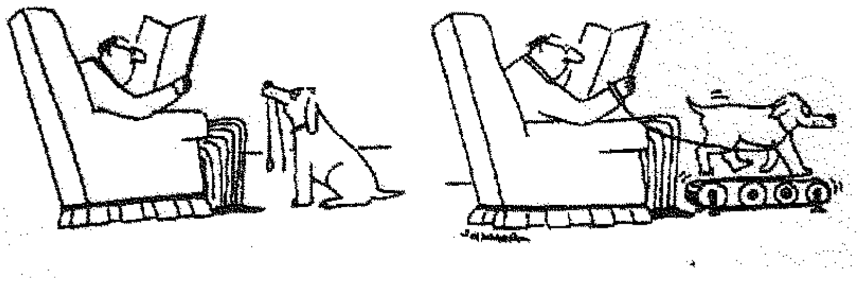
The Canine Charter For Human Health

While in my doctors surgery I saw a notice, 'The Canine Charter for Human Health' which was:

1) Owning a dog can help to reduce stress.
2) Stroking a dog can help to reduce blood pressure.
3) Owning a dog can boost your immune system.
4) Dog owners take more exercise.
5) Dogs can help safeguard against loneliness and depression.
6) Dogs' owners are more likely to recover from a heart attack.
7) Some dogs can be trained to detect epileptic seizures.
8) Dogs can help to increase the attention-span of children with learning difficulties.
9) People who have a dog tend to live longer.
10) Dog owners visit the doctor less.

Nathan, Mike's Dog.

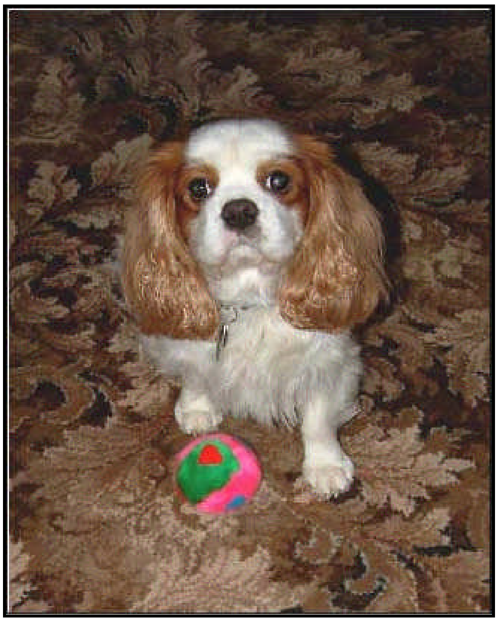
About five years ago I published a feature in the local ME group newsletter about how I chose a dog. When I was working there was very little justification to have one. For me, having a dog is one positive benefit of M.E. Before choosing a dog, I did my research. So how have things gone in the meantime ?



Firstly there was the problem of puppy puddles. These were mainly due to anxiety about Marmalade, my cat. After several months, they just stopped. One strategy was to take Nathan into the garden last thing at night and first thing in the morning which avoided dog mess in the house. Another problem was apparent vomiting. It was clear from day one that there was a problem. I eventually identified the problem as coming from dried tripe, used by many owners as a dog treat. Tripe is a cooked and dried cows stomach. The vet reckoned that somehow it was contaminated. Another problem was that Nathan developed a cataract in his right eye. This according to the vet is a breed problem. As only one eye is affected, and it has sight, I decided to leave it as is. More recently Nathan has had a trapped nerve in his neck.

Ever since he was a puppy, he has occasionally yelped with pain, maybe only for a few seconds. Various trips to the vet didn't identify anything until recently. His entire head would become very sensitive, even with gentle stroking. The vets identified it as a trapped nerve in his neck. Fortunately, this is controlled by Prednisolone and Rimadyl. The vet wanted him to have an £800 MRI scan. I didn't insure Nathan because the policies were expensive and have more exceptions than inclusions and a massive excess just like car insurance. I decided to insure Nathan myself, and so far I'm well in pocket.

