Pathways

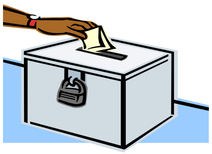
Price £ 2.50 (Free to members)

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

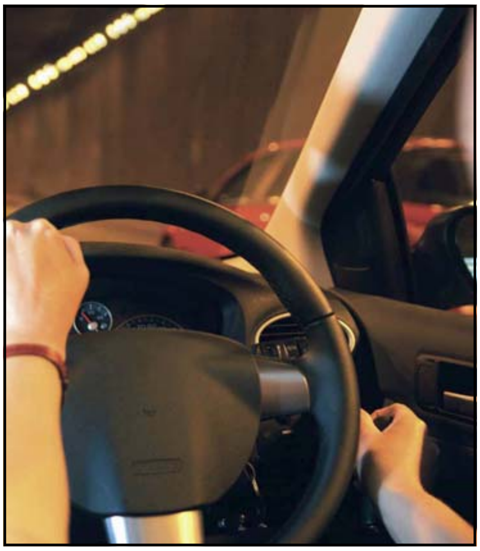
Doncaster Doctors are still reluctant in sending patients to the Sheffield NHS ME/CFS Clinic.

Yes, it is true, members who have recently made contact report this to us, but why is not clear. In this issue we have reproduced the services available and the referral criteria, which members can print off and take to their doctor. Yes, we were promised an outreach clinic in Doncaster BUT there is no money available to do this. *See page 6*

The Countess of Mar chaired a group of MPs in an inquiry into services for ME patients.
See page 10.



ME/CFS-related issues in the forthcoming general election..
See page 5.



ME/CFS and driving.
Issues from the DVLA and Insurers *See page 12*

We all know that smoking this is the number one cause of lung cancer causing 90% of cases, but what about the number 2 cause, which causes about 9% of cases. What can you do about it ?
See page 18

Can you help Lyn find a better bra?
See page 19

Recent Panorama Programme: What A Visiting Martians Report:

Gwen Writes: I normally get Bezalip prescribed for my cholesterol problems, for which it works fine. A few weeks ago, I was give a substitute Fibrazate. Within several days of taking that, I got joint pain, muscle pain, nausea and general ME problems. I am told that the strength and amount of drug are the same - but there is not doubt in my mind that Bezalip and Firbrazate are different, and all my symptoms stopped when I stopped taking Fibrazate and went back to Bezalip. If these drugs are supposed to be the same - how can there be different effects on me?

Bezafibrate is the active ingredient of both products. Bezalip is an brand name of manufacturers Actavis , while Fibrazate is the brand name of manufacturers Sandoz. There are possibly other manufacturers as well. Why you got Fibrazate instead of Bezalip I don't know. I would guess that the cash-strapped NHS encourages doctors to substitute the cheapest brand where possible in the interests of economy, or your doctor prescribed it as bezafibrate i.e. by its chemical name, rather than by brand name. Different pharmacies have different supply chain arrangements, and depending on where you get the prescription dispensed you could get either brand. My advice is to contact your doctor and ensure he prescribes Bezalip on the prescription rather than just bezafibrate.

NHS guidelines for some drugs like lithium and theophyllins stipulate that the patient should receive the same manufacturer's product that they were started on. In these cases the differences between the manufacturer's products can cause dangerous variations in the actual blood levels achieved from the same strength product. The difference is that apart from the active ingredient there is really no consistency about the excipients, which are fillers, binding agents, colouring coatings and so on. Each manufacturer will use their own formulation. Here there may be an explanation. Both medicines are licensed I the UK, and I have listed the excipients from the list on the 'electronic Medicines Compendium' (eMC).

Bezalip (Actavis) OK	*Fibrazate (Sandoz) Issue*
Lactose, Povidone, Sodium laurilsulfate, Hypromellose, Silica, colloidal hydrated, Magnesium stearate (E572), Polymethacrylic acid esters, Macrogol 10,000,Talc (E553b), Titanium dioxide (E171),Polysorbate 80, Sodium citrate (E331).	*Polyethylene oxide, Magnesium stearate, Purified siliceous earth, Talc, Hypromellose, Macrogol 4000,Titanium dioxide (E171).*

You can assume that the ones on the left are OK, but the list on the right has something that you are sensitive to. A simple matter of deduction will lead to polyethylene oxide as the most likely suspect. It is basically a plastic, and is also know by its trade name of Carbowax. It is basically polyethylene glycol. I've come across this before as a possible cause problems with people with ME on several other occasions. Basically I think it is a potentiates a late phase adverse immune reaction. It obviously must work on the mechanism which causes ME. It's possible a complement mediated reaction, but beyond that I don't have a clue. This polyethylene oxide stuff appears in many cleaning products, air freshener, cosmetics pharmaceuticals and toiletries. There is really no practical way you can be desensitised to it - the only option is avoidance. I would recommend that you contact your doctor, and have this endorsed on your medical records, and the same applies to your local pharmacy. Also in future check the excipients of any dispensed medicines, and anything like vitamins & mineral and even over the counter painkillers. It may be that the reaction is specific to you, and a few other people, in the country. While Bezalip may be safe for you, someone else may experience an issue with that product and find Fibrazate safe.

Whatever you do, keep taking Bezalip, and have your cholesterol levels checked at lease once a year for continuing cardiovascular insurance.

Pathways Photo-Story Competition.

Send us a photograph with an interesting narrative attached to it. A disaster, success, achievement, something you've enjoyed, about hobbies, pets or pastimes or just something you think which that will be of interest to Pathways readers. Obviously what you send has to be publishable in Pathways, and if necessary can be anonymous. Don't worry about technical perfection, as long it is something Pathways readers would like to see. The winner will receive a certificate and the title Pathways Photo-story Winner 2010.

Trudy Writes Like most I expect, I have found the winter incredibly difficult to cope with and I am only just keeping my head above water emotionally. For the past year I have been thinking about moving down South to Cornwall. I have family there and I think the change of scenery and sea air would be good for my health M.E and MCS. My question is, my health condition is the same and nothing would change except a change of address so could I change my benefits easily (like the normal change of address procedure when you move house) or, if I move county, do I risk an ESA assessment? I have searched the internet for advice on this but can not find any clear answers. Your feedback would be helpful.

Really I think if you feel miserable in Doncaster, the same will happen wherever you go. Marginally they have milder winters, but I wouldn't like to put money on it. Having said that, parts of the Mediterranean have had as cold weather as us recently. So the people who have retired to Spain have not found it as comfortable as they expected. If you move, you immediately come under the control of another DWP area. I don't know if they are any more or less sympathetic. What I can say is that a move to another area (as opposed to moving around Doncaster), would trigger an immediate review. Certainly you would get an ESA assessment before your time, and that in turn would trigger a DLA review. So in other words things would start at square 1. Just think about the hassle that you have had with DWP etc. and the struggle to get your welfare benefits. If you move, the first question that will be asked is why. I can also say the benefits are more difficult to get now that they were two years ago. So I certainly think a new claim would be a potential problem. Really only you can make that sort of decision. There is nothing stopping you having a holiday with your relatives, and sussing things out? I've also got a neighbour who is retired and moved to the seaside. They stuck it out for a couple of years, and then moved back to Doncaster. I've heard this very often with other people as well. Another thing that springs to mind is that in that part of the world, things are more expensive, and you need a car to get around as out of towns transport links are rural. Also have a look at the radon map of Cornwall on page 18 of this issue of Pathways.

Gillian Writes Having suffered, since 1967, from a "condition" diagnosed as post-natal depression and sinusitis which was treated by GPs with anti-depressants and antibiotics, until I discovered homeopathy in '89 and nutritional medicine in '91. The ‘condition’ was eventually diagnosed by the nutritional specialist as ME/CFS and various tests discovered vitamin deficiencies, candidiasis, food intolerances, leaky gut, mercury poisoning, parasite infestation and mitochondrial malfunction. With the various prescribed vitamin and mineral supplements (including regular intra-venous nutritional drips to remedy poor food absorption), removal of the amalgam fillings as well as using supportive complementary therapies I managed to live half a life and eventually became involved with the local ME/CFS self help group in Hull.

The" highs and lows" still exist, but now aged 74 I began to blame the lapses to some degree on ageing. However, recently a mutual sufferer was being very indignant about ME/CFS being classified as neurasthenia, now designated by the BMA as a nervous condition which, I understand, is a diagnosis advantageous to insurance companies who use this description to apply limits on disability and medical coverage of psychiatric diseases. Having, on my journey, I had the usual visit to a psychiatrist and was assured that there were no worries in that direction. I had not spent much energy or time keeping up the psychiatric opinions except for feeling very frustrated by the barriers put in the way of physical research.

The new definition of neurasthenia seemed to have been firmly established in 1982, but, fortunately my Oxford Reference Concise Medical Dictionary of 1980 describes it thus:

“Psychological and physical symptoms such as fatigue, headache, dizziness, anxiety and intolerance of noise, possibly caused by organic damage e.g. head injury or due to neuroses (my underlining). Now there was a different interpretation!

Until then the group had only one member I knew of who had developed his illness following very bad head damage but, since coming across this definition, enquiries of other members have revealed more head damage prior to illness- some significantly close to their loss of health. My own head accidents number four including whiplash and occasional severe clatters when not bending low enough to enter the car. This sometimes preventing me from making the journey.

Many ME/CFS sufferers may not have head damage in their history, though osteopath, Dr. Raymond Perrin maintains that a significant numbers of his ME/CFS patients have incurred whiplash damage. For people suffering from untreated head damage, possibly causing hydrocephalus leading to neurasthenia and its consequent misbalance of mind/body messages, having to deal with life's physical and mental traumas must put an enormous strain on a variety of functions as well as aggravating incurred and inherited weaknesses. A 1982 dictionary describes neurasthenia (no longer a technical term) as extreme lassitude and inability to cope with any but the most trivial tasks. Now that is an appropriate description of the ME/CFS condition but why miss out the possible cause? I do think this should be further investigated and that the neurasthenia diagnosis may be correct for many sufferers when interpreted to include the likely cause of head damage?

