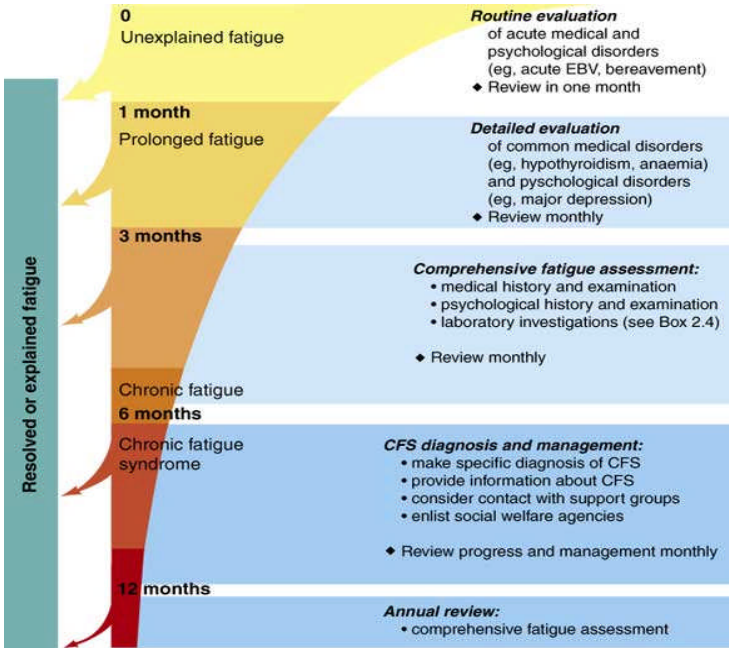
Price £ 2.00 (Free to members)

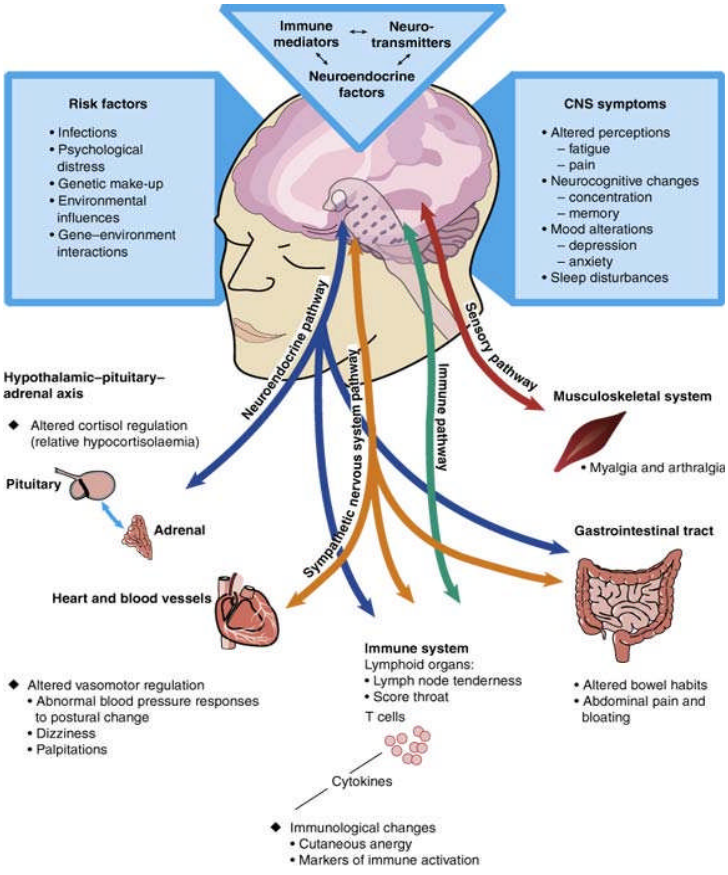
Pathways

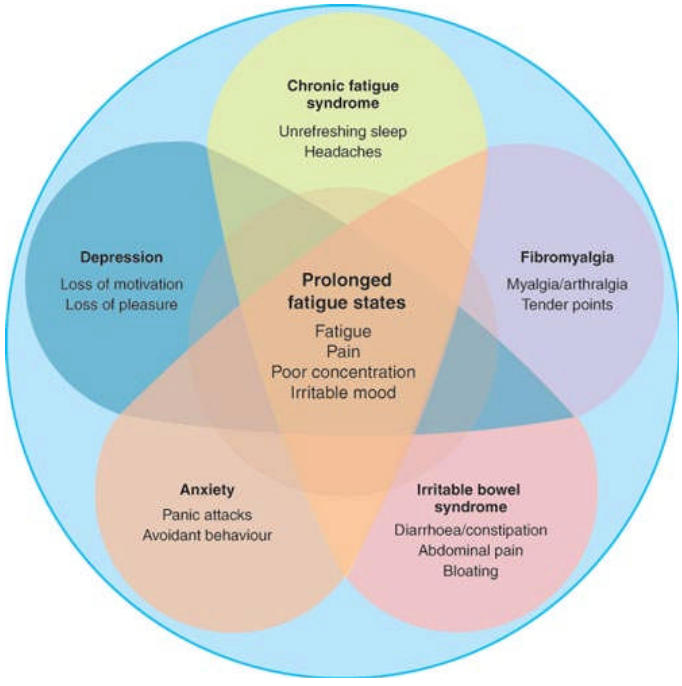
The newsletter of Leger M.E. Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Sheffield CFS/ME Clinic-Access Officially Extended to Doncaster

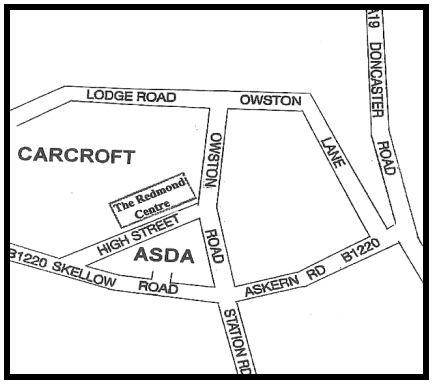
As from 1st April, Doncaster G.P.s may now freely refer their patients to the Sheffield CFS/ME clinic. Ann Nichol from The Sheffield ME/CFS Clinic gives a lecture to D.R.I. doctors (see page 8) The approach the clinic is using is based on the Australian Guidelines. We have reproduced below slides from the lecture about the Australian guidelines . However, the M.E. Association would like to see the Canadian guidelines used. (see page 6).







Leger ME Members' Announcements



The Redmond Centre High Street
Carcroft Doncaster DN6 DN
Tel: (01302) 724501

Leger ME Meetings. ***(****4th Friday in month Redmond Centre 1.00pm)*
28th July. Welfare Rights Clinic Drop in.
25th August. Linking-Up. Summer Meeting Drop in.
22nd September. Annual General Meeting.

Redmond Centre Community Group Events
July 6th 6.00-9.00 pm Therapy Evening.
8th August 10.00 a.m. -12.00 Coffee Morning.
15th September 6.30 - 8.30 pm Beetle Drive Pie & Pea supper.

Subscriptions. As a result of the resolution at the last AGM, the financial year will run from the end of April instead of September. Members who paid subscriptions in September will only need to pay £3.50 for the half year until the end of March 2007 to keep their subscription current.

March Members Survey. To date 30 members have submitted forms. We will produce a full report for the Summer newsletter. Please post yours on if you haven't already done so.

Helpline. Following malicious calls being received, anyone who withholds their telephone number will be automatically routed to an answering machine. We will of course ring back providing a message is left.

New C.V.S. Welfare Service A service provided by Liz Pennington has been launched which has access funding to help with legal issues. I have referred several members with DLA issues. I will feature this in a future issue of Pathways.