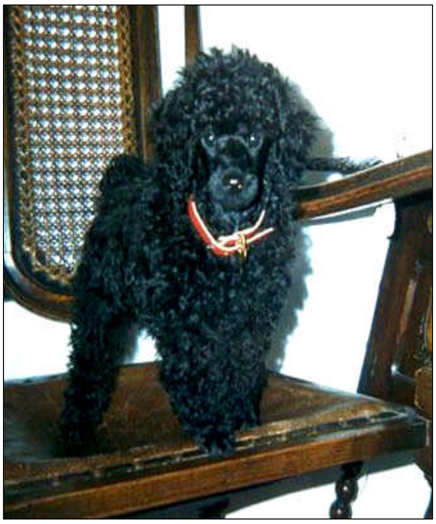
Being a King Charles Spaniel Nathan is a friendly dog, who makes friends with everyone he meets. He follows me from room to room and at night would get in to bed with me if I let him. He sleeps in a big dog cage at night and sometimes snores very loudly. The breed has a tendency to be easily distracted, so outside he has to be kept on a lead . A dog is a good alarm clock. They can tell you to within a minute what you should be doing. If I'm late going to bed, there is a little tail-wagging dog looking at me. He will tell me he wants a drink by sitting by his empty dish. He prefers cat food to dog food. There is no fighting between him and Marmalade, but if he gets too close Marmalade will lash out with his claws.. If Nathan wants something, say trying to scrounge food at meal times, he has a habit of looking at the object he wants and then at me. He will also tell me where a cat or other animal is hiding when out in the garden.



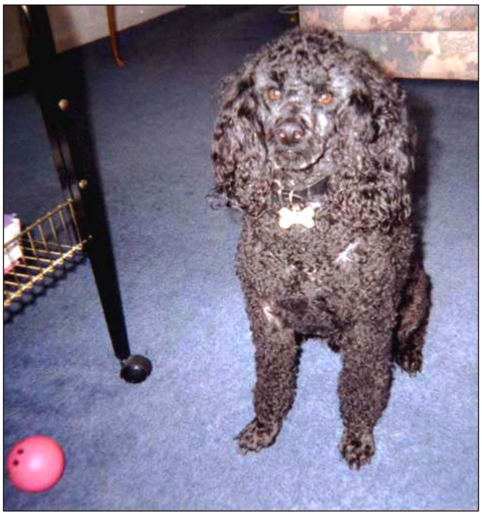
I’ve looked after dogs before when their owners went on holiday. The experience of your own dog is completely different. They become part of you, your best friend, know all your intimate whims and ways. The affection is unconditional as long as it goes Nathan's way...

‘Jackpoodle’ – the best decision *by Carolyn*

I’ve always been a ‘doggy person’ having had dogs in my life since childhood but as I drove to Leyland to collect my seven week old poodle puppy it was with very mixed feelings as I was now diagnosed with M.E., and I had many of the debilitating symptoms to go with it. This was going to be a big responsibility, and as I now lived alone, this tiny pup would only have his poorly owner to rely on.



We battled through those early months together as he learned to ‘go out’ for puddles, or at least use the paper put down by the door, and I set about training him, mostly from the settee. Walkies consisted of staggering foggy-brained between two lamp-posts in the back lane where hopefully very few people noticed us and games consisted of me sitting on the floor throwing a ball which he learned to fetch back and place into my hands. There were moments when I seriously did wonder what I’d done and how on earth I was going to manage!



But, all of this was seven years ago, and after those early months Jack and his owner have never looked back. Getting him, even though I have M.E., has proved to be the best decision I ever made. When Jack came in the door, out went the isolation, any feelings of being “alone” and all negativity. In came a reason to get my sleep patterns back to near normality, the way off the settee, and a gradual return to getting out and about locally to the shops, post office, park etc., on foot with my pal beside me. Into my life had come a great little healing power.

Over the years of slow but regular walks with Jack I’ve been pleased to see my weight come down, and the brain-fog lift. On our walks, friendships have been made with other dog owners, and people of all ages will stop to have a chat when we are out and about. You are never lonely when out with your dog. Just sitting stroking him or combing his coat brings a sense of calm in the most stressful day – he really is a healer. In December Jack will be eight years old and he is becoming gradually slowed up by the arthritis now affecting both of his back legs. Sometimes it is my turn to ‘carry him’, but Jack can be absolutely sure that his grateful owner will do everything she can to make the rest of her faithful little dog’s days just as happy, bright and full of the love and joy that he has brought into her life.

The Dogs Trust

If you would like to reap the benefits of rehoming a dog, please contact us at: Dogs Trust, 17 Wakley Street, London, EC1V 7RQ Tel: 020 7837 0006 Email: info @dogstrust.org.uk.

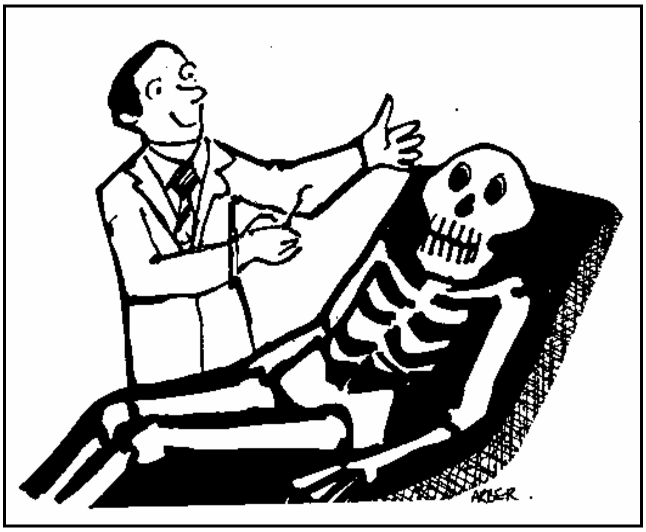
The latest news on fluoridation-*from Elizabeth McDonagh*