Neurasthenia is just a description of a cluster of symptoms which may or may not be related to ME/CFS. For example such problems can occur in the very early stages for certain types of cancer and many other diseases. Neurasthenia is a psycho-pathological term first used by George Beard in 1869 to denote a condition with symptoms of fatigue, anxiety, headache, neuralgia and depressed mood. It is currently a diagnosis in the World Health Organisation's International Classification of Diseases. However, because it is not a clear-cut description of a disease process or syndrome, it has become obsolete. There are many more current medical descriptions which are relevant and more accurate. Certainly, it is not used with in the NHS.

With regard to fatigue type symptoms following head trauma; there is no doubt that this is true, but is difficult to prove brain damage. I’ve no doubt given the resources and technology that this could happen in the future. In cases of brain damage, stroke, or brain tumours for example, it has been known for many years that fatigue occurs. So I think your inference is right about accident trauma. Some staff within the Sheffield ME/CFS clinic have experience in stroke-rehabilitation and long term neurological conditions, so in fact your inference comes full circle. Many of the management and coping strategies are in fact adapted from their experience with brain damage type conditions.

My stance with ME/CFS is that yes, there is some sort of damage to the brain, and other body systems. But as to exactly what it is remains a subject of research. Certainly Dr. Costa’s research many years ago showed specific abnormalities to blood-flow patterns. Any doctor who is familiar with ME/CFS will hold a similar view.

Carolyn writes. I have had CFS/ME for 18 months, and have gone from being an active, social and ambitious person to a state of considerable disability. I undertook the course of CBT offered with an open mind and a degree of optimism. I finished the course feeling depressed and like a failure. I now view CBT as akin to other quack 'therapies' such as the Lightning Process. Your recovery is in your hands. If you don't improve, you're a failure. My therapist seemed genuinely confused when I did not make any improvement, and in fact suffered my worst relapse to date whilst endeavouring, against my better instincts, to adhere to their GET and sleep programme. I completed the course doing less physical activity than when I had started, and feeling guilty for my own 'unhelpful illness beliefs'. I have since managed to get another referral to a different clinic. While they don't offer any miracle cures, they have a much more proactive attitude towards symptom management and recommend various supplements, vitamin B12 injections, breathing exercises and lifestyle-management. In the absence of any proper medical care why is money being squandered on CBT and GET when it could be better spent developing clinics such as the one at Sutton and, most importantly of course, on the bio-medical research we so desperately need? It is so sad that the medical profession continues to blame any poorly-understood condition on psychological factors. Why do they not research first, and conclude after, rather than the other way around?

This is noting new, and could apply to the local ME/CFS clinic. Really, you are right about research, BUT there are people who need help now, so what do you do, tell them to come back in 20 years ? I agree about CBT. When the NICE guidelines were being compiled CBT and GET were the only therapies where ‘reliable evidence’ was available. I know one person who took part in the process. The frustration was that interventions like B12 and supplements known to help did not have the evidence to back up the claims /beliefs/reputation where CBT did. Mike.

Tony Writes. Have you any thoughts on who to vote for in the forthcoming General Election?

Whatever the politicians are saying, the recent depression, in practice, has meant that every pound in your pocket will only buy 60p worth of the goods it would have bought 18 month ago. Initially many shops and business dumped goods onto the market to get their money back to ride out the storm, and avoid debt, so there was a glut of good cheap retail deals. Now, they need to increase their profit margins in order to keep in business, so prices are rising. For example as far as LME members are concerned the cost of a black ink toner cartridges has risen from £52 to £71. You can find similar examples in the supermarkets.

At far as ME sufferers go, this depression means the Government and the Charitable Foundations have lost revenue. Every job that is lost has a double knock-on effect. Firstly, in terms of National Insurance and tax revenue lost, and secondly in terms of paying out state benefits. So, this means that there will be a squeeze on public spending, including the NHS, and state benefits. If the Labour Government cut public spending instantly, it will be unpopular, and will induce further poverty and could create a second recession, so they talk of a five-year quantitative easing period. The Conservatives certainly would cut viciously now, to save money if elected.
The minor parties—forget about them. It's not well known, but NHS managers have been told to cut back by 40% next year, and that applies to services in Doncaster. So really the only choice in voting is how the cuts are to be made. Both parties will make them, but in different ways. 'Interaction', the Magazine of Action for ME, recently published 'A manifesto for ME/CFS Party' to which the three main political parties gave responses. It went something like this.

The Labour Party. *Acknowledged ME, quoting 'our measures are working', saying that under Labour the disability employment has risen from 42% to 48%. They have introduced the Expert Patient Programme, the complex issues like Work Preparation and the Job Introduction Schemes. Emphasized is that Labour will begin reassessing all customers receiving Incapacity Benefit, and move them onto Employment and Support Allowance. They promote the Access to Work programme which they claim the Conservatives are committed to scrapping.*
The Conservatives *acknowledge long terms conditions like ME. They say that drugs should be available faster on the NHS (eh, what drugs for ME ??), and talk of individual health budgets. Another thing is Welfare to Work (wasn't this one of Tony Blair's punch lines at the last but one General election?). They talk of an integrated back to work programme (to what jobs?) and a Conservative government would protect those in this position.*
Liberal Democrats *wrote waffle about ME & school issues. They did not have a clue about ME/CFS.*

In a general election, a vote for anyone but the two major parties is really wasted, as it won't count. At the time of writing, a general election was expected on 6th May. It's really its up to you. If you don't vote, it's a vote against the party you want.

Ross writes: I have grade 3 ME/CFS, and arthritis. I am on high rate mobility. I need a car and mobility scooter. So I took a good look at the prices on them. I can find the same scooter for £4995 in London but in Leeds £1995 and Bradford £2995. A lot of people are making fortunes out of disabled people! With arthritis, I can have a car—a basic one. However, for a mobility car, I need a big MPV or 4X4 so I can climb in up a step so to get out I slide out but that entails putting up front £8000 for a three-year lease then at the end no car also I lose it if some yob keys it down the sides.
I will stick to running old bangers and keep my mobility money to run it. What is the point of a new car that you can't afford to run due to my mobility money going to a car dealer?

I think you are right. The mobility scheme is run by a Government charity; the claimed advantage of the contract hire scheme is that it is supposed to be VAT and car-tax free. In recent years, the cost of a mobility car has been about the same as getting a good private deal for the same car new. There are pros and cons, but it think it is still better to use the mobility money to own your own car. Scooters for what they are, new, there are certainly many excessive prices going around. There is usually no shortage of good second hand scooters, and as long as they are maintained they are reliable, so why buy new?

News from Fairlawns.

(The South Yorkshire and North Derbyshire CFS/ME Service)

I attended the Local Patient Involvement Group at Fairlawns on the 12th March. Generally this involves a lot of boring committee work. Here is a digest of the more interesting things that were discussed.

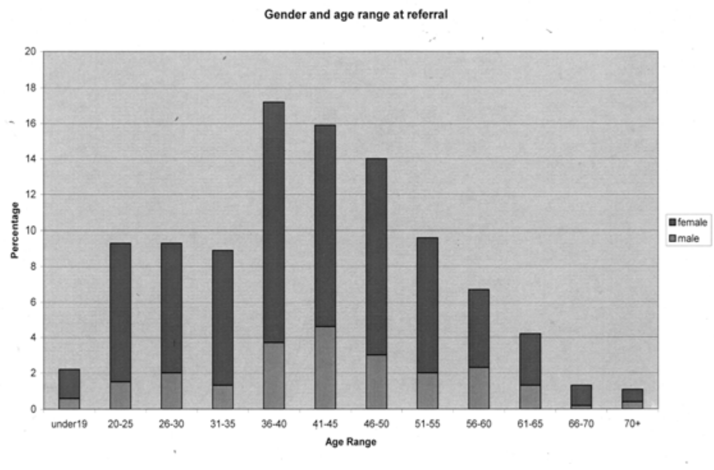
Restructuring of Primary Care Trusts. The NHS is a political target of politicians and subject to reorganisation at the whim of the government of the day. The latest idea is that the PCT will be split into two arms. Firstly the fund-holders, and secondly the service-providers. The idea is that the service-providers have to bid for money from the fund-holders. The fund-holders can choose who they buy the services off, and in the Sheffield clinic's case they could go outside the area. So if Leger ME had the resources, we could bid in competition with the Sheffield clinic to get funding for the current service. In fact anyone could. The trouble is that this restructuring and reorganisation causes much office and administration-time to be wasted to benefit the whim or further the career of whoever is in charge at the time. This uses money which could be better spent on patient care

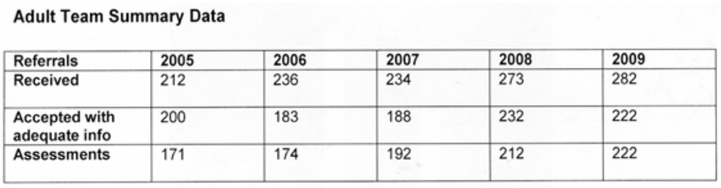
Changes to the Service. For the people who are referred there, there is a waiting list. Much head-scratching goes on as to how to reduce waiting times and get better access more quickly. The biggest gripes from Doncaster are the distance to travel, which is a barrier to many people attending. Telephone consultations and postal questionnaires in some cases have speeded people's access to the clinic. Feedback from our members indicates that the first letter people receive is a bit daunting, and this will be simplified. It was felt that people referred to the service should be give preliminary advice 'stop-gap' measures of a general nature in the form a leaflet e.g. pacing so a least some intervention is available before people are assessed by the service.