Pathways by email. Some groups are emailing their newsletters with significant cost savings. If anyone would prefer to received their pathways by email, please let me know.

Clouds Counselling Service. In order to provide the service we need a minimum of £1,500, mainly to cover the various registration fees and insurance. It is becoming quite clear that a specific ME/CFS service will not attract the necessary funding. From meetings that we have already had with CVS and the PCT, it is quite clear that other illness support groups require a similar service. There is no point in starting a service provided by a single funder or grant, because once the money runs out, the service would have to stop. We have therefore decided that Clouds will be a separate organisation to which we can refer people. This option is more attractive for CVS and the PCT. I have written to the press asking for interested parties to contact me. Discussions are ongoing. More in the next *Pathways*.

WHAT CAN COUNSELLING OFFER YOU?

The Clouds counselling service will provide Professional one to one support. This is available to all who may be experiencing difficulties. Sometimes it may be difficult to talk to families and friends about personal problems. Counselling allows you to speak to someone you have not met before and who will listen sympathetically. Counselling may help you to make more sense of things, which have previously seemed confusing.

Counselling is not about giving you advice, making judgments about your life or telling you what you should do. Counselling can be useful when facing difficulties at work, facing relationship problems, feeling isolated and down, coping with bereavement and coping with medical conditions.

Counselling is a process which helps sharing, understanding, enabling, listening, trusting, encouragement, support and empowering.

Sometimes people find they feel uneasy about using a counselling service at first, because they often think that somebody else wouldn't find their problem important enough and also have a fear of being judged. Clouds Counselling Service believes that all problems are important, and any issues will be given considerate and sensitive action. We are not here to judge. The Clouds Counselling Service is here to help. We are happy to answer any queries that you may have.

The Linking Up Service

Linking Up has now been running for well over a year and it is good that we now have 27 members. The latest 'Update' of *Linking Up* will be sent out to you all, under separate cover, very shortly after you receive this edition of *Pathways*. If anyone has any ideas on how we could add to, or improve, the Linking Up service we would be pleased to hear from you. In fact, if you have any comments at all about *Linking Up*, let us know.

See page 3 for details of the Linking Up Summer meeting.

Either contact Mike on 01302-787353, or Carolyn, *Linking Up* Coordinator, on 01204(Bolton)-495727
email:- carobee@btinternet.com

British Gas Winter Rebates.

British Gas is offering a Winter Rebate scheme to their customers receiving a certain benefits. Households buying Gas and/or Electricity from British Gas, where someone in the house is receiving certain benefits are eligible for the following rebates:

Gas - £60 a year paid in two instalments - ;30 in the last quarters bill in 2006 and the first quarters bill in 2007.

Electricity £30 a year paid in two instalments - £30 in the last quarters bill in 2006 and the first quarters bill in 2007.

Families need to phone 0845 601 2006 and have their British Gas and/or British Gas Electricity account numbers available. Registration is simple and effective for autumn 2006. There is a short registration period so people need to register as soon as possible.

Benefits List for eligibility:
Disability Living Allowance, Housing Benefit, Carers Allowance, Income Support, Child Tax Credits, Income based JSA, Working Tax Credits, Pension Credit, Incapacity Benefit, Attendance Allowance, Severe Disability Allowance, War Disablement Allowance, Council Tax Benefit, and War Pension.

P.S. NPower have a similar scheme. So may other suppliers. Ask! Mike.

Salmon Steaks with Muscadet, Watercress and Dill Potatoes

Preparation time less than 30 mins, Cooking time 10 to 30 mins. Serves 4

Ingredients

750g/ 1½ lb potatoes

1 small bunch dill

fresh salmon steaks
75g/ 3 oz unsalted butter
4 salmon steaks, each weighing about 200g/ 7 oz
50 ml / 2f1 oz Muscadet or other dry white wine
120 ml/ 4f1 oz fish stock or chicken stock
1 tbsp fresh parsley, chopped
75g/ 3 oz watercress
25 ml/ 1 fl oz virgin olive oil
1 tsp white wine vinegar
sea salt and freshly ground black pepper

Method

1. Cut the potatoes into long, triangular finger-length pieces. Place in a pan with the dill (keeping a few sprigs to garnish) and simmer gently in salted water.

2.
Clarify 25g/ 1 oz of the butter by melting it gently in a small pan then leaving it for 4-5 minutes until the solids fall to the bottom. Pour the clear butter off into the frying pan. Season the salmon steaks with salt and pepper. Heat the clarified butter then add the salmon and brown on both sides. Remove the pan from the heat and leave for 30 seconds. Pour over the wine, place the pan in the oven and cook for about 5 minutes.

3. Remove the salmon steaks from the pan and keep warm while you make the sauce. Pour the stock into the pan, bring to the boil and add the remaining butter. Boil rapidly to reduce the volume by half, then add the parsley.

4. Arrange the salmon, watercress and the potatoes on four warmed plates. Mix together the olive oil, wine vinegar and ½ tsp of salt, and spoon over the watercress. Pour the sauce over. the fish and serve.

You write

Michele writes: "Just received letter from DWP to say that I have passed the medical to continue getting Incapacity Benefit so am feeling very happy & relieved! Thank you so much again for your help in completing the form and the guidance in Pathways was invaluable".

We are pleased to be of service! For the information of new readers, we have produced a CD ROM which contains all our leaflets, past pathways issues and much other useful information price £1.

Yvonne Writes: Just read Dr. Myhill's latest hand out. 'CFS is Heart Failure Secondary to Mitochondrial Malfunction'. I have just got out of hospital (as I was 'presenting' with the symptoms of a stroke. I had a CT scan but nothing showed up. The doctor said that I was a 'mystery' but that he knew that there was 'something' wrong. I am now waiting for an appointment to see a neurologist. I was rushed into hospital four times the year before last. They said that I was having a stroke or a heart attack. I was given all the usual heart/stroke medications to which I reacted very badly. On the usual tests nothing showed up but I was given the diagnosis of Syndrome X. Dr. Myhill's paper explains everything that's happened to me and I intend to have the Mitochondrial tests done as soon as possible.

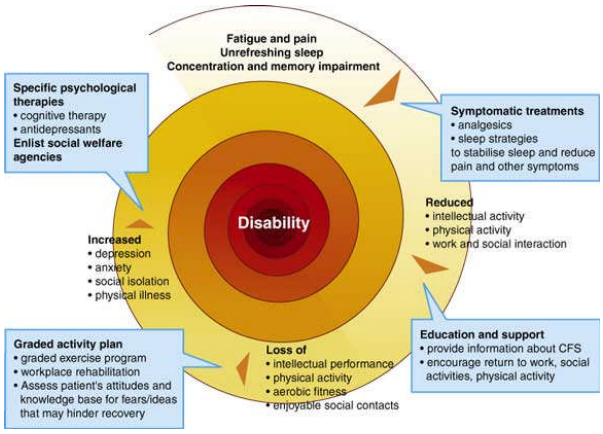
It is well known that some patients are admitted displaying symptoms of a stroke or heart attack, but turn out to have 'nothing wrong'. However emergency staff have to err on the side of caution. The heart is a bag of specialised muscle and nerve tissue which can be affected by M.E. Perhaps Syndrome X is part of ME/CFS symptomology ?