The Government has just released the draft regulations for consultation of the public on fluoridation. The consultation will apparently take the form of an advertisement (or advertisements) by the Strategic Health Authority (SHA), asking for the opinions of local residents and workers, of the local authority and of local businesses, especially those involved in the manufacture of food and drink. It is important that we look out for these adverts and respond to them.

The SHA's address is:-
WRSHA, Blenheim House,
West One, Duncombe Street,
LEEDS, LSI 4PL.
(Phone:- 01132952000)

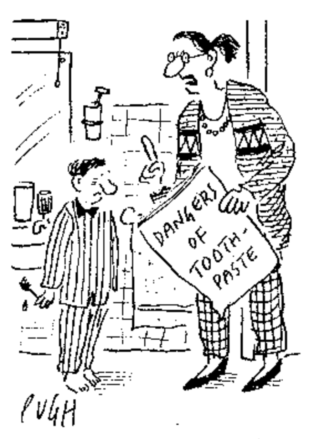
The National Pure Water Association is opposed to the consultation on grounds that voting to force people to take a medication against their will is in contravention of Fundamental Human Rights.

I have recently obtained a video:
-"Leading Dental Researcher Speaks Out Against Fluoridation"



“Ah yes, but your teeth are in perfect condition

The video shows Dr Paul Connett, Professor of Chemistry at St Lawrence University, New York, interviewing dental researcher Dr Hardy Limeback, Head of Preventive Dentistry at the University of Toronto. Toronto has been artificially fluoridated for thirty years. Dental fluorosis in young children there is high. Dr Limeback says that fluoride used topically (eg in toothpaste or mouthwash) is effective in reducing dental caries but ingested fluoride does little to protect teeth. Research in his Department has shown considerable differences in fluoride content of hip bones between residents of Toronto and those of unfluoridated Montreal.



"How many times do I have to tell you not to brush your teeth before bed?"

Limeback is concerned that fluoride may cause delayed eruption of teeth, arthritis, bone fractures, osteosarcoma (bone cancer), thyroid problems, interference with reproductive mechanisms and subtle changes in cellular enzyme systems. He says the dental community is largely unaware of the toxicology of fluoride, or that the hexafluorosilicic acid used in artificial fluoridation is a waste product of phosphate fertilizer manufacture, contaminated with lead, arsenic, radium and other undesirables. If you would like a copy of the video please contact NPW A 180 Milton Road, Hoyland, Barnsley S749BW The cost is £5 including postage and packing.

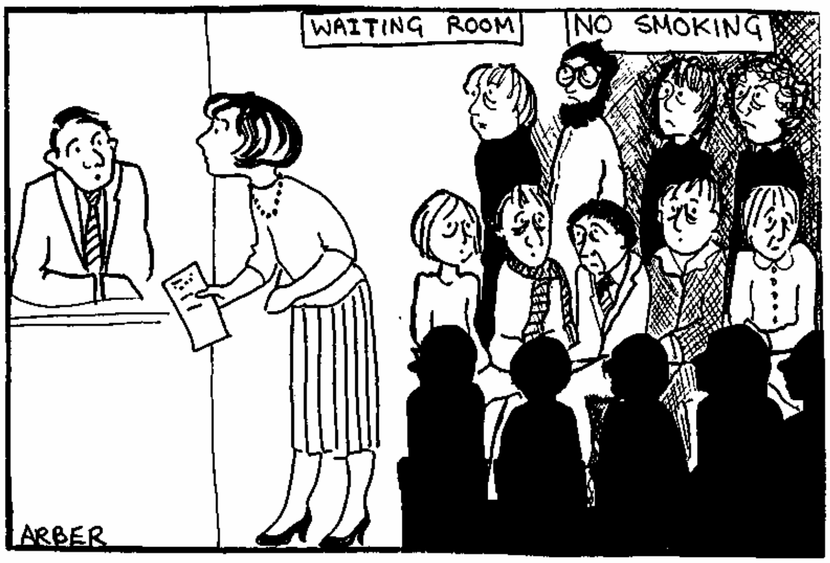
In the USA, fluoride toothpaste has a poison warning on the carton. Fluoride is only effective when in the mouth, not when swallowed.