Use of volunteers. Some people, past patients have volunteered to give time to the clinic. These individuals help with clinic in various ways, usually as host or ME pals type role.

Other issues raised

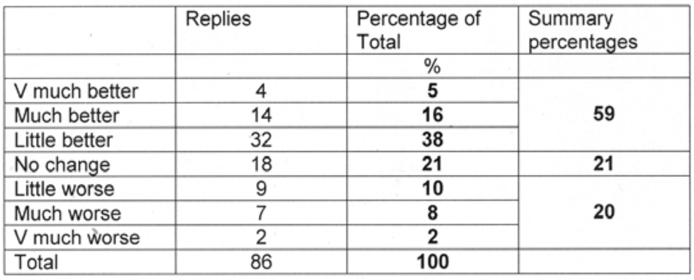
a) Driving & ME from the Sheffield ME Group Newsletter- This is reproduced in this issue of Pathways
b) Use of Medicines for ME/CFS. At present there no guidelines or best practice experience within the ME/CFS clinic about NHS medicine use. Information is to be sought from other sources as to what other clinics are using for ME/CFS, and the matter reviewed.
c) Stakeholders Meeting. There has not been one for some time now. One will be organised when the time is ripe.
d) Guidelines for nurses for dealing with people with ME/CFS. A report was received that these have been written for the Sheffield hospitals. Further information is being sought.
e) The clinic very often has requests for information about alternative & complementary therapies. A resource is being investigated.
f) Some doctors, although giving a diagnosis of ME/CFS, are not aware of the clinic's existence or how to access its services. The clinic will be doing a 'doctors mailing'. For the convenience of members who may wish to take a copy to their G.P., I have listed some information on the following pages.
g) Here are some statistics which may be of interest regarding the clinic:-





Adult Team Summary Data

Referrals	2005	2006	2007	2008	2009
Received	212	236	234	273	282
Accepted with adequate info	200	183	188	232	222
Assessments	171	174	192	212	222



	Replies	Percentage of Total	Summary percentages
		%	
V much better	4	**5**	**59**
Much better	14	**16**	
Little better	32	**38**	
No change	18	**21**	**21**
Little worse	9	**10**	**20**
Much worse	7	**8**	
V much worse	2	**2**	
Total	86	**100**	

NHS CFS/ME Service for South Yorkshire and North Derbyshire
'Fairlawns', 621 Middlewood Road, Sheffield, S6 1TT
Tel: 0114 229 2937 Fax: 0114 229 2943
Service Manager: Anne Nichol

Guidance for Early Diagnosis of CFS/ME, and Referral to the CFS/ME Adult Team

If you have a patient aged over 16 years with debilitating fatigue that is not the result of exertion, not relieved by rest and typically suffers from delayed setbacks after physical and mental activity, they may have Chronic Fatigue Syndrome. We suggest patients over 65 are assessed first by an elderly care physician.

If the patient is under 16 years old, please refer to your local Paediatrician, who can then access our Children and Young People's Team.

A positive diagnosis can only be confirmed by recognising the presence of a characteristic set of symptoms, together with the screening and exclusion of alternative diagnoses.

CFS/ME guidelines recommend early diagnosis and intervention in order to increase the likelihood of successful management.

Characteristics of CFS/ME include:

Debilitating persistent or relapsing fatigue (not caused by conditions such as inflammation or chronic disease)
Fatigue of definite/new onset but of several months duration
Fatigue not due to on-going exertion and not substantially relieved by rest
Fatigue that is severe enough to cause substantial reduction in previous levels of occupational, educational, social or personal activities

Additional characteristic symptoms include :

• Sore throat • Memory/concentration problems • Unrefreshing/disturbed sleep • Tender lymph nodes • Muscle pain or twitching	• Multi-joint pain without swelling or redness • Headaches of a new type, pattern or severity • Post-exertional malaise lasting more than 24 hours

(Fukuda diagnostic criteria includes at least 4 of the above symptoms present in addition to the fatigue)

Differential diagnoses.

It is important to ensure there is no clinical evidence of other causes of fatigue, including:

• Adrenal insufficiency	• Anaemia
• Chronic infection	• Coeliac disease
• Immuno-deficiency	• Malignancy
• Primary Mental Health Problem	• Obesity (BMI>40)
• Major neurological diseases	• Primary Sleep Disorder
• Rheumatic diseases	• Thyroid Disease
• Somatisation	• Organ failure (e.g. emphysema, cirrhosis, cardiac failure)
• Alcohol/substance abuse	• Reversible causes of fatigue (e.g. medication, recent surgery)

If in doubt about diagnosis do not hesitate to contact the service for advice.

NHS CFS/ME Service for South Yorkshire and North Derbyshire

Referral to the CFS/ME Adult Team

The Adult team is currently only accepting direct referrals from GPs. If you are a GP and wish to refer a patient to the CFS/ME service, we do require a referral letter, which includes the following information, as well as the results of the screening tests. As we are a therapy service we have no facilities for carrying out any investigations and rely on detailed referral information to enable us to triage referrals adequately.

If you do not include this information we will not be able to accept the referral:

- Reason for referral to the Service
- Confident diagnosis of CFS/ME
- Narrative of the illness
- Relevant past medical history including mental health
- Information about interventions already tried
- Current medication

Minimum requirement of the following tests having been carried out (see below)

Screening tests

All people who are referred to the service must have a set of screening tests done within the last 3 months.
If you do not include copies of the results of these tests, including their values and the date taken, we will not be able to accept the referral.

- Full blood count
- ESR
- CRP
- Urea and electrolytes
- Serum Creatinine
- Calcium profile
- Creatine kinase
- Liver function tests
- Thyroid function tests
- Urinalysis for protein blood and sugar
- Serum glucose
- IgA tissue transglutaminase Ab for coeliac disease

Exclusion criteria for the CFS/ME Service:

- Major psychiatric illness with psychotic or manic features
- Concurrent rehabilitation from another service
- Ongoing medical investigation

Please send all referrals to:

Anne Nichol

Service Manager

CFS/ME Service for South Yorkshire and North Derbyshire
‘
Fairlawns’, 621 Middlewood Road, Sheffield, S6 1TT

Tel: 0114 229 2937 Fax: 0114 229 2943

I quite often get asked what support is available from the service. I have listed information from a leaflet sent to one of our adult members. There is also a separate children's service. To access their services you have to be referred to the service by your NHS G.P.

The aim of all therapies within the CFS/ME service is to enable individuals to manage their condition. Therapies are based on the belief that managing energy-levels will improve an individual's quality of life. The therapy options therefore aim to explore the relationship between symptoms, activity, rest and sleep. As a service we offer a jointly agreed number of sessions to help individuals reach a point where they feel more confident managing their condition. It is preferable that an individual chooses one therapy to focus on. Sessions can be undertaken at 'Fairlawns', or for those who find it difficult to travel, over the telephone, email or in liaison with therapists closer to home. The therapy options available are:

Activity Management with an Occupational Therapist. This focuses on managing all the activities a person is involved in across the days and weeks. The aim is to achieve a balance between energy and rest. Activities demand varying degrees of energy and can range from self-care tasks such as getting washed and dressed, to leisure pursuits, as well as work and vocational activities. Therapy initially involves promoting awareness of the daily pattern of these activities. Therapy then aims to enable an individual to adapt their routines to incorporate rests and adjust individual tasks in order to balance energy and rest in a consistent pattern. Once a sustainable level of activity is reached, it aims to enable a person to then gradually increase their activity levels. *Member’s feedback: Very positive.*

Graded Exercise Therapy (GET) with a Physiotherapist. GET is s an evidence-based approach to improving a person's CFS/ME symptoms and functioning, aiming towards recovery. The-first step is to set a sustainable baseline of physical activity or exercise, The duration of the physical activity or exercise is gradually increased in a planned way that is tailored to the individual. This is followed by an increase in intensity when the individual is able. The physical activity or exercise involves two individual sessions, followed by a six week supervised group exercise programme. There is also the option to follow an unsupervised home exercise and stretching programme. *Member’s feedback: Nothing positive reported.*

Cognitive Behavioural Therapy (CBT) with a Clinical Psychologist. This focuses on becoming aware of and understanding how thoughts, beliefs, feelings and behaviour impact on an individual's management of CFS/ME symptoms and their patterns of activity and rest. Therapy may also involve identifying barriers to managing one’s condition, as well as problem-solving how to view things in a different way. Therapy may also explore the emotional impact of CFS/ME and how it affects an individual's adjustment to the condition. *Member’s feedback: Nothing positive reported.*

Group programme. A group of up to 12 people meet over 6 consecutive weeks with a 3 month follow-up session. The group lasts for 1½ hours and is facilitated by 2 therapists. By drawing on the knowledge and experience of the other people in the group, this therapy aims to develop coping strategies and discuss varying aspects of managing the condition as well as pacing, sleep, and relapse management. The group can also support people in exploring different experiences of having CFS/ME, and promote management strategies in order to enable an individual to improve their quality of life. *Members feedback: Very useful.*

Relaxation group. This is a group of up to 10 people who meet over 6 consecutive weeks with a 3 month follow-up session. The group lasts for 1½ hours and is facilitated by 2 therapists. The group is a talking and practical programme. It aims to introduce relaxation and rest into daily living so as to enable people to manage their energy and therefore their condition. It offers education on differing practical relaxation techniques in order to develop a continued approach to relaxation and support committed home practice. *Member’s feedback: Very useful.*

Any medicines e.g. for sleep issue or pain control need to be obtained from your G.P. Other treatments e.g. pain control strategies need to be referred to the local pain control clinic.

The All-Party Parliamentary Group on ME/CFS.