Heart-muscle cells are rich in mitochondria and if there are any abnormalities, this will affect the heart. The tests are offered by private doctors treating ME and are expensive. A number of members have had these tests done. Only one has come back without any glaring abnormalities and this is borderline. For many members, it is the first time they've seen something on paper that proves they have a real physical abnormality. As these tests are new, expertise in interpretation is limited. However, the tests do point to possible treatments and it will be interesting to see what the outcomes are given time. One member took a copy of these tests to an ICB medical and they were pivotal in the DWP doctor deciding to award our member ICB for life. I have spoken to Dr. Myhill. These tests have been developed in the private sector, and some doctors are concerned that they haven't been given the high level of scrutiny that would happen if the development were NHS-led. There is some resentment within conservative medical circles which is causing problems with acceptance by the medical journals and some local G.P.s I think this is a remnant of the culture of disbelief prior to the CMO's report. Personally, I didn't start to improve until I used private sector treatments. With my healthcare background, I'm in a position to make a judgment. I've had these tests done myself. This has led to a treatment that has been around on pharmacy shelves for years and it has backed off my ME around 25% . NHS please take note.

Isabel Writes: Thank you very much for sorting out my DLA. I wonder if you can help me get my Barclays Bank pension released. I became ill in 1992, and in 1994 they terminated my employment. The whole issue revolves around their medical adviser refusing to entertain the concept of permanent disablement in someone in their mid 30's. I'm sending you copies of case papers.

The last things Banks do is give away money. Awarding an occupational pension to someone in their 30's confers a liability on the scheme for 40–50 years as opposed to the 10-20 years for retirement at 65. Given the current climate of over-commitment of occupational pension funds, there will be even greater reluctance for future claims on this nature. Is it appropriate to write someone off healthwise in their mid 30's as opposed to near retirement age ? Conversely, you have paid into a scheme for retirement, from my point of view Barclays have unfairly deprived you of your money, because it is needed now and there is no guarantee that you will get better. You may not live until 65 to claim your pension. We will of course look into the issue and do what we can. Have any other Pathways readers encountered similar problems with Barclays or any other pension scheme ???

Chris writes: I have had ME/CFS for 15 years. Having heard about (*apparent -ed)* miraculous results and recovery using Inverse Therapy, I tried to get information. The therapists were evasive, and said that the only way to find out would be to give it a try. I booked three two hour sessions for £500 and had to sign a declaration of secrecy. Firstly there was discussion about the circle of disability. The whole process is based on stopping negative thoughts from my past. This involved me walking around room bursting balloons with a hat pin attached to sheets of paper displaying negative thoughts, to try to think positively. After two one hour sessions I was abandoned by the therapist because it didn't work. It worked for other people, and it was my fault it didn't work, because I wasn't doing it properly. My telephone calls to the therapists were not answered. I feel that I've been duped!



The circle of despair used by Inverse Therapists

*No treatment is guaranteed to work. Your story is similar to several I've heard. There is a fashion for '********' Therapies at present, some claiming miraculous results. If someone had a misdiagnosis having psychosomatic disorder or had recovered from ME, then Inverse Therapy apparently would work by giving a good dose of self confidence. However, ME/CFS is a physical illness, and until that problem is treated people will not get better. I spoke to Sally, who is a trained psychologist. She told me that these therapies are based on the 'rewind technique', a strategy of thought manipulation used for many years by qualified counsellors and packaged to look attractive. What is worrying is that I've heard of people remortgaging their homes or borrowing large sums of money they can ill afford, to pay these therapists. Apart from the financial aspect, I am aware of one case from a therapist that caused a patient to be scheduled and admitted to a psychiatric hospital against her will after she had paid out £6,000. What is even more of a concern is at least one local G.P. is advocating Inverse Therapy.*

If anyone feels that they wish to try a complementary or alternative therapy, they should firstly discuss it with their G.P. who will usually recommend someone. A responsible therapist will first take a full medical history prior to making an assessment and offering treatment. Usually the therapist will inform the G.P. of their intentions before proceeding. At that point any costs should be fully explained and discussed. A reasonable charge might be £30—£90 per hour. The therapist will usually have professional indemnity insurance and be registered with the appropriate professional body. The problem is that at present only Osteopaths and Chiropractors have the same level of professional scrutiny as doctors and other health professionals. There are proposals to bring other therapists into line in the future. For some therapies, there are many professional associations. In the case of Aromatherapy, there are five. A report on Complementary and Alternative Medicine (CAM) by the House of Lords Select Committee on Science and Technology in 2001 defined CAM according to three categories, based on a combination of evidence, use and regulation. Other classifications of what is included within the term complementary and alternative therapies and/or medicines also exist - see, for example, the listing provided by the Institute for Complementary Medicine (website: www.icmedicine.co.uk)

Group	Status	Therapy Examples
I	Individual diagnostic approach, well developed self-regulation of practitioners.	Acupuncture, Chiropractic, Herbal medicine, Homeopathy, Osteopathy
II	Therapies which do not purport to embrace diagnostic skills and which are not regulated.	Alexander technique, Aromatherapy, Flower remedies, Hypnotherapy, Massage Meditation, Reflexology, Spiritual healing, Nutritional medicine, Yoga, Shiatsu.
IIIa	Long-established but indifferent to conventional scientific principles	Anthroposophical medicine, Ayurvedic medicine, Chinese herbal medicine, Eastern medicine Naturopathy, Traditional Chinese medicine
IIIb	Lack any credible evidence base	Crystal therapy, Dowsing, Iridology, Kinesiology, & Radionics.

ME Politics: The Canadian Clinical Guidelines for ME/CFS

comment by Jacqui Footman of the M.E. Association.

At the beginning of the year, The ME Association acting on a democratic members' vote became the latest national ME charity to adopt the Canadian Clinical Guidelines as the basis for its ME campaign work. Leading the debate in favour of adoption was MEA member JACQUI FOOTMAN who writes about what drove her to take a leading role in the internal discussion.

Why we should unite behind Canada

Since discovering the Canadian Clinical Guidelines in 2003, I have felt they have made such a positive difference to me personally on my own ME path that they should have much wider circulation so that people with ME could share such positive effects. I have written many times to politicians and doctors to try to help bring this about. I must urge anyone with ME, or who cares for someone with ME, who has the resources to do so, to read for themselves the 109-page original paper, published in *The Journal of CFS* in 2003, entitled "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols" and available online at www.mefmaction.net/documents/journal.pdf. If that is too long, try to read at least the first 20 pages of the Overview, written by two main authors of the original document and published last year. This is available for downloading online as a pdf at http://eastanglia.me.uk/Canadian.aspx

Diagnosis

I first read the CCGs in November 2003. I had in August 2003 been given a tentative diagnosis and had read all the usual books and information packs. As is often the case, however, there remained odd doubts, especially as my ME had a gradual onset. Having read the three-page definition/ diagnostic chart in the first section of these new clinical guidelines, and sensed the authority with which it was written *(the introduction states that the consensus panel of authors had between them diagnosed and/or treated over 20,000 patients with ME/CFS),* I no longer had any doubts that this was what I had, and experienced a great sense of relief from feeling secure in that knowledge. I printed a copy to show my GP and, from this point on, we had a shared confidence in his original tentative diagnosis.

The importance of this sort of confidence cannot be underestimated. Subsequently, others joining my local South Molton group in North Devon have been able similarly to benefit from this particularly clearly formatted clinical working definition. Put this in the context of research published in the influential journal *Family Practice* in August 2005 which told us that only 59% of GPs are confident about diagnosing ME/CFS, 52% about treating ME/CFS and a mere 12% enjoy working with ME/ CFS patients. You don't have to be a doctor or health professional to know that, if you are not given the proper tools for the job, you are unlikely to particularly enjoy dealing with that task unless you are that rare person who gets a real buzz from solving overwhelming challenges. So we needn't be surprised at these figures. But where does that leave the patients? In around 50% of cases, still without effective help and support from their GP.