“Seeing is Believing” *by Margaret Lewis*

Eleven months ago I plucked up courage to face my G.P. and explain how tired I was feeling. I hate the word “tired” because if only we were “tired” we could have an early night or two but as we know this isn’t the case. To my surprise my G.P. listened and didn’t dismiss my ramblings but arranged for me to have the usual blood tests and to see a doctor at my local hospital. Needless to say all the tests came back O.K. and the doctor at the hospital made me feel like a fraud and I even began to think that I imagined the fatigue.

My G.P. continually re-assured me and suggested she write to the Chronic Fatigue Clinic at Seacroft hospital Leeds. The waiting time for the appointment was about eight weeks. My daughter duly arrived and off we went to my appointment. The hospital was relatively easy to find and there was assistance at the gate to point you in the right direction for each department.

My daughter parked her car and helped me out. I think she was more excited than I was. She said “look mum it really does exist, see the sign”. Yes there is was a large sign with a blue background and written in white letters “Chronic Fatigue Clinic – Ward J”. During the past months I have felt that both medics and lay people held a question mark over their believe in my condition but now I could prove it. There it was for all to see.



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

We entered the clinic and it was unexpectedly silent. Not what you expect when entering a large hospital. We quickly found the receptionist who showed us to a waiting room. Again no crowds, just a quiet room where we were able to relax and wait to be seen. Exactly on time an occupational therapist and a nurse came and took us to another room. The consultation lasted about one and half-hours and not once did I feel uncomfortable. I was treated with respect and dignity and we discussed my symptoms at a pace I could handle, resting as and when I felt it necessary. I felt comfortable and somewhat cocooned in their understanding and belief in my illness. I know there aren’t any magic “pills”, I understand the trauma this condition causes but when I left Seacroft I can only say that if nothing else happens I was so uplifted by the approach of their medical staff that this in itself was a tonic.

Within three days of my first assessment I received a telephone call to inform me that they were referring me to one of their consultants. I appreciate I shall have to wait a few weeks for an appointment but I do feel I am now on the right track. The illness itself causes us to suffer fatigue, exhaustion and in many cases leads to depression etc. These conditions are disabling enough. We do not need to be made to feel degraded and demoralised. All I ask and I am sure I speak for most of us is that our symptoms and condition are accepted as being **REAL.** My thanks to the staff at Seacroft hospital.

Measuring Up ME/CFS by Mike Valentine

When you hear in the news about someone being taken to hospital, say from a fire, you hear something like "...45% 3rd degree burns...". Most medical conditions have some system or method of measuring the severity of the disorder. More relevant to this area are the compensation claims for chest disease by coal industry ex miners. Here one method to measure the degree of lung-damage is to take an x-ray and literally to count the area of disease. The problem is that for M.E., there is no universally accepted method because of the lack of a diagnostic test. This is important because:

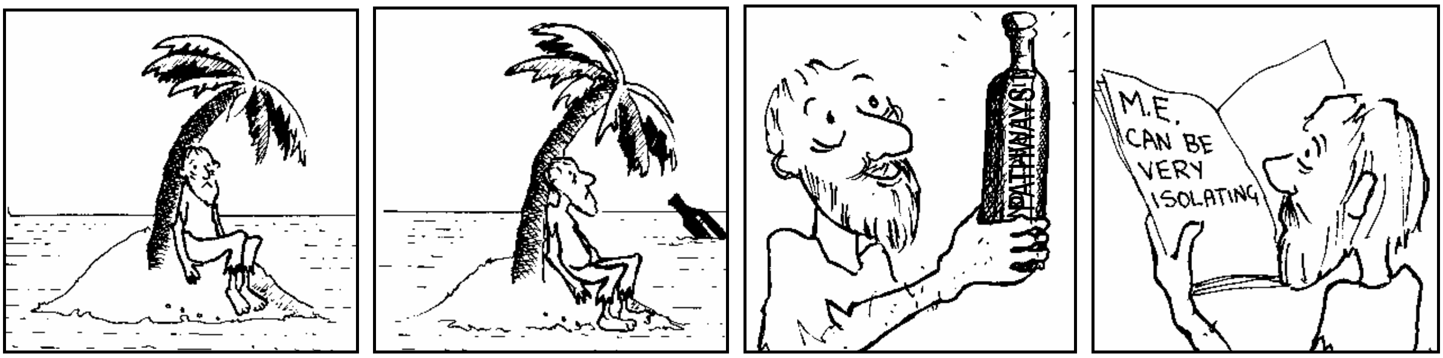
a) There is difficulty in assessing the degree of illness for state benefit purposes. This results in inconsistent decisions with what is in effect a post-code lottery.

b) For research or clinical audit purposes, it is necessary to assess the effectiveness of a particular treatment strategy.