The Countess of Mar chaired a group of MPs in an inquiry into services for ME patients. Over 400 responses were considered from service providers, charities, sufferers and carers. The interim report has now been issued which includes the following recommendations:

1) ***Finding:*** There were a significant number of submissions from PCTs stating that they do not have accurate patient numbers. PCTs who do offer adequate services could only supply numbers of how many people are using their particular service. There will also be an unknown number of other sufferers within the community.
Action: The Department of Health should undertake research to determine accurately the numbers of patients with ME/CFS.

2) ***Finding:*** It is clear from the evidence that there are probably sufficient numbers of patients involved and sufficient uncertainties about the nature and availability of services to justify a measure in addition to the NICE Guidelines.
Action: A national service framework should be created to complement the NICE Guidelines.

3) ***Finding:*** The All Party Parliamentary Group felt that many of the concerns and experiences submitted as evidence by patients, carers and patient organisations would have been addressed had the Independent Working Group Report to the Chief Medical Officer (CMO) of 2002 been acted upon adequately.
Action: The DoH should revisit the report to the CMO and ensure that the recommendations relating to service provision are adequately addressed and are implemented promptly.

4) ***Finding:*** From the evidence supplied by PCTs and patients, the Group has ascertained that there is lack of consistency in treatment-options offered to patients in different PCTs. The APPG finds the degree of variation in the availability and access to services unacceptable. Patient evidence also indicates people want services that are physician-led, multidisciplinary, and are situated in locations that are easily accessible to those with significant mobility problems.
Action: The APPG recommend the DoH take steps to remedy the variation and ensure that each PCT offers a full range of services promptly. This process should involve meaningful consultation with local patients or patient support groups.

5) ***Finding:*** Through the evidence supplied to the Group, it is clear that there is a significant lack of services available for children and adolescents. Many services offer treatment options only to patients over 16, which has led to many children not receiving adequate care. This is unacceptable and can lead to tragic consequences.
Action: The APPG therefore call on PCTs, Strategic Health Authorities and the DoH to undertake a detailed review of current services for children and adolescents to ensure that all receive adequate care and that all decisions are made in conjunction with personal carers, education authorities and social services where appropriate.

6) ***Finding:*** From correspondence with the Royal College of Physicians and the Royal College of General Practioners, the Group is not convinced that medical students receive sufficient training on ME/CFS, including how to clinically assess and diagnose these patients and advise on appropriate forms of management.
Action: The Group recognises that ME/CFS does not have the same obvious impact as cardiovascular disease or cancer, but that it is necessary for medical students to receive adequate training in ME/CFS. The relevant Royal Colleges should ensure that students receive training in this disease.

7) ***Finding:*** There were a large number of submissions from patients that stated their experience with GPs was poor due to lack of awareness of the disease amongst primary care-givers.
Action: GPs should receive ME/CFS awareness training as part of their continuing professional development and ensure they are able to adequately recognise the symptoms of ME/CFS and deliver a correct diagnosis. They should also be aware of the various management pathways.

8) *Finding:* The Group noted evidence that there were serious concerns about acceptability, efficacy and safety with some treatments such as cognitive behaviour therapy (CBT) and graded exercise therapy (GET). This may be due to the lack of training given to professionals but evidence was given that it was in part due to fixed attitudes about causation by some health-professionals. The Group feel that it is inadequate for professionals to treat patients with ME/CFS when they have not been fully trained in the particular characteristic of this disease.
Action: It is essential that all healthcare professionals i.e. dieticians, nurses, occupational therapists, physiotherapists and psychologists, involved in treatment should have adequate training in ME/CFS and the relevant professional bodies should ensure this occurs as a matter of real urgency. NICE should carry out a detailed review of their management guidance on ME/ CFS, in particular the mounting evidence for the need to broaden the range of appropriate therapies beyond CBT and GET, and to specify that all such therapies should be delivered by specifically ME/CFS trained professionals.

9) *Finding:* As noted in the Gibson report, there has also been far too much emphasis in the past on psychological research and insufficient attention to biomedical research. The Group welcomes the recent MRC initiative to attract new researchers and new technologies into this area.
Action: However, the Group is sure that it is vital that further biomedical research is undertaken to help discover a cause and more effective forms of management for this disease.

10) *Finding:* It is clear from the evidence submitted to the Group that currently, ME/CFS patients receive little assistance in the complicated process of application for benefits and that refusal rates are worryingly high. Applying for benefits is an extremely prolonged and strenuous task, especially if patients are forced to appeal the original decision where their application was denied.
Action: The Department of Work and Pensions should review its guidance to decision makers to increase the awareness of the specific difficulties faced by ME/CFS sufferers. Furthermore the Group recommends that ATOS Healthcare staff should also receive increased training to ensure that they are fully aware of ME/ CFS and the limitations that it places on patients.

11) *Finding:* The APPG is aware that many patients who are severely affected by this disease are receiving either inadequate care or no NHS care at all, which is clearly inconsistent with the NICE Guidelines.
Action: Specialist referral services must ensure that high priority is given to the needs of the severely affected, especially in relation to domiciliary services and in-patient facilities for assessment and management.

(Thanks goes to the Bolton & Bury group for bringing this information to our attention.)

Recipe Corner

Banana and Honey Teabread

115g (4oz) unsaturated margarine
115g (4oz) light soft brown sugar
115g (4oz) set honey
2 eggs, beaten
225g (8oz) self-raising flour (white or wholemeal)
½ teaspoon ground nutmeg or cinnamon
Squeeze of lemon juice

To Make:- Preheat oven 180°C/350°F/Gas Mark4. Lightly grease and line a 900g (2lb) loaf tin. Beat together margarine, sugar and honey in bowl, until light and fluffy. Gradually beat in eggs, then fold in flour and nutmeg or cinnamon. Peel bananas; mash flesh with a little lemon juice. Fold mashed bananas into teabread mixture until well mixed. Spoon mixture into prepared tin and level surface. Bake in oven for 1-1¼ hours or until risen, golden brown and firm to touch. If necessary, cover lightly with non-stick baking paper or foil towards end of cooking time to prevent top of loaf over-browning.
Cool for a few minutes in tin; turn out onto wire rack and serve warm or cold in slices.

Naughty Choccy Mousse Cake

(Serves 10).

300g dark chocolate
275g caster sugar
165g unsalted butter
5 large eggs
1 tbsp ground almonds

To Make:- Put the chocolate, sugar and butter in a bowl over barely simmering water and allow to melt. Whisk eggs with the ground almonds until well mixed and use a spatula to fold into the chocolate mixture off the heat. Pour into a 20-23cm cake tin (buttered and dusted with ground almonds) Bake in oven for 35-40mins at 180°C/Gas Mark 4. Allow to cool (it may crack slightly) and dust with icing sugar.

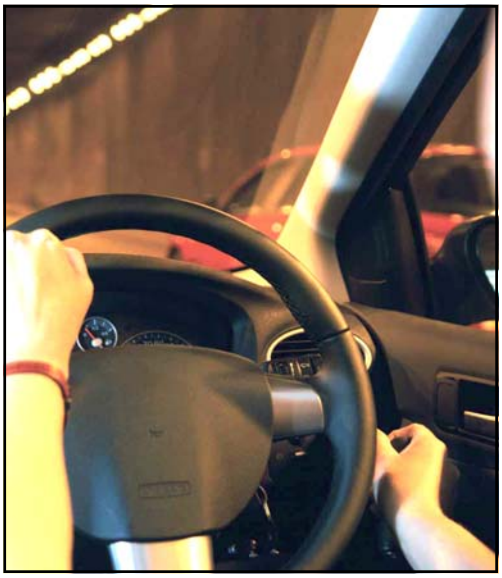
The DVLA Driving and ME/CFS

From SheffieldME/CFSgroups newsletter Spring 2010 by Joanne, SheffieldME/CFSGroup.

Recently a member posed a question about whether the DVLA should be informed if you suffered ME/CFS and whether the consequence of notifying could result in the withdrawal of your driving licence. Investigating the DVLA website information and speaking with staff at the NHS CFS/ ME Clinic, Dr. Jack Czauderna and Mike Valentine from the Doncaster Leger Group helped highlight the following points:

Medical Practitioners' Guide To The Current Medical Standards Of Fitness To Drive At A Glance Guide Feb 2010 (www.dft.gov.uk/dvla/medical/atagiance.aspx):

"It is the duty of the licence holder or licence applicant to notify DVLA of any medical condition, which may affect safe driving. On occasions, however, there are circumstances in which the licence holder cannot, or will not do so."



One of the most important aspects of having ME/CFS is being mobile. People who have high rate mobility DLA can qualify for a mobility car and free adaptations to make driving safer and easier.

The General Medical Council has issued clear guidelines applicable to such circumstances, which state:

"The DVLA is legally responsible for deciding if a person is medically unfit to drive. They need to know when driving licence holders have a condition, which may, now or in the future, affect their safety as a driver."

From the Medical Standards guide it states expected information about age and driving: "Age is no bar to the holding of a licence. DVLA requires confirmation at age of 70 that no medical disability is present, thereafter a 3-year licence is issued subject to satisfactory completion of medical questions on the application form. However, as ageing progresses, a driver or his/her relative(s) may be aware that the combination of progressive loss of memory, impairment in concentration and reaction time with possible loss of confidence, suggest consideration be given to cease driving. Physical frailty is not per se a bar to the holding of a licence."

Apart from age, the medical conditions listed are neurological disorders, including epilepsy; Cardiovascular disorders; diabetes; drug and alcohol dependency; visual disorders; sleep & respiratory disorders; miscellaneous conditions and physical disabilities. Dr. Czauderna advised that ME/CFS is not a proscribed condition and as such does not have to be disclosed, however, if there are other accompanying issues such as sleep problems (sleep apnoea in particular) then notification would be necessary. (For those of you wanting to investigate further, refer to the Guide Chapter 7-8 or speak with your GP).