Because things went relatively smoothly for me personally in terms of obtaining a diagnosis, good management advice and GP support, I was determined to do what I can to help more people with ME benefit from early diagnosis. My objective has been that more GPs have access to these useful diagnostic guidelines. I am not alone in this idea. In Southern Australia, the Health Department has circulated to GPs a 17-page document based on the Canadian document. And, in the UK, the East Anglian ME Patient Partnership has obtained several thousand copies of the Overview for circulation to doctors via people with ME. These copies carry on their back cover the endorsement of two NHS M.E. specialists, Dr Terry Mitchell and Professor Leslie Findlay. Dr Mitchell, CNCC Coordinator for East Anglia, has felt it important enough to use some of his education budget to distribute printed copies to all primary health care practices in Norfolk, Suffolk and Cambridgeshire. The Overview will also be provided to patients who receive a referral to his clinic. The Irish M.E. Society has sent

some 2,600 copies out to doctors in Ireland, and in North and East Devon local M.E. groups have, in partnership with their LMDT, mailed copies to all GP practices in their area to mark M.E. Awareness Week.

A number of national UK charities including the Tymes Trust and The ME Association have now also adopted the CCGs as a basis for their working practice. Personally, I would like to see the ME Alliance here request our Department of Health to send out this diagnostic guidance to all GPs. It is all very well for the Department of Health to sit back comfortably saying they have instructed NICE to produce guidance but this will not be ready until next year at least, by which time an estimated further 25,000 people will have gone down with ME/CFS and will have taken their chances in getting recognition and diagnosis from their GPs.

Treatment

The Canadian document is very detailed about treatment. I quote here, for instance their important caution on the use of exercise/rehabilitation programmes (p46):

"Externally imposed programme may not respect the patients' autonomy and impede self-direction. Most patients are well motivated to improve their condition and have lost much more than they could possibly ever gain by becoming ill. We must be very careful concerning any program that presupposes that patients are merely wrong-headed about their illness and activity limits."

There is also revealing information in the summary paragraph that discusses CBT/GET (p49):

"The question arises whether a formal CBT or GET program adds anything to what is available in the ordinary medical setting. A well informed physician empowers the patient by respecting their experiences, counsels the patients in coping strategies, and helps them achieve optimal exercise and activity levels within their limits in a common sense, non-ideological manner, which is not tied to deadlines or other hidden agenda."

The overview document goes one step further, suggesting that the term 'CBT' be entirely replaced by 'SHS', Self Help Strategies, where treatment of ME/CFS is concerned. This leads me to think that the expert authors of this document might also ask why the Medical Research Council is wasting so much of its research budget on the PACE and FINE trials.

Conclusion

I believe that the international ME community should unite in accepting the Canadian definition and protocols for immediate use of the education of health professionals worldwide. Let's get on with it!

Gooseberry Fool

Preparation 30 mins to 1 hour
Cooking time 10-30 mins
Serves 4-6

Ingredients

450g/1 oz elderflower cordial

For the custard:-

2 egg yolks
1 tsp arrowroot
150ml/5 fl oz milk
30g/1 oz sugar
150ml/5 fl oz double cream or, fromage fraiche.
fresh elderflowers to decorate

Method

1. Top and tail the gooseberries. Put them into a pan with the elderflower cordial. Bring up to the boil and then simmer gently until soft and pulpy. Leave to go cold, and then place in a serving dish.

2. **Make the custard**
Heat the milk up in a pan to the point of boiling. Beat the egg yolks, arrowroot and sugar together in a jug and pour the hot milk into the jug. Mix well and then return to the pan. Heat gently until the custard thickens, but do not boil. Strain into a clean bowl and cool.

3. Whip the cream to the same consistency of the gooseberries.

4. Gently stir the cream into the gooseberries and then fold in the custard. Try to give it a marbled effect in the serving bowl. Place a few elderflowers on top to decorate.

The Sheffield NHS ME/CFS Clinic

based on a Lecture given at DRI by Anne Nichol, Clinical Services Coordinator for South Yorkshire and North Derbyshire at DRI on 17/3/2006, to around 45 doctors.

Background

In the past, CFS/ME patients have been given labels e.g. Yuppie flu, wasters, malingerers, lazy shirkers and 'all about ME ME ME'. However *CFS/ME is "A complex and debilitating chronic illness, characterised by abnormal levels of overwhelming and debilitating fatigue".*

- "CFS" is a descriptive term used to define a recognisable pattern of symptoms that cannot be attributed to any alternative condition.
- The symptoms are currently believed to be the result of disturbed brain function, but the underlying pathophysiology is not known.
- Therefore CFS cannot be defined as a specific entity at present. Indeed, there is growing evidence the disorder is heterogeneous, and it will be found to have no single or simple aetiology.
- CFS/ME has been around for a long time under different guises.

The landmark came with the Chief Medical officers report in 2002, National funding and the CMO Working Party. Reference: http://www.doh.gov.uk/cmo/publications.htm

- "CFS/ME is a relatively common clinical condition, which can cause profound, often prolonged, illness and disability, and can have a very substantial impact on the individual and the family."
- "Patients and carers often encounter a lack of understanding from healthcare professionals associated with inadequate awareness and understanding of the Illness."
- National Funding.

The Impact of CFS/ME in Young People is massive. It is the largest reason for absence from school. The mean time out of school is 1 year, 33% of children obtain no qualifications and 57% of children are bedridden at some stage. Other issues relate to parental time off work, impact on other siblings and relationship factors. For a ME/CFS sufferer there are often problems due to over protectiveness, problems with family roles and rigid belief systems leading to over optimistic expectations. Socially problems come with the lost of contact with social group, withdrawal from regular activities and peer relationship problems

We estimate population prevalence as 0.2-0.4% for adults 0.05-0 1 % for children.. A general practice of 10,000 patients likely to have 20-40 adult patients and 1 child with CFS/ME. for South Yorkshire and North Derbyshire population 156 million, we would expect 3,000-6000 adults and 700-1500 children patients. Half of these may require specialist input. ME/CFS can occur at any age, most commonly early 20's to mid 40's and in children the peak age is 13 to 15. It seems to be more common in women and affects all social classes and ethnic groups.

Diagnosis

'If you have to prove you are ill, you can't get well', Hadler 1996

Characteristics of CFS/ME are post-exertional fatigue not alleviated by rest, fatigue of new/definite onset, sore throat, post exertional malaise, memory and concentration problems, unrefreshing sleep, headache, pain and abnormal sensitivity to various stimuli. The Characteristic Clinical Entity is disabling fatigue that is NOT due to exertion and NOT relieved by rest. There are delayed setbacks after increased physical or mental activity. Although there is no validated diagnostic test, a firm or even provisional diagnosis of CFS is an essential first step in active management. A positive diagnosis should be made based on the pattern recognition of the characteristic symptoms. Alternative diagnoses must be excluded by taking a careful history and physical examination and relevant investigations. Diagnosis can only be confirmed by recognising the presence of a

characteristic set of symptoms together with the exclusion of alternative diagnoses.
The following reinvestigations are recommended and should be considered as a matter of routine: Full blood count and film, erythrocyte sedimentation rate and C-reactive protein. Blood chemistry including urea electrolytes & calcium, creatinine kinase. plasma glucose, serum calcium and phosphate, Liver function tests, thyroid function tests. Coeliac antibodies and Urinalysis. For a Differential Diagnosis the following should be considered

Minimum Symptom Prevalence in Symptom Syndromes

Symptom	CFS	Fibromyalgia	Multiple Chemical Sensitivity	Depression
Fatigue	100%	85%	90%	77%
Arthralgia	80%	94%	63%	78%
Headache	35%	45%	63%	78%
Sleep	80%	60%	60%	65%
Depressed	50%	35%	67%	90%
Gastro Intestinal	60%	35%		50%