At a conference I attended a couple of weeks ago to set up the new South Yorkshire ME/CFS Service (yes the funding has been agreed), one of the biggest issues discussed was how to measure the degree of M.E./ CFS. What follows is an example of three different systems currently in use.

Findley System. This the grading scale used by Professor Findley et al at the National ME Centre. Romford, Essex. It is similar to the grading of many other diseases.

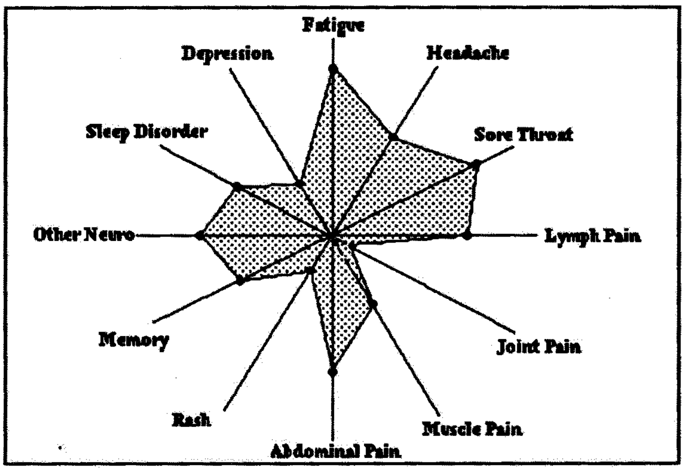
Grade	Description	Ability of Patient	Proportion
0	Normal	Lives a 'normal' life.	
1	Mild	Mobile and self caring and able to manage light domestic and work tasks, with difficulty	25-33%
2	Moderate	Reduced mobility and restricted in all activities of daily living, often having peaks and troughs of ability, dependent on degree of symptoms. Usually stopped work or limited capacity, requiring many rest periods.	50–60%
3	Severe	Will be able to carry out minimal daily tasks, i.e. face-washing, cleaning teeth, has severe cognitive difficulties and is wheelchair-dependent for mobility. Often unable to leave the house except rarely.	25%
4	Very Severe	Unable to mobilize or carry out any daily task for themselves. Bed-ridden the majority of the time.	1-2%



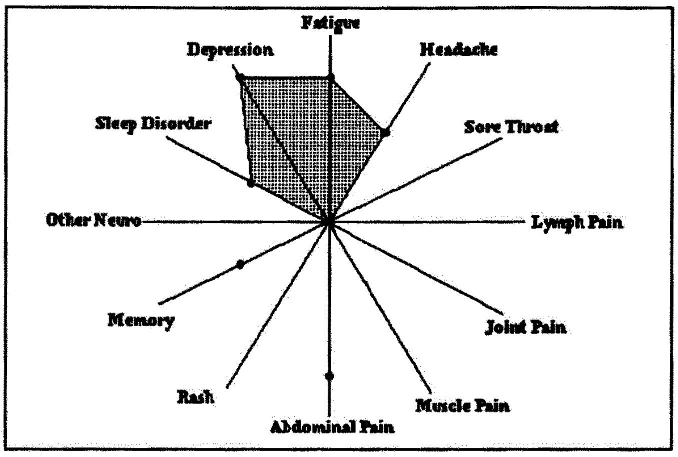
Bell System. This is after Dr. David Bell in the USA. This is used by Dr. Myhill and other private practitioners. It is self explanatory and the most commonly used system.

Disability	**Ability**	**Description**
0%	100%	No symptoms at rest; No symptoms with exercise; Normal overall activity level; Able to work full-time without difficulty.
10%	90%	No symptoms at rest; Mild symptoms with activity; Normal overall activity level; Able to work full-time without difficulty.
20%	80%	Mild symptoms at rest; symptoms worsened by exertion; minimal activity restriction noted for activities requiring exertion only; able to work full-time with difficulty in jobs requiring exertion.
30%	70%	Mild symptoms at rest; some daily activity limitation clearly noted. Overall functioning close to 90% of expected except for activities requiring exertion. Able to work full time with difficulty.
40%	60%	Mild to moderate symptoms at rest; daily activity limitation clearly noted. Overall functioning 70% to 90%. Unable to work full time in jobs requiring physical labour, but able to work full-time in light activity if hours flexible.
50%	50%	Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity. Overall activity level reduced to 70% of expected. Unable to perform strenuous duties, but able to perform light duties or desk work 4-5 hours a day, but requires rest periods.
60%	40%	Moderate symptoms at rest. Moderate to severe symptoms with exercise or activity. Overall activity level reduced to 50%-70% of expected. Not confined to house. Unable to perform strenuous duties but able to perform light duties or desk work 3-4 hours a day, but requires rest periods.
70%	30%	Moderate to severe symptoms at rest. Severe symptoms with any exercise. Overall activity level reduced to 50% of expected. Usually confined to house. Unable to perform any strenuous tasks. Able to perform desk work 2-3 hours a day, but requires rest periods.
80%	20%	Moderate to severe symptoms at rest. Unable to perform strenuous activity. Overall activity 30%-50% of expected. Unable to leave house except rarely. Confined to bed most of day. Unable to concentrate for more than 1 hour a day.
90%	10%	Severe symptoms at rest. ; Bed ridden the majority of the time. No travel outside of the house. Marked cognitive symptoms preventing concentration.
100%	0%	Severe symptoms on a continuous basis. Bed ridden constantly; unable to care for self.