Mike Valentine concurred with Dr. Czauderna and went on to say "however, non-disclosure of 'material facts' to an insurance company could render the insurance invalid in the event of the claim. ME/CFS cases have been involved in massive insurance payouts in the past that have gone to the high court, so it is a liability as far as insurance is concerned. The advice I give to my members is firstly to discuss with G.P., then tell the DVLA they have ME. DVLA normally send out a form to your doctor. Usually a letter follows saying that the DVLA have no issue and you can keep your licence. This letter will usually also stop questions from insurance companies. No -one I know has been refused a driving licence because they have ME. What you won't get is a PSV (bus) or HGV (big lorry) licence. I do know several people with ME/CFS who are taxi drivers with a good safety record."

Mike also revealed that some of the more cut-price Insurance companies may charge an administration fee, or increase your premium if you notify them of your ME/CFS as they have to make changes to your premium and it may be that you have to pay them for the current year but worth noting for the future are the companies which offer Insurance for Motability and the larger insurers such as these are more likely to accept medical conditions without imposing extra charges on premiums. It may even be worth using an Insurance Broker: Although, it may cost a little more for their services, you can at least talk to them and they will deal with any issues like ME/CFS etc., so everything will be disclosed.

Personally, I think all responsible drivers are generally courteous to others and decide on a daily basis whether they are fit or capable to get behind the wheel. Whether you have a headache, flu, stomach bug or virus, all may impair not only your cognitive functions but decrease manual dexterity and speed of reaction, cause limb tiredness even poor vision - thus impeding the ability to drive safely. Whilst there are many ME/CFS sufferers who drive, there are probably just as many who decide not to.

The Medical Standards advised there is "no simple marker for assessment of impaired cognitive function although the ability to manage day to day living satisfactorily is a possible yardstick of cognitive competence". It clarifies in-car assessments as ruling out features present which are "liable to cause the patient to be a source of danger, e.g. visual inattention, easy distractibility, and difficulty performing multiple tasks. In addition, it is important that reaction time, memory, concentration and confidence are adequate and do not show impairment likely to affect driving pel1ormance".

Note with reference to medication:

Motability
The leading car scheme for disabled people

. Section 4 of the Road Traffic Act 1988 does not differentiate between illicit or prescribed drugs. Therefore, any person who is driving or attempting to drive on the public highway, or other public place whilst unfit due to any drug, is liable to prosecution.

- All drugs acting on the central nervous system can impair alertness, concentration and driving performance. This is particularly so at initiation of treatment, or soon after and when dosage is being increased. Driving must cease if adversely affected.
- The older tricyclic antidepressants can have pronounced anticholinergic and antihistaminic effects, which may impair driving. The more modern antidepressants may have fewer adverse effects.
- Pain killing drugs (opiates) may impair a person’s ability to drive. This applies particularly when treatment is just started or after dosage adjustment.
- Benzodiazepines are the most likely psychotropic medication to impair driving performance, particularly the long acting compounds. Alcohol will increase the effects.
- Doctors have a duty of care to advise their patients of the potential dangers of adverse effects from medication and interactions with other substances, especially alcohol.
- Always notify your GP that you are a driver and seek clarification as to the affects of any medicines prescribed.

In summary, Dr. Czauderna confirmed that whilst ME/CFS is not a specifically listed medical condition requiring notification, in the main it seems a wise option to discuss with your Doctor and your car insurance company. Ute (Sheffield Group chairman) herself is one of many who have notified the DVLA and has received their return letter acknowledging her notification. As she says, "At least it's on their files, I've done my bit!” Mike Valentine recommends that members who are less confident about their driving may benefit from a refresher driving course or even have a go at the advanced driving test, which can increase confidence and sharpen up skills to compensate for ME/CFS.

An Rare and Unusual Case of Cancer.

My name is Tony and I am a CFS/ME Sufferer and member of the Leger ME group. Here is my diary.

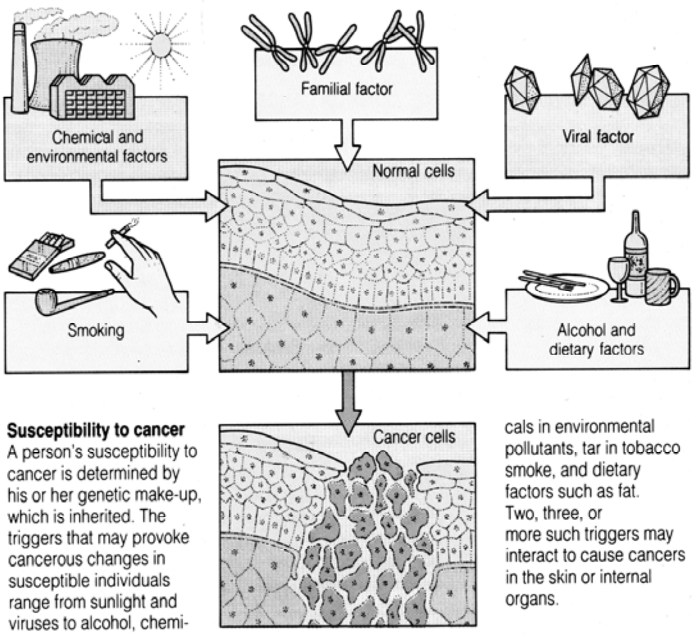
Day 01	20/04/09 Evening	A lump was found in my left breast by my wife. The next morning I was at the doctors. At the check up the doctor explained that she thought it was a cyst and didn't appear to be attached to anything. She said that to be on the safe side that she would write to make me an appointment at the hospital to have a scan.
Day 10	30/04/09	At the appointment a biopsy was also taken and I was informed, by the doctor that he thought, quote "it looks a nasty little devil !",
Day 17	07/05/09	I had another appointment at the Jasmine Centre, to receive the results of the scan and biopsy. I was told that it was cancer at stage 2.
Day 21	11/05/09	A Macmillan nurse, Carol, came out to our home to answer any questions we had and what was going to happen next.
Day 24	14/05/09	I had another appointment at the Jasmine Centre for a mammogram. (All you ladies who have had one of these, you have my greatest respect).
Day 29	19/05/09	I had an ultra sound and met the doctor who was going to perform the operation to remove the cancer.
Day42	01/06/09	I had a meeting with the anaesthetist, to go over his part in the operation. because of my medical history he informed me of the difficulties I had to go through during the operation. During this meeting everything was discussed in a light hearted, but serious manner. He informed me that he had never lost a patient and I wasn't to be the first. At this my response was to say that once I was asleep it didn't matter, I wouldn't feel a thing.
Day 46	04/06/09	I was admitted into the hospital for the operation.
Day 47	05/06/09	On the morning, I was prepped for the operation and had my sexy white surgical stockings put on. Got myself onto the meat wagon and wheeled to the theatre. Just before going into the theatre, I met the both the doctor and the anaesthetist in their gowns and hats, which I thought was funny. On meeting them I asked them if we were going to a fancy dress party or into the theatre. They both thought it funny. But the next thing I knew it was all over and I was in the recovery room.
Day 48	06/06/09	After informing my good lady wife I was ok I spent the night in the high dependency ward, with no problems. The next morning a member of the crash team said I could be moved back to the wards as I looked better than him. I had had a full mastectomy and all the lymph nodes on my left side removed. Because of the difference between a man and woman's breast, males cannot get rid of the fluid which had to be drained away on numerous occasions.
Day 60	18/06/09	I was given the all clear, told that the cancer hadn't spread and that it had all been removed. I am now on a 6 months recall and only have to take one tablet a day for five years of tamoxifen, an anti-oestrogen drug usually reserved for ladies.

As a footnote, on average 45,000 women/year are diagnosed with breast cancer, to 300 of us men. So please, please gents, if you don't fancy feeling your own breasts, let your wife/girlfriend check for you. I've been very lucky and fortunate that this illness was discovered early and because of all the brilliant staff at the Jasmine Centre I'm here to write this narrative for you. To the same staff at that JASMINE CENTRE I am and will be eternally grateful.

In Tony's case everything went as well as it could. At the time of writing, March 2010, Tony is still clear of cancer, and it will be five years before he is said to be cured. Of course he still has his other health problems including ME/CFS.

What is cancer?

When an egg and sperm ell combine, the resulting cell divides, multiplies and grows, eventually forming a baby which grows into an adult. The whole process is controlled by genes within the chromosomes. Genes tell cells how and when to divide, what to grow into, and when to stop. Hence an orderly organised person is produced. Cancer can by thought as a group of cells becoming mutinous or dissident, and or following their own agenda. They grow, usually in an uncontrolled way to form a tumour, and in many cases spread over the whole body with disastrous results when a key organ is affected. Getting cancer itself is like a reverse lottery; you are entered every day of your life, and pick up the pre cancerous risk tickets.



Susceptibility to cancer
A person's susceptibility to cancer is determined by his or her genetic make-up, which is inherited. The triggers that may provoke cancerous changes in susceptible individuals range from sunlight and viruses to alcohol, chemicals in environmental pollutants, tar in tobacco smoke, and dietary factors such as fat. Two, three, or more such triggers may interact to cause cancers in the skin or internal organs.

The more risks you have, the more pre cancerous tickets you get. This happens quite frequently in a normal healthy person. To get cancer, you enter your precancerous tickets into a of biochemical game of snakes and ladders. Fortunately there are many checks and balances built within the body, particularly within the immune system, which detect and kill cancer-like cells. The best defence is a healthy immune system and to avoid known risk factors, particularly smoke.

Key signs and symptoms to report to your doctor.

Experts and doctors agree the following lists of symptoms are the most important ones to look out for and they will be keen to see you if you have noticed any of them. If you develop one of these symptoms it doesn't definitely mean you've got cancer - usually, they turn out to be something much less serious. But it's important to get it checked out because it could be.