Adrenal insufficiency	Primary sleep disorder, including Obstructive Sleep Apnoea
Neurological conditions e.g. multiple sclerosis or myasthenia gravis	Psychiatric and mental health disease problems including anxiety and depression
Chronic infection e.g. Lyme disease	Rheumatic diseases
Coeliac disease	Somatisation disorder
Eating disorders including obesity	Substance misuse including alcohol
Hypertension	Thyroid disease
Immunodeficiency	Testosterone deficiency
Malignancy	Travel and tropical diseases
Medication side effects	Menopausal symptoms
Anaemia	

Management principles

Aim for a positive diagnosis and engage the patient using a partnership approach to managing fatigue, activity, sleep, drug therapy, and psychosocial issues. CFS/ME can be a long-term and relapsing condition for adults. The recovery rate for children is 54 - 94%. A shorter illness-duration has been shown to be a predictor of sustained remission, highlighting the importance of early detection and early intervention. Lifestyle management, pacing, graded activity, and cognitive behavioural strategies are the cornerstones of successful management. It is important to work with the patient NOT push through any particular intervention. A baseline which is achievable is needed, which must be individualised, using the toolbox of strategies and techniques for the individual to self-manage. First contact with a patient is very important as many patients will often have had a poor experiences. Individuals are often very well informed, and the therapist has to work with this. Self-management is the long-term goal to re-establish control and enable the patient to learn from experience.

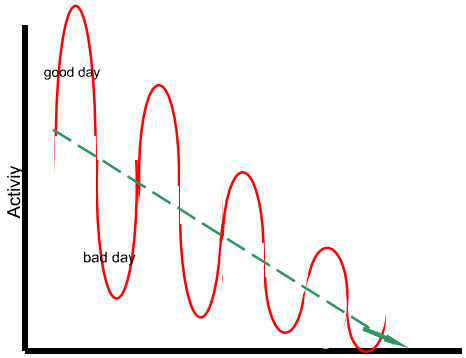
The Sheffield CFS/ME Service

The service has been established to support development of local services, provide training, advice and consultancy, and offer direct clinical work where appropriate. This is achieved through a one-off assessment with a local package of care, telephone support and advice, co-working and a full treatment package with follow-up support. The clinic can be contacted at 621 Middlewood Rd, Sheffield, S6 1 TT. Tel: 0114 2292920

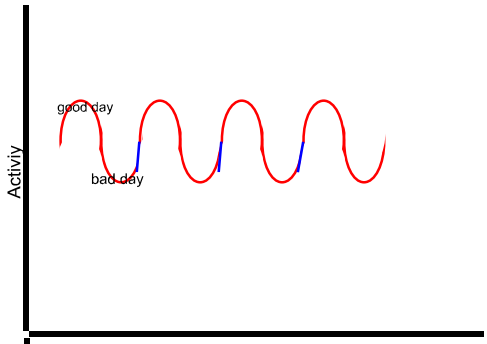
Fairlawns in Middlewood, the home of the Sheffield ME/CFS Clinic

Staff	Adult Team	Child team
Occupational Therapists	1.4 wte	0.7 wte
Clinical Psychologist	1 wte	0.7 wte
Physiotherapist	0.2 wte	
Medical	GP with special interest 0.1 wte	Consultant Paediatrician 0.05 wte
wte = whole time equivalent	*(0.1 wte = half a day a week)*	Staff Grade Paediatrician 0.1 wte

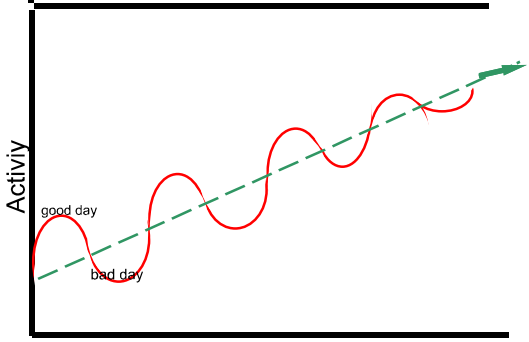
Outcomes of Pacing Strategies



a) Without pacing there is a gradual relapse



b) With when the pacing is balanced the patient is stable



c) When the pacing is working, there is a gradual recovery.

Comment

Over the years I have found that many ME/CFS patients have found out about pacing for themselves. It is a good start for the clinic since pacing is appropriate to almost all cases.

Myself, Liz and other group members have held several consultative meetings with Mark Adams regarding other treatment and management strategies that we would like the clinic to use. A meeting will be held in a few weeks' time to discuss what are best described as 'lifestyle management' issues. This will include dietary matters, use of supplements, complementary and alternative therapies.

Likewise there are welfare and benefits issues which are just as important as treatment and management to ME/CFS patients. In particular, there are issues with school, college employers, and state benefits like DLA and ICB with which the clinic could help. I have raised some issues already on behalf of some members. Again there will be a meeting to discuss these issues later in the summer. Would anyone who wishes to contribute to either of the meetings please contact the helpline. –Mike.

How Leger ME is liaising with the clinic

Myself, Ian, Liz, Sally and Kath have been to the clinic on numerous occasions since 2004 when the first consultation meetings were held. The first patients were seen on a trial basis on early 2005. On the 17th May Sally, myself and some other members attended an open day at Fairlawns. We had a table alongside other groups from the area on which our literature and newsletters were displayed. We had a presentation by members of the clinic staff, which was mainly NHS management issues. Given the NHS cutbacks making the headlines I got the distinct impression that the staff were trying to justify to the powers that be the existence of the clinic. Several of our members have already been involved with the clinic. At the time of writing the service rollout to Doncaster was being implemented. This means that G.P.s in our area can now refer patients to the Sheffield clinic. At the same time access to the Leeds CFS/ME clinic at Seacroft Hospital will no longer be available to new patients. I am monitoring the situation. If anyone has any comments, problems or feedback of any sort, please let me know via the helpline (01302 787353). The next stakeholders meeting is on the 5th July. *Mike*

Massive data-crunch points to basis that ME/CFS fatigue has genetic roots.

by Helen Pearson. News from Punchstock

The largest study yet of chronic-fatigue syndrome (CFS) has revealed a battery of genetic changes that might explain how the mystery disease arises. The condition, sometimes called myalgic encephalomyelitis (ME), causes exhaustion and problems with sleep and memory. It was dubbed 'yuppie flu' when it came to public attention in the 1990s, because of the view that sufferers were simply burned out or that the symptoms were psychosomatic. But although some doctors remain sceptical, many now take the syndrome seriously; it is estimated to affect one million people in the United States alone. But researchers have struggled to find an underlying cause for a disease that weakens the entire body yet has no obvious physical basis.

Researchers at the US Centres for Disease Control and Prevention (CDC) in Atlanta tackled the problem in a new way. They handed four teams of scientists a massive set of information about the symptoms and biology of CFS patients, and challenged them to pull out anything that might explain the disease. One study showed that patients with CFS tend to have a characteristic set of changes in 12 genes that help the body respond to stress. They showed that a particular combination of gene sequences could predict whether a patient had CFS with over 75% accuracy. The teams have now published their results in 14 papers in the journal Pharmacogenomics, producing what they say is the most comprehensive picture of the disease's roots so far. "CFS is a real bodily dysfunction," says Ben Goertzel of Biomind, a biotechnology company based in Rockville, Maryland, who led one of the groups. "The idea that these people are just tired is pretty clearly refuted by this batch of results."

CDC investigators zeroed in on Wichita, Kansas, telephoning residents to assess whether they had symptoms of CFS. They did this, rather than recruit patients from a clinic, because most people with the condition are never diagnosed. The team identified 227 patients and a comparable healthy group, and brought them in for two days of study. The researchers collected information about subjects' sleep, memory, and nervous systems. They also took blood samples and analysed the sequence of a handful of genes implicated in CFS, and the activity of 20,000 more using gene chips. Next, four research teams were tasked with using computer algorithms to sift these data for features of the patients' biology, such as genetic sequences, that matched their symptoms. The CDC called it the CFS Computational Challenge. A similar challenge might help to crack other unfathomable diseases, such as autism, says CDC Director Julie Gerberding: "This approach is likely to work for a number of vexing public-health issues."