<u>Radial Plot System</u> Here the patient is given a questionnaire about their symptoms. They are then scored and plotted on a diagram. The area (shaded) is calculated, and this gives a indication of the degree of illness.



This plot (left) is a from a CFIDS (the USA equivalent of CFS/ME) case, used by some American insurance companies. The method does have an advantage in that it can show variations in symptoms and is capable of being diagnostic.
It adapts well to information technology systems.



This plot (left) is a classic depression case. It is different in shape, and visually shows the difference between depression and M.E. Doctors do not always appreciate this difference.

For further information see: Bell D.S. ‘The Disease of a Thousand Names’, Pollard Publications, P.O.Box 180 Lyndonville, New York, 14098

WARM FRONT GRANTS

There is a heating initiative called "Warm Front Grants" that has been running for a number of years, but surprisingly, not many people know about it. The Eaga Partnership give free grants to make homes warmer and healthier. The scheme gives grants of up to £1500 to those on selected benefits including: Working Tax Credit, Child Tax Credit, Housing Benefit, Council Tax Benefit (which must all include a disability premium,) Attendance Allowance, Disability Living Allowance, Income Support, Industrial Injuries, Disablement Benefit or a War Disablement Pension (which must include the mobility supplement or Constant Attendance Allowance). Those over 60 may be eligible for a "Warm Front Plus" Grant.

They can supply and install new central heating systems, draught proofing, cavity wall and loft insulation, and energy efficient light bulbs free of charge. All central heating systems, new or existing, are covered against repairs and breakdown for 12 months after you are accepted for the scheme. You must be a private home-owner or rent your property, and be over 18yrs to qualify, in addition to being in receipt of one of the above benefits. The current waiting list to get your home surveyed for what work is needed stands at about 28 days. The time involved to get everything installed varies upon what needs doing. Many energy suppliers, such as Scottish Power have similar schemes, but you must pay about 50% of the costs in most cases, whereas this is free. To find out more, or apply for a grant from Eaga, call 0800 316 6011 or visit <u>www.eaga.co.uk</u>

SUCCEEDING WITH ME *Pam Turner – Bury/Bolton ME/CFS Support Group*

Today I received a report published by **The Young ME Sufferers Trust (TYMES Trust).** The report is about 'virtual education' for children and young people with ME/CFS and addresses their educational needs. A quote from the report by Jane Colby states, "It is tragic that unsuitable educational demands are a key feature of relapse. Children are made more sick and achieve nothing. Their futures are being wrecked. But it doesn't have to be like that." TYMES Trust has formed an educational partnership that is to change the problems faced by young ME sufferers regarding education provision and recognition of their needs.

The report states that children on this scheme have achieved a 96% GCSE pass-rate at grades A-C

- It is ME friendly
- It costs less than home tutoring
- It addresses pupils' isolation
- It can be used when a child is well enough
- It can be repeated in order to address concentration lapses
- It can be used for revision
- It enables the child to work at a suitable pace
- It enables rest breaks
- It can be done at any time of day
- It is personal and individual
- It enables each child to progress at an individual rate

IT IS FUN

The 'click-on classroom' is an internet programme geared especially for children with ME and it allows them to interact with the teacher as if they were in a classroom, or they can record the session and use it later to study. A statement from Jerome Burne of The Times says "This project promises to transform the way that children who cannot go to school are taught." Families who have already used this system have been delighted with the results.

The TYMES trust/Nisai Education partnership information explains the background to the scheme for pupils with ME/CFS. "Nisai Education co-founded the Nisai-Iris Partnership, a non-profit consortium of L.E.A's dedicated to developing and sharing online resources and best practice for the education of children unable to access mainstream education. Nisai Education now provides a quick response service for students requiring education out of school. This service works closely with each L.E.A. to deliver a service that will complement and extend the current educational provision. Students are tutored by teachers in other UK education authorities and attend live online classes with students from other areas." This method not only allows the child to be educated in his/her own home at his/her own pace but also allows them to interact with other children. This project was launched in the House of Lords on 26th April 2004 and was warmly welcomed.