- An unusual lump or swelling anywhere on your body
- A change in the size, shape or colour of a mole
- A sore that won't heal after several weeks
- A mouth or tongue ulcer that lasts longer than three weeks
- A cough or croaky voice that lasts longer than three weeks
- Persistent difficulty swallowing or indigestion
- Problems passing urine
- Blood in your urine
- Blood in your bowel motions
- A change to more frequent bowel motions that lasts longer than six weeks
- Unexplained weight loss or heavy night sweat
- Any unexplained pain or ache that lasts longer than four weeks

Especially for women:

- An unusual breast change
- Bleeding from the vagina after the menopause or between periods

Cancer is multifaceted, and comes in all sort of different types and different manifestations, some very bizarre. Some types are benign and localised but, others are malignant and spread. There are many ways it is assessed and it varies depending on the specific cancer, e.g. Gleason score for prostate, Duke's for bowel. There is a Cancer staging system in use - TMN system. The T means Tumour size scores 1-4, 1 describes is the smallest and 4 the biggest. N means lymph node involvement. The lymphatic systems drain body fluids to the nearest lymph nodes where the immune system tries to kill cancer cells. This gives a score of 0-3, 0 being no lymph node involvement, 3 being maximum involvement (marked swelling). M stands for metastases or secondaries, which are spreading of the cancer to other parts. Zero represents no metastases and other numbers mean spread.

Treatment options fall into several sorts. The ideal way is to 'cut it out' by surgery, which is know as excision. Where the cases are caught early enough, this can be curative, but sometimes surgery is used to control the disease. Chemotherapy is the use of drugs to control the cancer cells. In some cases it can be curative when vicious combinations of four or five drugs are used. In some cases 'chemo' is used for insurance after surgery, mopping up, to delay the disease process or to control symptoms in which case usually only one or two drugs are used. Radiotherapy is the heavy use of x-rays or atomic particles to kill affected cells, and is usually focused on some part of the body. Palliative care is treatment to control symptoms, but without intention to cure. This may involve pain control, alternative therapies or lower doses of chemotherapy drugs.

Leger ME Experience on Cancer Related issues.

The early stages of some cancers resemble ME/CFS, and are undetectable. The saddest piece of news in recent years is learning of the death of two people in our region from lung cancer. These people thought they had ME/CFS. The Barnsley area is a hotspot for lung cancer. At a recent meeting I heard from Allen, a colleague's husband. The first sign of trouble was a shortness of breath after fell walking in the Lake District. His wife, being a health professional pushed him for a hospital check-up. Examinations and tests were done coming out clear, and just as last reassurance a chest x-rays was taken, but it showed a shadow. Subsequent treatment involved operations, chemotherapy and radiotherapy. Eleven years later, he is still around. The most unexpected things for me was him saying that classic symptoms, cough, haemoptysis (coughing up blood, chest discomfort, recurrent chest infections) didn't appear until the cancer was fairly advanced. Usually early warnings of cancer (or other diseases) appear as abnormal blood test results. One of my standard pieces of advice is that everyone with ME/CFS has a yearly check-up, apart from the need for welfare benefits. Not going to your doctor is a sure fire recipe for future problems.

Major disease or minor problem is one thing I ask about when dealing with members. Any deviation from the normal ME/CFS picture indicates a problem needing follow-up. People with depression very often think that they have cancer. A common question from ME's is "Do I have a brain tumour?" That can be excluded, as brain tumours progress quickly within a period of months. One of the reasons for a waiting time for ME/CFS diagnosis is to exclude cancer issues. Another common question is if ME/CFS makes people more susceptible to cancer. From the information I have and from the ME Association the answer is no. The risk is about the same. Experience with group members bears this out.

Ways to contact Cancer Research UK There are a number of ways to make contact depending on your query. The contact details for the National Office are:
Cancer Research UK, P.O. Box 123, Lincoln's Inn Fields, London WC2A 3PX,
Registered charity no. 1089464
tel: (Supporter Services) 020 7121 6699
tel: (Switchboard) 020 7242 0200
fax: 020 7121 6700

About Macmillan nurses.

For many people affected by cancer, Macmillan nurses are a valued and trusted source of expert information, advice and support - free of charge. There are over 3000 Macmillan nurses across the UK, working both in hospitals and in the community. All Macmillan nurses are registered nurses with at least five years' experience, including two or more years in cancer or palliative care. They also complete specialist courses in managing pain and other symptoms, and in psychological support.

Macmillan nurses are usually employed by the NHS and their posts are funded by Macmillan for a set time, commonly the first three years. After that time, the long-term funding is taken up by the NHS or other partner organisations. The nurses work in NHS hospitals and the community, but are not usually associated with private health care. They do not undertake routine nursing tasks, but if you need this kind of support, there are many other kinds of nurse that can help.

Types of Macmillan nurses

Some Macmillan nurses specialise in particular cancer types or treatments. For example, Macmillan chemotherapy nurses give chemotherapy treatment to patients, and help them to cope with the side effects that may occur. Macmillan breast cancer nurses support women from the screening and diagnosis stage helping them to make informed decisions. They give practical and emotional support and help some women come to terms with a mastectomy. Macmillan paediatric nurses help children with cancer and their families. They provide support for the child and parents at home and in hospital, and help to keep children at home with their families as much as possible. Macmillan lead nurses are senior nurse managers, helping shape the future of cancer and palliative care services in their area.

How to get a Macmillan nurse

To obtain the services of a Macmillan nurse, you must be referred by your GP, your hospital consultant, a district nurse or a hospital ward sister. Don't hesitate to ask them if there are Macmillan nurses available in your area. Macmillan nurses are available in most areas of the country, but if there is not a Macmillan service in your local area, you can be referred to alternative specialist services. Find out about getting a referral for a Macmillan nurse.

Ask Macmillan

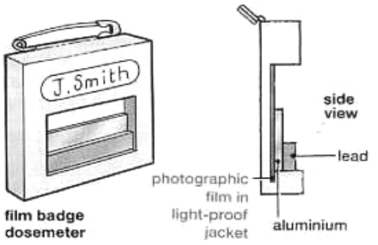
If you're affected by cancer you want to know there's always someone you can turn to for help. Someone who can answer your questions, whatever they may be. Our cancer support specialists are here to offer practical, medical emotional and financial support, whether it's you or a loved one that has or has had cancer.

Questions?
Call free on 0808 808 0000 www.samaritans.org
Our online community is always open and full of people ready to listen and offer support.

What is radioactivity?

Radioactivity will darken ("fog") photographic film, and we can use this effect to measure how much radiation has struck the film.

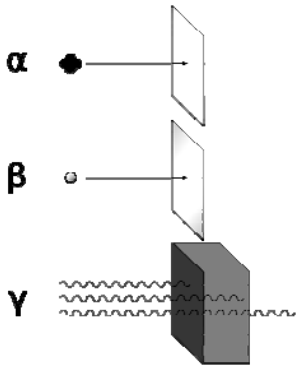
Workers in the nuclear industry wear "film badges" which are sent to a laboratory to be developed, just like your photographs. This allows us to measure the dose that each worker has received (usually each month).



Uranium was known to the Romans, who used it to give an orange/yellow colour to glass. In 1896 it was Antoine Becquerel that discovered the phenomenon of radioactivity. Uranium in naturally occurring minerals was found to fog nearby photographic plates without expositing them to light. Certain minerals also glowed when brought near these uranium containing minerals, as used in luminous paint. It was eventually found that something was emitted (radiated) from these mineral substances that passed through light proofing. These substances were said to be ‘radio active’. The film-fogging phenomenon is in use today in organisations where radio active materials are used e.g. hospitals, nuclear power stations to check radiation exposure levels of individuals, and also to x-ray certain industrial structures.

Basically the naturally-occurring heavy metals above number 82 in the periodic table all exhibit some degree of radio activity. The atomic nucleus is unstable, tries to get to a more stable state by spitting (emitting) something out, and in effect is a nuclear down-sizing, which is known as radioactive decay. The time taken for half the atoms to down-size in any one sample is known at the half life. These decay products then themselves radioactively decay through a series of similar processes until they become lead, which is stable. For uranium the half life is measured in millions of years, whereas some of its decay products have half lives of fractions of seconds. Many elements occur in different variants know is isotopes. The most well known for Uranium are 235 and 238. Most of the naturally occurring Uranium is 238, while just less that 1% is 235. The latter variant can be used to make nuclear bombs and fuel. The industrial plant process used to separate the two, a machine known as a gas centrifuge, is at the centre of the current political storms in North Korea and Iraq. Each isotope has a characteristic half life. For carbon, there are two natural isotopes C12 which is stable, but the rarer C14 is radioactive and has a half life of 5730 years. Within a living organism (animal or vegetable), the proportion of C14 is always the same, but when it dies, the C14 content decays. Archaeologists use C14 levels to calculate the date ancient bones or plant remains.