The new results fit the existing idea that people develop CFS when events such as infections, injury and trauma disrupt the hypothalamic-pituitary adrenal axis, which is activated by physical and emotional stress. Eventually this has effects throughout the body on the immune and other systems, causing symptoms. The researchers suspect that people with CFS fall into four or five different categories with slightly different conditions. They hope to find a profile of genes and proteins to diagnose CFS and its subtype. This could help to select the best treatment. For now, it's important for different laboratories to repeat these studies, says Leonard Jason, an expert in CFS at DePaul University, Chicago. "It's really the beginning. We're talking decades of work."
ref: Pharmacogenomics, 7. 355 - 501(2006).

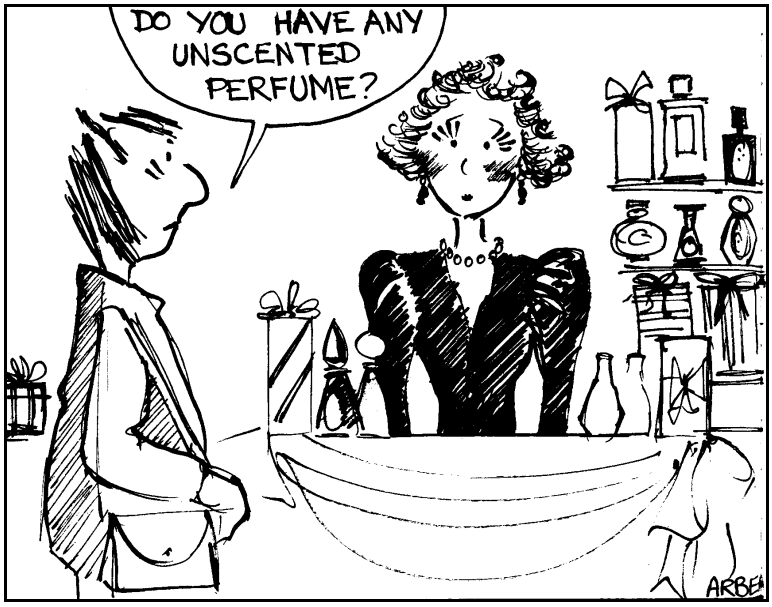
The Hidden Dangers of Perfumed Products ?

Comment by Richard Steel

Society has taken many years to wake up to the dangers of smoking and passive exposure to tobacco smoke. Smoking is now becoming banned in more and more locations. Now, surely it would make sound common sense not to go down the same long road again with dangerous neurotoxic chemicals. You only need to observe cars in the average supermarket car park to see that cigarette packets on the dashboard are now replaced by so called 'Air Fresheners' hanging from the drivers mirror. In the enclosed space of the interior of the motor car with the added benefit of warmth this is the legal intoxication behind the wheel the latest form of glue sniffing for all ages.

People are exposing their children to these so called 'Air Fresheners' despite the fact that exposure to these and other perfumed products is believed to be responsible for the rise in cases of very premature puberty in children. Experiments have been done on mice exposed to 'normal' levels of air freshener in an enclosed space: result, the mice died. What more proof do we need that these products are the latest form of Nerve Gas. Many people's quality and freedom of life is now being restricted by the proliferation of both air fresheners and fabric conditioners. Whilst others are becoming 'Smell Blind' due to exposure and are as a result exposing themselves to ever greater concentrations of the offending chemicals.

EFFECTS TO SENSITIVE PEOPLE: Many shops and offices become impossible to enter. Goods in shops become polluted (food products included) and have to be thrown away due to smelling (or tasting) of perfume. Library books cannot be brought into the home as they have been soaking up the smells like a sponge in the library and in the homes of other borrowers. Enter a smelly shop or office and your clothing becomes polluted in an instant. This contamination will then cause further problems when inhaled in the closed environment of your car. Air Fresheners do not freshen the air they pollute it, they simply mask one smell with another. The only true air freshener is an open window. In a built up area one can walk along a street and get bombarded by the stench of the fabric conditioner coming from washing lines and tumble driers. This can even be noticed in rural areas when driving past an isolated property, the car can become filled with the smell through the air intake. The smell can be moved by the wind considerable distances before dispersing. In the home it can become impossible to get any fresh air into the property. You can be forced to live with windows shut even in the heat of the summer due to the pollution from surrounding houses. People can and become so trapped within their own home that they are forced to sell and move to a more remote location away from other people, as this becomes the only way to gain a supply of natural fresh air.



WHAT HOPE FOR THE FUTURE ?: Air fresheners and fabric conditioners have been around for many years and have not been a problem until recent years because; in the last five to ten years the amount of brands on the market and the types of methods of smell release have proliferated like wild fire. Competition between chemical companies competing for market share has meant stronger and stronger smells in the products. Also consumers have become more and more 'smell blind' or immune to the existing smell levels and therefore require stronger smell levels to be able to even notice the smell. The long term effect on the health of the country is not known, BUT what is known is that more and more peoples lives are becoming affected. Chemicals in these products are bio cumulative, they are forever building up inside us and not being excreted. Chemicals in these products are hormone disrupters. People with M.E / C.F.S. are made worse by exposure. Asthma is epidemic in young children (could it be due to indoor pollution). Road rage - is it chemical intoxication? Most of the population would not dream of glue sniffing or inhaling butane fuel, - yet that is what they are doing, as many of the petrochemicals are the same in air fresheners. Why are these issues not taken seriously by the people in power? What is the cost to the country and the tax-paying public in damage to people's health; visits to G.P. s , visits to consultants within the N.H.S. with symptoms that they cannot relate to. What are the costs in Incapacity Benefit? Should we not have a 'Human Right' to be able to breathe fresh air as unpolluted as possible? Should we be forced to breathe in a cocktail of chemicals as we go about our daily lives? Should many shops, offices, taxi cabs and other forms of transport, public buildings, become places that one cannot enter? The effects of environmental illnesses are already being experienced, how bad must it become before action is taken by the Government to have these products banned ?

ME/CFS and Myasthenia Gravis (M.G.) compared.

adapted from MGA NEWS Winter 2001.

M.G. means 'grave muscle weakness', but now the outlook is not as 'grave' as it once was. It is characterized by weakness and rapid fatigue, drooping eyelids, double vision, difficulty talking, chewing and swallowing, weakness in limbs and respiratory difficulties which is characterized by fluctuating, sometimes fatal, of muscle skeletal weakness. Like with ME/CFS activities taken for granted by most of us become difficult or even impossible at times for myasthenics. Simple things like eating food, lifting arms, speaking to friends or laughing. M.G. affects about one person in every 10,000 in the UK. The disorder can start at any age from childhood onwards and the chance of developing it increases with age. In the younger age group, women are affected about twice as often as men are. However, in later life it is commoner in men than women. The prognosis of myasthenia gravis is good.

Between patients, the disease varies widely in severity and pattern of progression. In the early stages, the weakness can be intermittent. Often the first sign is drooping of the eyelids or double vision. About 15 percent of patients only ever have eye muscle weakness – this is called ocular myasthenia. The others also have more widespread weakness - generalized myasthenia. These patients can develop weakness of the face, swallowing, and chewing muscles, slurring of speech, and weakness of the limbs and neck. In severe cases, weakness of the breathing muscles can occur. Problems with swallowing or coughing can cause choking. Chronic fatigue without weakness is not a feature of myasthenia.