The report includes the all too familiar story of a family with a sick child who had to battle with the Education Authority and the total lack of understanding experienced by many families.

The report includes a page ‘The Families’ Voice’ with a list of things that should be part of the curriculum:-

- Compassion for each other is vital
- We can afford it
- We should afford it to each other
- Above all we must have time for it in order to bear some semblance of humanity

REMEMBER

- If your child has ME/CFS he/she is legally entitled to help
- Don’t be fobbed off
- Find out all you can about the illness
- Hold your ground
- Fight your corner
- Don’t let people bully you and accuse you of neglect or Munchausens Syndrome by Proxy

This is a real physical illness. You live with it. You and your child are the experts. Make people listen. Don’t let them lose compassion. Jane Colby of TYMES trust (ex head teacher) tried out the virtual classroom herself to give a lecture and she says – “Yes, the children are right, it is fun.” When a sick child is having fun they’re learning. And they’re **not learning** “I’m a failure, I can’t manage my work. I can’t get to school so I’m falling behind.” They **are learning** “I can do it, I am worth something, I am a success.” This excellent report is available at a cost of £6 from TYMES Trust, PO Box 4347. Stock, Ingatestone, CM4 9TE. Tel: 01245 401080 (11am to 1pm and 5pm to 7pm Monday to Friday) Website address www.tymestrust.org

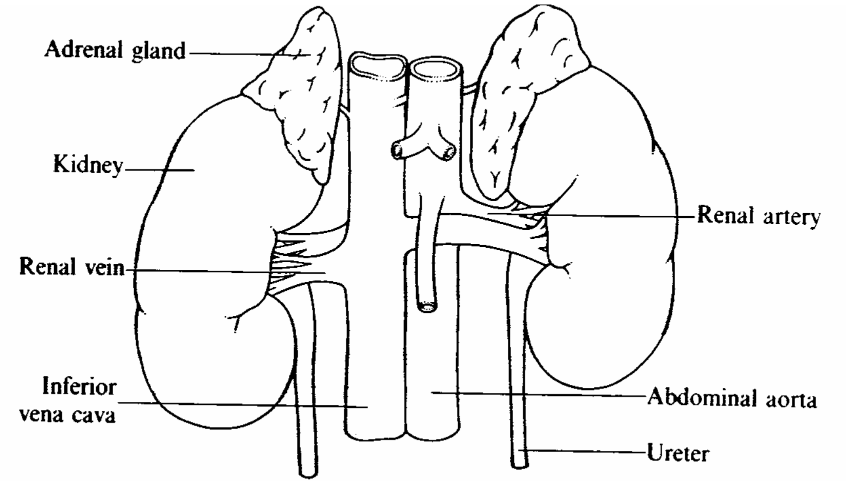
GOD'S BALANCING ACT

God was bored and went missing for six days. The Archangel Gabriel found him resting on the Sunday, about half past two.
"Where've you been?" " We were getting worried and if you don't come home soon the Yorkshire puddings will be ruined."
"I've been creating," said God. "I've created this 'ere planet Earth, and by gum, it'll be a place of great balance."
"What do you mean 'balance'?" said Gabriel.
And God explained.
"Well, sithee." "North America will be wealthy and South America will be poor."
"Over there, I've placed a continent of white people, and over there a continent of black people."
God talked of different countries.
"That 'un'll be reight hot and that 'un'll be covered with ice."
Gabriel was impressed and pointed to an area in England.
"What's that?" he said.
"Ah," said God, "That's a bit special." "That there is Yorkshire, the most glorious place on Earth." "There'll be beautiful lakes, streams, rivers and hills, dales and moors." "There'll be great music, architecture, and sporting giants."
"People from Yorkshire will be modest, intelligent, and witty." "They'll be sociable, hard working, and high achievers." "They'll be known throughout t'world as diplomats and peace makers."
Gabriel gasped in admiration, thought a minute and said "But, what about balance, God?" You said there will be balance."
"Ah," said God, nodding sagely. Now let me tell thee about Lancashire...................

Adrenal gland problems in CFS—why they occur *by Dr. S. Myhill*

I see chronic fatigue syndrome as a stress induced disorder, by which I mean infectious stress, physical stress, mental stress, emotional stress and so on. The body deals with stress in ways which are either specific to that particular stressor (such as immune activation with a virus) or a general response to stress. As a part of that general response to stress, the adrenal glands are centrally important. This was well illustrated in some work done after the Second World war by the German physiologist Hans Selye.

Selye stressed rats in nasty ways (which you and I do not want to think about). If he sacrificed these stressed rats he found that the adrenal gland had got larger. This was in order to allow it to produce more of the stress hormones cortisol, DHEA and probably others as well. If Selye took some rats and stressed them and then gave them a rest, he found that the adrenal glands had returned back to their normal size.