A Geiger counter, that detects and counts radio active emissions. Different tubes are used for α, β & γ radiation

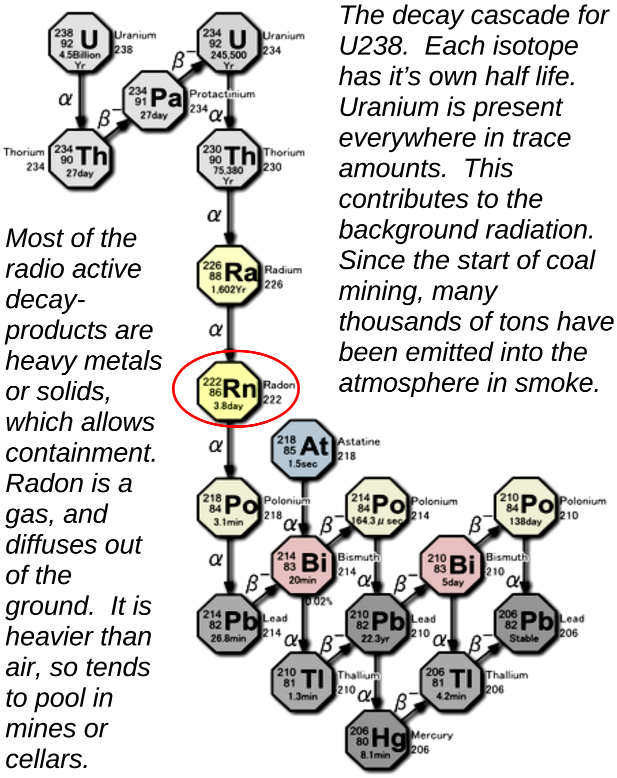


The most common types of radioactive emissions are known as alpha (α), beta (β) and gamma(γ) rays. The alpha emission is a particle, a slow moving helium nucleus with a positive charge, the beta a fast moving electron with a negative charge (as in CRT type VDU’s), and the gamma is a form of X ray-like electromagnetic radiation which travels as the speed of light. The alpha particles may be completely stopped by a sheet of paper, beta particles by thin aluminium shielding, but gamma rays can only be reduced by much more substantial barriers, such as a very thick layer of a heavy metal like lead or depleted uranium. An alpha particle is capable of damaging DNA by knocking atoms of DNA out of line a bit like a snooker ball e.g. from radon gas. The beta particle can cause damage to various biological processes akin to oxidative and free radical damage, unless the gamma rays have sufficient strength, they just pass through biological materials.

Radioactive substances are double edged swords, having beneficial as well as sinister uses. While uranium is raw material for fuel for atomic reactors in power stations, it is infamous as in atomic bombs. Radium, a decay product of uranium, has medical uses and the most common use was in hospitals, where radioactivity can used to treat cancerous growth and tumours. Many small medical devices are sterilised by radiation. e.g. syringes. Perhaps the most significant isotope for ME/CFS’s was Dr. Costa’s ground breaking research into brain blood flow patterns using radioactive technetium 99 as a tracers in the ground breaking SPECT brain scans.

The Radon Gas Hazard *from the UK HPA*

Radon is a natural radioactive gas. You cannot see, hear, feel or taste it. It comes from the minute amounts of uranium that occur naturally in all rocks and soils. Radon is present in all parts of the UK, although the gas disperses outdoors so levels are generally very low. We all breathe it in throughout our lives - for most UK residents, radon accounts for half of their total annual natural radiation dosage. However, geological conditions in certain areas can lead to higher than average levels. Some of the highest radon levels have been found in the southwest, but levels well above average have been found in some other parts of the UK. Exposure to particularly high levels of radon may increase the risk of developing lung cancer.

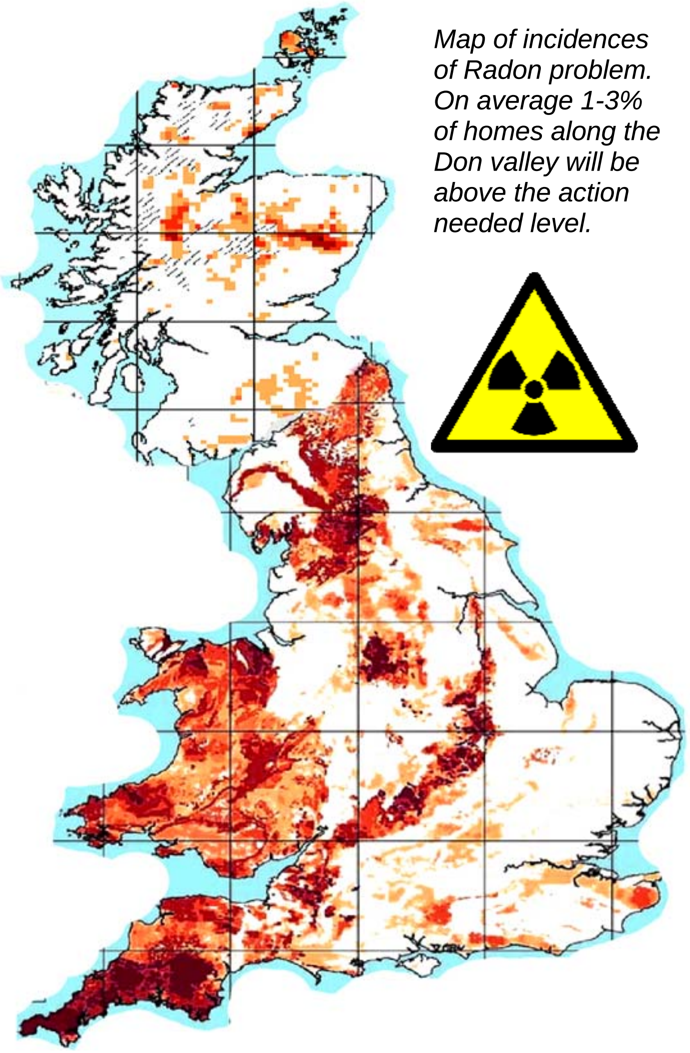


The decay cascade for U238. Each isotope has it's own half life. Uranium is present everywhere in trace amounts. This contributes to the background radiation. Since the start of coal mining, many thousands of tons have been emitted into the atmosphere in smoke.

Most of the radio active decay-products are heavy metals or solids, which allows containment. Radon is a gas, and diffuses out of the ground. It is heavier than air, so tends to pool in mines or cellars.

- Radon increases your risk of lung cancer
- The higher the radon, the longer the exposure, the greater the risk
- Radon causes over 1,100 cases of lung cancer each year in the UK
- Half of these deaths occur among the quarter of the population who are current smokers

Radon produces a radioactive dust in the air we breathe. The dust is trapped in our airways and emits radiation that damages the inside of our lungs. This damage, like the damage caused by smoking, increases our risk of lung cancer. There is no consistent evidence that radon causes cancers elsewhere, or other harm. Have your home's radon levels checked, and if high take steps to reduce it.



Map of incidences of Radon problem. On average 1-3% of homes along the Don valley will be above the action needed level.

The Health Protection agency has advised that indoor radon above an Action Level of 200 Becquerels per cubic metre should be reduced. Most homes in the UK have fairly low radon levels, with an average of about 20 Becquerels per cubic metre. The HPA conducts radon surveys for government departments, local councils, other organisations, and private householders. Small radon detectors can be sent directly to householders by post, and returned at the end of a three month period. Radon causes invisible damage to the plastic inside the detector. This damage can be measured and used to calculate the radon level. The householder is sent the result by letter. There is a Radon measurement service for householders. For a fee you can order a radon detector pack from the www.ukradon.org.uk website. The estimated radon potential for an individual home can also be obtained through the website. The most effective way to deal with radon is to fit a 'radon sump' to a property to vent the gas into the atmosphere. A sump has a pipe connecting a space under a solid floor to the outside. A small electric fan in the pipe continually sucks the radon from under the house and expels it harmlessly to the atmosphere. *To request a pack, please email your name, address and postcode to radon@hpa.org.uk or leave your name, address and postcode on the HPA free radon answer phone (0800 614529).*

From Sheffield ME Groups Spring Newsletter ….

Oh Gimme a Bra, a Comfy Bra Oh gimme a bra, a comfy bra, one I can wear with ease.
A bra that gives mi figure a boost & stops 'em touching me knees.
A bra I can wear cum wind, sun and rain,
One that doesn't keep causing me pain.
The ones I now wear do cause me to swear as they clamp mi poor bones like a vice
So some on mi friends please can you advise and find me a bra I can wear

Is it just me or does anyone else have problems finding a comfy bra? I have Fibromyalgia and some of the worst pain I experience on, a daily basis is in my spine, ribcage and shoulders which worsens when I wear a bra. When I mentioned this to the consultant at the pain clinic his reply was 'Don't wear one then'. Sensible advice really but of course he's a man otherwise I might just have received a little more in the way of sympathy and some understanding that as a woman I need to feel feminine even when in pain. And when you are a little on the large size in the boob department a good bra is even more essential.

A recent visit to M&S to be measured for a new bra filled me with dread and it still failed to solve my problem. Five feet tall, or should that be small, slim shouldered but on the weighty side, I was already in a 42B I'd bought on my last visit earlier this year but I knew I needed a larger size. The total support range is no good to me at all as I feel I am being strapped into a straitjacket. To keep trying on one bra after another only serves to cause me more pain with the assistant pulling and tugging it into place despite me telling her beforehand how tender I am and how painful I find it all. What a wimp she must think I am.

I already wear most of my bras with a bra extender to help lessen the pain but this simply causes the boobs to sag and the shoulder straps to slip off. I've even tried the vests with the hidden support but they don't help at all. Anything that just grips me in the most gentlest of ways becomes incredibly painful after a very short period of time. On my most recent visit the assistant measured me under the bust only and didn't bother with the around the bust measurement.

“You're a 40, you look a D cup” said the assistant.
“No!” said I, “I'm...in a 42 B cup now and it causes me pain, the C cup was too large.”

After expressing her surprise she brought in a selection of 42Cs most of which didn't even go round me properly. She assured me that by going up a cup size it would be larger round the back than the one I came in, resignedly I paid for it and went home. At home, I took it out of the box and laid it against the one I had been wearing: they were exactly the same length! It would still cut into me and cause me pain. There was no extra room in it at all.

I can't be the only one who has this problem of severe to excruciating pain when trying to wear a bra all day. I wear one when I go out but it is the first thing I take off when I get home.

I have this well rehearsed trick of being able to take my bra off without taking my top off! Quite spectacular really, along with the sound effects I produce of pure heavenly relief. Goodness know what the neighbours think if they can hear me.

From Lyn, bra-less and comfortable.