Like many other diseases, M.G. is an autoimmune disease caused by abnormal antibodies carried in the blood stream. Nerves release a chemical called acetylcholine that activates receptors on muscles to trigger contraction. The myasthenia antibodies interfere with this process by binding to specific sites on the surface of the muscles. The commonest antibodies are directed against the muscle acetylcholine receptor. In 75 per cent of patients, the abnormal antibody-production is associated with abnormalities of a gland in the chest called the thymus, which is part of the immune system. About 10 per cent of patients have a tumour of the thymus (a thymoma) that is usually benign. There are very rare genetic abnormalities that cause problems similar to myasthenia gravis. These diseases are called congenital or inherited myasthenias and usually present in infants. In most patients, blood tests can detect the antibodies that cause myasthenia gravis. Electromyography (EMG) is a very sensitive method to assess the changes in muscle electrical activity caused by myasthenia. Sometimes an injection of the drug edrophonium hydrochloride is given (the Tension test), which causes a swift but brief improvement in most patients' muscle weakness. Many patients have a chest CT scan to assess the size and shape of the thymus gland.

Acetylcholine is broken down in the body by enzymes called cholinesterases. This action can be blocked by anticholinesterase drugs such as pyridostigmine. These drugs can control myasthenia in some patients but many others need additional treatment. Surgical removal of the thymus gland (thymectomy) is performed in patients with a thymoma and can also help some other patients, especially those who develop myasthenia before the age of about 45. Drugs such as prednisolone (a steroid) and azathioprine that suppress the immune system are often used in patients with disabling weakness, especially those who do not have, or fail to respond to, thymectomy. When rapid improvement is needed, for example severe weakness causing breathing or swallowing problems, patients can be admitted to hospital for plasma exchange, which removes antibodies from the blood. Another option is an infusion of intravenous immunoglobulin. The benefits of these emergency treatments last only for about six weeks.

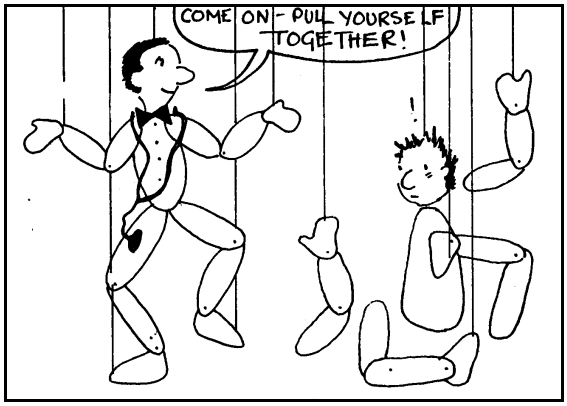
M.G. is a condition which shares many characteristics with ME/CFS. It is one of the conditions that has to be excluded before a diagnosis of ME/CFS can be given. As always, any queries should be addressed to your doctor.

Further information: Myasthenia Gravis Association, Keynes House, Chester Park, Alfreton Road, Derby, DE21 4AS, Tel (helpline): 0800 919 922 Web: www.mgauk.org

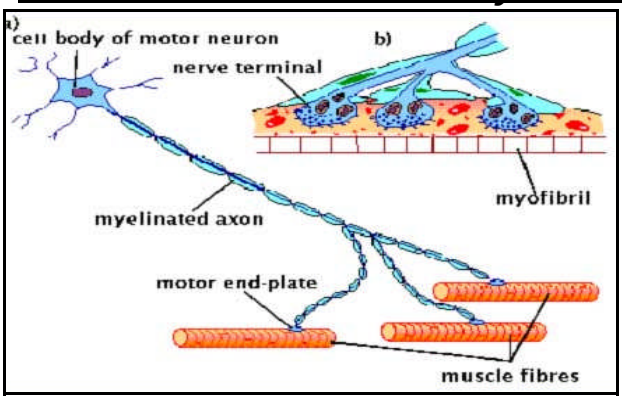
Myasthenia gravis and ME/CFS Compared.

Characteristic	M.G.	M.E./C.F.S.
Prevalence	0.1%	0.15–0.2%
Age at onset	Any, rare before 10	Any, mainly 30-50
M:F Ratio	Age 15-40 M:F=1:3 Age 50-75 M:F=3:5	1:3
Disease Process	Damage to NMJ acetylcholine receptors. 75-85% (typical) or muscle activation (atypical).	Not known, Recent research show gene expression and mitochondrial abnormalities.
Origin	Autoimmune sometimes thymoma-mediated.	Auto-immune.
Disease progression (worsening)	30% fatal in 10 years if untreated. Untreated, 'active' for 5-7 years, and progressive.	Changes are immune & neurological with variable involvement of other organs.
Variability	Symptoms can vary in severity and time. < 20% spontaneous remission	Onset usually severe 50-60% of ME cases show variability.
Fatigue/Pain	Fatigue, but painless	Pain and other neurological abnormalities often present in most cases.
Exercise-weakness	Rapid, improves on resting	Always present. Sometimes delayed 1-5 days.
Muscles affected	15% eye muscles generalized face, swallowing, jaw, limbs and neck.	Mainly shoulders, arms and thighs.
Impact on life	90% cases obtain full control with treatment	25% Mild 25% Severe. sometimes controllable.
Other organs affected & complications	with breathing muscles, potentially fatal weakness can occur. Thymus gland.	Intensity-related depression. Endocrine system, soft tissues.
Main Treatments	Cholinesterase inhibitors, immunosuppressants e.g. Azothiaprine, steroids thymectomy if secondary.	Nutritional, analgesics,. NSAIDs, pacing.

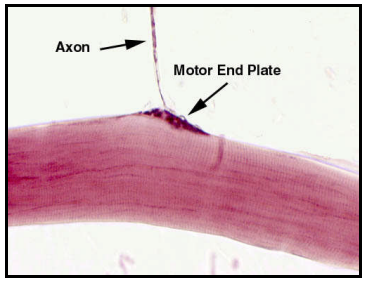
Rita Goldthorpe who veteran members will remember from AFME days now works for the MG Association. She said “We have an excellent clinic based at the John Radcliffe Infirmary in Oxford where many people go to either get a definite diagnosis or to get their medication sorted out. Anyone can be referred (there is a charge to your local health authority of around £160) and this may be particularly useful for people with ME who are showing Myasthenic 'traits'. i.e. drooping eyelids, slurred speech, fatigue without pain, difficulty with swallowing”.



The Motor End Plate and Myasthenia Gravis

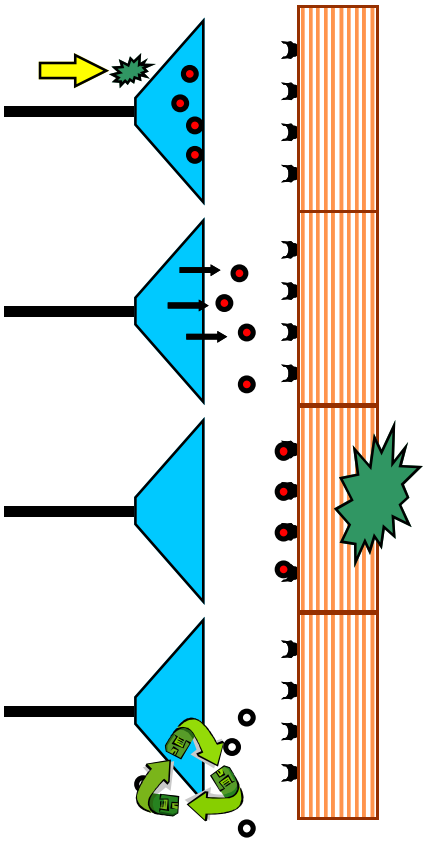


When the brain decides to move a muscle, an impulse (signal) is sent via a motor neuron, a nerve cell specialising in activating muscles. The impulse is sent along the axon. The axon may divide into branches each ending in a motor end plate, which connects the signal to the muscle fibres.