In a third experiment Selye took rats and stressed them unremittingly with no break or rest. Initially the rats appeared to function fairly normally. However they suddenly became ill and died and when he examined them, he found that the adrenal gland had wasted away.

I suspect this is what is happening in many of my chronic fatigue syndrome patients. I liken the adrenal gland to the gearbox in a car. When the stress goes on one can move up into third or fourth gear or even into overdrive to cope with that stress. However, one then needs a time of rest and recuperation for the body to recover. This system is necessary because if we all went round in overdrive all the time, we simply would not be able to fuel all of that activity and we would die from starvation. The body has to able to adjust its level of arousal to cope with the stresses of life.

In evolutionary terms we are evolving faster now than at any previous stage and this involves us having to make changes to our lifestyle. Changes, whether that be change in relationships, moving house, changing jobs or whatever are inevitably stressful events. That combined with the fact that the population of the world is increasing and therefore we have more viruses which spread rapidly round the world causing infection, combined with the fact that the quality of our food is declining and we are further contaminating ourselves with toxic chemicals, means that our stress levels have never been greater.

Different people can tolerate different amounts of stress. However, we all have our limits and anyone who is sufficiently stressed will eventually develop a burnout syndrome. This is what happens when the adrenal glands fail. Coming back to the analogy of the car, this means that when the stress goes on we can no longer move into fourth or fifth gear to cope with the stress, we can only struggle on in first. This manifests in the body clinically with severe fatigue, both physical and mental, sleep disturbance and many other physical symptoms, which of course are all the symptoms of a chronic fatigue syndrome.

In order to allow the adrenal glands to recover, one needs a long time of reducing mental and emotional stress, excellent diet, good nutrition and reduction of toxic stress in order to allow the adrenal gland to recover. It does, but it takes time.

North of Doncaster by Trevor Wainwright

Hi I'm Trev Wainwright from Castleford, freelance writer, ME campaigner, poet and fundraiser for research into the biochemical causes of ME. Welcome to my column North of Doncaster, the first of what I hope will be many bringing you news of what is happening North of the A638 and elsewhere. One such event is the Castleford Aid for ME Annual Conference, their first ever, details elsewhere in the newsletter.

Now who am I? Age - irrelevant, I have been fundraising since 1997, supporting the work of the Chronic Fatigue Syndrome Research Foundation (CFSRF) formerly the Persistent Virus Disease Research Foundation (PVDRF), and the Blue Ribbon for the Awareness of ME Campaign (BRAME), Later on, the Tymes Trust telephone help line was added to the list, and I am not the only fund raiser in Castleford. I would like through this column to pay tribute to Jeanette Koziol who, before I even started, on hearing her best friend had been diagnosed with ME said "I'm going to do what I can to raise money to help find a cure". She has raised thousands, through tombolas, naming events, collections, you name it, she's done it, and if there is a prize needed she'll get it.

Well back to 1997—my campaigning started during the Fighting for the Truth petition to reject the Royal Colleges' Report. I went to the House of Lords to see it presented, thus putting Castleford on the map so to speak. 1998 and I'm back again, this time to the House of Commons with another petition at the BRAME Parliamentary Awareness meeting, and again in 1999 when the PVDRF became the CFSRF. This was a chance to meet and get to know those involved in research, and tell the donors what their money was helping to achieve. In 2002 Fighting for the Truth became Research into Myalgic Encephalomyelitis and over 2,000 signatures went from Castleford petitioning the MRC for money to research the aetiology and epidemiology of ME.

2003 London again this time in charge as organiser of the first ever official ME Awareness Day Demonstration. Jeanette is with me, as part of the presentation team to 10 Downing Street, and again this year when our numbers were swelled by the inclusion of the MEA and their petition, calling for research into the physical causes, which in 6 weeks obtained more signatures than AfME did in one year, this time over 4,000 signatures from Castleford.

In my next column I will be writing about the work of the Chronic Fatigue Syndrome Research Foundation. Disclaimer - The views expressed in this column are entirely my own and not necessarily those of members of any group I belong to or any other individual.

Castleford Aid for M. E. Annual Conference

Castleford Salvation Army Citadel, Booth Street, Castleford

Saturday 25th September 2004, 1.00 pm to 4.30 pm

Open to all. Admission free including light refreshments

Speakers

Dr Betty Dowsett (ME and young people)
Specialist (for over 30 years) in the physical aspects of ME

Gary Frankum former speedway star now ME sufferer

Gail Brook & Heather Shaw from the Harrogate Pain- management Clinic

Awareness Exhibitions & Stalls

PLUS the world-famous CAME Poetry Exhibition.