CAN ANYONE OFFER HELPFUL SUGGESTIONS?

Enzyme Potentiated Desensitisation

I *quite often get asked about E.P.D. Usually the questions start when people hit a brick wall with the NHS, and find that they are not getting better, usually 18 months to two years after diagnosis. EPD certainly treats the complications of ME/CFS like allergies and IBS. I also think it does have some disease modulatory effect for ME/CFS for 8-10 weeks after each treatment. It is not a cure, more a control treatment. The expert for ME/CFS is Dr. Myhill, for further details 01547 550331.* Here are the basic details on E.P.D.

What does it treat? Rhinitis, Sinusitis, Asthma, Eczema, Urticaria, Migraine, Chronic Headaches Irritable Bowel Syndrome, Ulcerative Colitis, ME/CFS & Chronic Fatigue, Arthritis, Hyperactivity, Food and Chemical Allergies.

What is E.P.D? Enzyme Potentiated Desensitization is used to treat allergies and intolerances to inhalants, foods and chemicals. The treatment uses very small doses of the things that you are allergic to (allergens) and alters the body's response to them. The method was developed by Dr. Len McEwen in the 1960s, initially to treat hay fever. Since then he discovered it worked for other types of allergy.

How Does It Work? Allergies can be treated by using "classical desensitization" where small amounts of specific allergens are injected. This treatment is only available in some hospitals and is potentially dangerous. E.P.D. is very safe since only minute quantities of the allergens are used. An enzyme (which is naturally occurring in the body) is mixed with the allergen and this enhances the desensitizing effect. An E.P.D. injection contains a mixture of allergens, so more than one allergy/ intolerance can be treated at once. It is not always necessary to know exactly what you are allergic to and allergy testing is usually not necessary.

What Happens? You will have an initial consultation to assess your suitability for E.P.D. Treatment involves a fine needle injection into the skin of the forearm. This only takes a few moments but you will need to stay at the clinic for about 30 minutes afterwards. Breathing tests (peak flow) are carried out before and after treatment. You can then carry out your normal everyday activities.

How Many Treatments? For hay fever and other simple allergies only one or two E.P.D. injections may be needed. More complex allergies may require several treatments repeated at three monthly intervals.

Is Anything Else Involved? Diet is important when treating food intolerances and it will be necessary to restrict certain foods around treatments. Some allergens may have to be avoided for a few days before and after treatments. Vitamin and mineral supplements will also be prescribed according to your needs.

Who Can Have E.P.D.? Anyone can have E.P.D. including children. You cannot have E.P.D. if you are pregnant of suffering from an acute infection.

Who Uses E.P.D.? Only medically qualified doctors, who have trained in this specialised technique, can carry out this treatment. It is not available on the NHS in Doncaster, but available in other parts of the country by postcode lottery. Each treatment costs about £100. The two nearest private clinics are:

Dr. Sheena Roper, Sheffield Clinic of Complementary Medicine, 378 Ecclesall Road Sheffield S11 8PJ. 0114 2680236. (Dr Roper is an allergist, and not an ME/CFS expert)
Dr. Damien Downing M.B. B.S., (Nutrition Associates Ltd, Galtres House, Lysander Close, York, YO30 4XB 01904 691591. (Dr. Downing offers the full range of ME/CFS support services).
If you are prepared to make a long journey to rural South Wales:
Dr Sarah Myhill, Upper Weston, Llangunllo, Knighton, Powys, LD7 1SL, Wales 01547 550331.

North of Doncaster *Personal comment by Trevor Wainwright*

Recent Panorama programme: A Visiting Martian's Report.

I had been observing the humans only for a short time, along with my fellow agents, I was given the part of Earth they call the UK. They had sent probes to my home planet, Mars, they had yet to discover us, we were good at concealment, we had to be, and our past history had proved that. My cloaking-device made it easy for me to move among them, almost like one of their ghosts, in a dimension that made me unnoticeable. I had found the humans a strange but interesting species as if at times they were as two tribes, one trying to destroy their planet, one trying to save it. I wondered if this came from their sport where there were times when there were either two combatants or two tribes of combatants, to two differing groups of watchers, each cheering their choice of combatants.

There had recently been something in their news which again had brought about the two tribe conflict. Their newspapers had carried stories of one of their females who had helped a younger female end her life force. She had been made to account to a people's court for what she had done, but some had said she had done what the younger female had wanted. I had thought it strange how someone would want to deliberately stop their life force. I had noticed that the humans did it to their animals for food, but why to one of their own kind whom they would not eat. I also noticed that when one of their animals was ill the animal would have its life force ended, often this would cause much grief to the humans but they would say the animal was in a better place and out of pain. I wondered if this was so with the young female. I was determined to find out, my elders back on Mars had said as such.

The young female had been called Lynn, the older female had been her mother, she was called Kay, and I couldn't help but think why a mother would do such a thing. I had seen the bond between some human mothers and their children; this made it all the more puzzling. The stories in the newspapers said Lynn had some condition that affected the parts of the body responsible for maintaining the life force of the humans, I heard the term ME. Some humans said it was all imagined, others said it was real and devastating, and apparently there were more stories where people had ended their own life force. But this was the first time anyone had been taken to the people's court over it. I needed to know why.

Their newspapers carried conflicting stories; again it was the two tribe's syndrome as it split the human's opinion. Some said it was wrong, others said Kay was brave to do what she did. I was puzzled as to how best find out. I had seen pictures of Kay and other members of her family as the people at the court in judgement of Kay had found she had done nothing wrong. There was a comment from the male in charge, the Judge he was called, and he had called the people sensible, but had made a condition to Kay's freedom.

I found out that there was to be a programme on one of their communication systems a box that sat in the corner of a room or was fixed to the wall "the telly" it was called. Their communications systems were not as advanced as we were but getting there. My cloaking device switched on I made my way to a gathering of humans who were going to watch the programme.

The programme started, still images first and voices, a mans voice first he called himself Jeremy then a question "what happened the night she died". A second voice, a female, I guessed it was Kay's and it was. There appeared an image of her standing in a room with the man called Jeremy. Kay said they never used the room it is just Lynn's room, as they were looking at an empty bed beyond which were long window which led to a green area on which were chairs, no doubt Lynn would have sat in them at one time, as humans liked to do when their weather was warm. Kay was talking about Lynn's last hours. There then followed an image of Kay and Lynn, Lynn on the bed with a tube going into her nose, I thought it was to help her breathe, later I would learn it was how she was fed. Kay attending to her both were smiling, looking closely I could see the emotion the humans call, love in their eyes.

A picture of Lynn on her own followed, yes she was very pretty, why did it have to happen I thought as in the background Kay was talking saying why what was done had to be done. Kay was obviously in some mental pain her eyes gave this away; humans are capable of saying so much without words just by the eyes. Kay was then talking about Lynn about her growing up. The programme changed to show what Lynn's dwelling was. I noticed the emotion of sadness on the faces of those watching as a male and female talked, this was something very relevant and important, no one spoke, which was unusual as often "the telly" was a source of great debate.

On it they were talking about one of their kind who had a strange condition which meant she was confined to a small cell. It was some condition that affected the parts of the body responsible for maintaining the life force of the humans, I heard the term ME. The female spoke to the male in a slow voice something about her face said she too was feeling sadness; it seemed she had lost someone she had felt the emotion love for. It seemed hard for the man talking to her to actually look her in the face as if he was sharing the sadness, as he spoke gently to her, asking her questions. Images would appear on the screen of a human female in a prone position with some form of equipment around her, a tube going to a hole in her face, which I later found out was how she was fed. It was obvious that the thing ME was serious. Further moving images of the young female being very active in time past proved this.

The scene then went to outside and people were talking about the female; they obviously knew and felt the emotion they call love for her. They were near violently-moving water which covered two thirds of the planet. It was as if they were making plans for her but on watching, I deduced they were talking about what was in the past. The male humans voice faltered, a strange sound came from his throat, then he was talking again. A younger male was also talking; he like the other male appeared to be part of the family unit, he talked about their hopes and how they had played together. It was obvious through the sadness there had been some joy at some time. But that the hopes were now gone because of the ME condition.

Then it came to me, the female had helped the younger female to end her life force at the younger females request, as she said that many of her life force functions were beyond repair including the ability to bear future generations, some thing I noticed a lot of female humans looked forward to. Now she was being punished for what she saw as obeying the young female's wishes. There was a male talking. He was standing outside a building; he seemed to think himself important. It was one of those that had decided that the female should be punished and stand trial. I saw one human whisper something to another referring to the man as part of the human body. They obviously didn't like him. The woman was travelling and meeting other people, she met a male with wheeled mobility who said it would be his choice against ending his life force should he decide. A female in the same situation said on no account should human life force be ended.

I continued to watch as other humans got together, one group celebrated the life force of the young female before it ended. Another group sold her possessions to help others, this was I thought a good act, she no longer had need of them. There appeared a female with a child who said she named it after the young female, I caught the name Lynn. As the programme ended I noticed some of the humans that had been watching had tears on their faces, common among humans at such times but also in happy times when they are called tears of joy.

I slipped away to go back to my craft where I would prepare my report thinking I had much more to learn about the humans and they too had much more to learn about themselves and the condition known as ME. It had been obvious that there had been disbelief by those in power who were called upon to help. This was what one of the humans said as the programme finished, "They probably have more chance of finding life on Mars than getting help". How right he could have been.

They did not seem to have anyone to champion their cause, I did hear of someone who had once raced motorbikes in their arenas of sport before falling ill himself. He had, despite the illness and at great cost to his own health, travelled to promote ME. It was said he was good at it and that he even arranged to be on the telly and was watched by many who lauded is work. Bu there were many other organisations who ignored it, it seemed a shame as he had done similar again, this time it went global, again no progress was made, eventually he would suffer disillusionment and stop this work.