An animal motor end plate

Normal end plate function

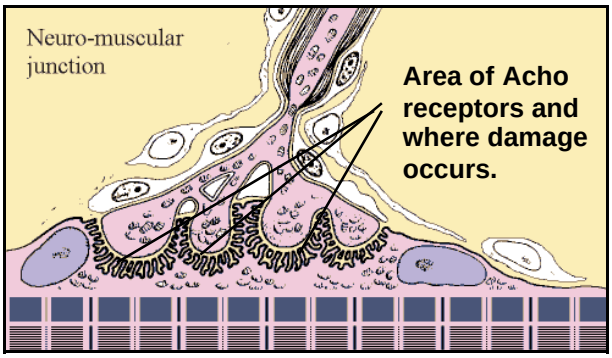


a) An impulse (signal) is received at the motor end plate site from the brain or spinal chord.

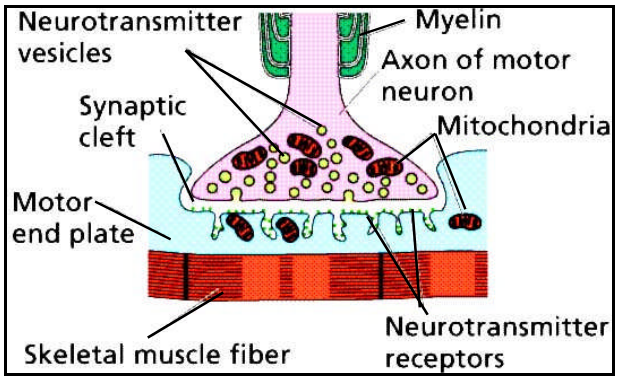
b) The neurotransmitter acetylcholine (Acho) is released, which diffuses across the gap (synaptic cleft).

c) The Acho attaches to a receptor site on the muscle, causing it to contract.

d) The Acho is removed by cholinesterase enzymes, the components are recycled back into the cell to be used again.

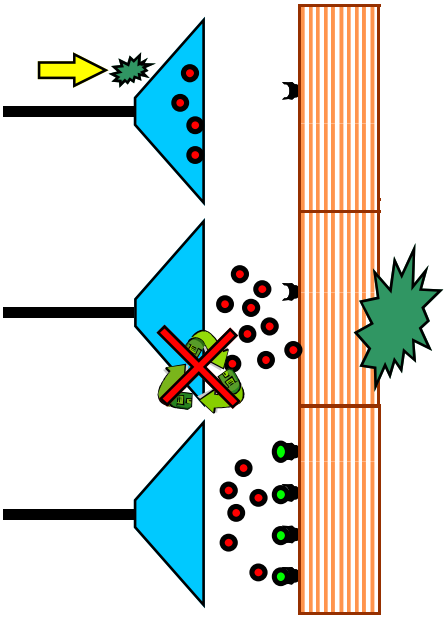


A drawing of a motor end plate as seen by an electron microscope



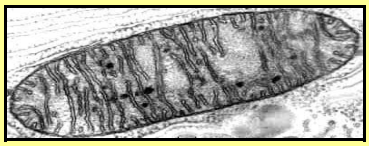
A diagram of a motor end plate to show the functional components.

Diseased and abnormal end plate function



In a diseased (MG) end plate the number of receptor sites is reduced, so the signal to the muscle stimulus is weak. If the cholinesterase is inhibited, Acho will build up in the synaptic cleft, and cause stronger signals thereby overcoming the shortage of receptor sites. Nerve gases used in warfare like Dyflos work like this, flooding the synaptic cleft with Acho thus blocking transmission and effectively paralysing muscles.

Drugs like curare (Indian arrow poison) used in some surgical operations bind to the muscle receptor, blocking the Acho, action thereby paralysing the muscle.



The Mitochondria are the power houses of the cell, which are in every cell in the body. There is increasing evidence that abnormalities in mitochondria are the roots of CFS/ME.

If the nerve or muscle cells are not working properly, then the motor end plates won't work properly. This is a possible reason why ME/CFS and MG share common characteristics.

North of Doncaster

Personal comment by Trevor Wainwright

May 12th: A Tale of Two Events. This year May 12 featured not 1 but 2 events.

The first event was the traditional May 12 Whitehall Rally, now in its fourth year. This was organised by Di Newman of Peterborough. At the demo outside DoH there were around 20, but no more than 12 or so at once. The sun shone, and there wasn't the chilly breeze blowing up from the river that we had the last 2 years, familiar faces, some new people too. Some of the more able-bodied (carers) asked people to sign the petition calling for a Petition for Science & Research Based Healthcare Policy in the UK, available online at http://www.petition.me.uk/ A lot of signatures were obtained, from people from all over the world. A copy of the short Canadian Guidelines for the attention of the Chief Medical Officer was left at the DoH. Presentations were made to 10 Downing Street on behalf of various groups and individuals, after which the party made its way to the House of Commons. The policeman who escorted the party to the Lobby said he had a friend with ME, so he was very interested in the demo. He goes round to help her out as much as can. He said she was very up and down with her symptoms - good days and bad days. Di was the only person lobbying; her MPs assistant came to meet with the group, a quiet corner was found and Di handed over the papers she'd taken. In Committee room 6, about 10 of the group had a talk about what might be done next year, as May 12 falls on a Saturday. Nothing was finally decided, but the suggestion that I think best was that we lobbied on Wednesday (9th) since that's the day of PM's Question Time so most MPs are likely to be there. The group talked till about 3.30, then packed up and left. Sadly no MPs came to see them. Di Newman's MP had said he might be able to but didn't.

The second event was the ME CONFERENCE 2006 organised by Invest in ME (IiME) a group formed only last year but hoping from their small beginnings to make a big difference. The conference consisted of top speakers in the field of ME along with a mixed audience of ME patients/ carers and doctors ready to listen and learn. The speakers and their subjects were:

Dr Bruce Carruthers, The principal author of the Canadian Criteria - The importance of diagnostic criteria. He sees the diagnosis and treatment of ME as arising from a clinical approach through which patient and doctor work together to take a thorough history, exclude a number of other conditions, tie down the symptoms, estimate their severity, develop a treatment programme, manage the treatment - modifying as necessary and preventing secondary symptoms (such as depression). Professor Malcolm Hooper (Emeritus Prof of Medical Chemistry) - The overlapping symptoms of ME, AIDS, Gulf War Syndrome and chemical poisoning - all affect the neurological, immune and endocrine (hormonal) systems . Jane Colby, former head teacher, ex-ME patient and Chief Exec of Tymes Trust - The plight of children with this condition

Dr Hyde traced the development of ME through Primary Infection Phase, Chronic Phase, Testable Brain Changes, Pain Syndromes, Major Sleep Dysfunction, Muscle Dysfunction, Vascular Dysfunction, Endocrine Dysfunction. He observed that often more than one family member became ill. Dr Jonathan Kerr is researching gene differentiation associated with ME. - A technical presentation showed the process at cellular level and tested the hypothesis that a number of genes involved in 6 key areas. Prof. Basant Puri - Started by describing how sophisticated MRI scans show that there are raised choline levels in brains of ME patients - this demonstrates that they are not making sufficient fatty acids. An Open Forum began with the heart-breaking contribution of a mother whose daughter with ME had been sectioned, following the police breaking down the front door, and received wholly inappropriate psychiatric treatment. After a fight the family got her back home. The daughter died, age 22 when she became unable to take food or drink.

One of the main points that came out of the day was The truth about ME is already out there - why does widespread ignorance and misinformation remain?

And so the campaigns must go on; as for May 12 next year it's a matter of 'watch this space.