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Pathways

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

There is money trouble ahead.

Don't we know it! In the recent budget, the government announced that VAT would rise from 17½% to 20% from January. It would be tempting to say that will just devalue your purchasing power by just over 2% - in fact it there will be cumulative on-costs which are likely to make it more like 7%. I don't think that the problems are over yet by any means. The cuts in public spending may cause a second dip recession as many civil servants are likely to lose their jobs, with reduced jobs, the benefits load is increased and disposable income reduced.

Nearer home, welfare benefits are to be targeted for austerity savings. The most vulnerable are those still receiving Incapacity Benefit. The Government's intention is to move them to Job Seekers Allowance rather than Employment and Support Allowance, thereby cutting the basic state benefit rate from £91 per week to £65 per week. An ICB to ESA migration trial is due to start in October in the Aberdeen and Burnley areas, with national implementation from April 2011. There have been rumblings about the fitness for purpose of the system which the DWP will use. Being refused a benefit causes much stress, and it is certain that this causes more harm to people with ME/CFS by delaying recovery. Evidence is being sought about the harm this causes. There is also a similar situation with Disability Living Allowance. How this could happen with ESA was covered in the last Pathways 24. We will not know how DLA will be affected but the autumn spending review might shed light on this.

Avoiding the pitfalls.

Leger ME is a Community Support Group. Ideally we would like to devote more time to deal with ME and its problems. The reality is that more and more members need help around state benefits. We can't cure ME - but we can do our best to ensure everyone gets their fair share of the support that is available and to which they are entitled. The biggest worry is DLA; since it's inception it was supposed to be an independent benefit, apart from ICB and ESA, but local experience indicates that ESA is becoming a pre-requirement for DLA. In previous editions we have covered DLA and ESA. In this edition we augment the basic guidance of Pathways 18, page 17 with hints and tips based on local experience and how to avoid the pitfalls.

Carolyn writes: I think that you should be warning people of an increase in BT charges via Pathways. I've just read in the press that there has been a leak that BT Line Rental going up 50p per month in October. Daytime calls are now 5.9p per minute and going up again 0.5p per minute. Call return 1471 is up to 4.2p per usage, and evening calls not cheaper until after 7pm (it has been 6pm for years). If I wasn't tied to them with the broadband being reliable over here I'd leave them because I'm absolutely disgusted with them. So that's BT and British Gas both in the dog house round here!!!. BT caused their own problems when they wrongly sold off the very viable 02, so now we are all paying as less and less people use their landline services. Did you say there was a payback for going paperless because I can't see it on their complicated and inefficient website? I think that BT are extremely sneaky and slow to tell their customers of these changes when they can get away with it. This time the line rental hike was leaked to the press so they have had no option.

Ah, well yes, I got my BT 'phone bill about four weeks ago and it was in one of those leaflets in chapter and verse that you always throw away. The local cable operator is even worse.

Joanne writes: The Sheffield ME Group is delighted to advise everyone that we have arranged for Dr Vance Spence, Chairman of ME/CFS. Research UK, to visit and be the guest speaker for the Annual 2010 Conference. The Conference will be held on 9th October, in The Circle, Sheffield, between 1pm and 4.30pm to allow for both a talk and a Question and Answer session. Please book this date in your diaries now and in the next newsletter we will advise on booking procedures as we are certain there will be high interest once this news is press-released!

We can arrange a mini bus to collect people from around Doncaster. If anyone is interested let me know. Mike.

Trev Writes: Hello Folks, I've just received this warning from a friend and am passing it on as requested.

A huge virus coming! Please read and forward! Huge virus coming! Please read & forward! This email has been checked with Norton Anti-Virus, and they are gearing up for this virus! I also checked Snopes, and it is for real. Get this E- mail message sent around to all your contacts ASAP. Please forward this warning among your friends, family and contacts! You should be alert during the next few days. Do not open any message with an attachment entitled 'Postcard from Hallmark', regardless of who sent it to you. It is a virus which opens a postcard image, which 'burns' the whole hard disc (C drive) of your computer. This virus will be received from someone who has your e-mail address on his/her contact list. That is the reason why you need to send this e-mail to all your contacts. It is better to receive this message 25 times than to receive the virus and open it! If you receive a mail called ' postcard,' even if it is sent to you by a friend, do not open it! Shut down your computer immediately. This is the worst virus announced by CNN. It has been classified by Microsoft as the most destructive virus ever. This virus was discovered by McAfee yesterday, and there is no repair yet for this kind of virus. This virus simply destroys the Zero Sector of the Hard Disc, where the vital information is kept. Copy this e-mail, and send it to your friends. Remember: if you send it to them, you will benefit all of us

Oops– you fell for the ruse! The originally alert is true for the 'Hallmark Cards Virus', but it's actually a false alert created by another virus. Fortunately there are better ways of detecting malicious programmes now both on home computers and servers. No computer should be without a current anti virus programme. Leger ME uses a double system, Rapport and Norton.

Wendy Writes: Just wanted to update you Mike. I have been accepted for DLA for high mobility and low care. Thank you so much, first time ever I have got DLA without having to appeal. I also had my ESA medical last week and the doctor said I was unfit for work, but I am waiting for confirmation in writing. This was at the second appointment. I had been for a previous appointment and I had been declined to be seen. The reason was that no one had read my medical records and because of previous medical history, I had to be seen by a doctor. There were only nurses there at Crossgates House. It was very uncomfortable. The chairs were too low with no arms, and customer service was terrible.

See our feature on Crossgates House for an explanation.

For breaking news go to: www.mirror.co.uk RELATED LINKS

DAD SENT BACK TO WORK 48 HOURS AFTER BRAIN OP

Officials axe his benefits

LUCY THORNTON lucy.thornton@mirror.co.uk

▲ BROKE Poorly Brian

A DAD had his benefits axed after officials ruled he was "fit for work" – 48 hours after an op to remove a brain tumour.

Bryan Haigh, 50, needed 32 staples in his head and was warned he could suffer seizures for up to six months.

But as he recovered at home a letter arrived from the Department for Work and Pensions declaring he was "officially deemed fit to work".

The dad-of-four, who was made redundant from his job as a scaffolder in April last year, has now had his £65-a-week benefits withdrawn.

He fumed: "I feel like I have been kicked in the teeth. When the letter came I just couldn't believe it. I want to work but I just can't."

His wife Samantha, 39, a teaching assistant, added: "How can someone who has just had brain surgery be considered fit for work?"

Since September, Mr Haigh had been receiving Employment and Support Allowance due to problems with his failing eyesight.

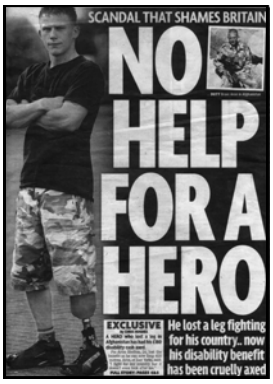
Doctors discovered the unrelated brain tumour during tests and booked him in for surgery at Leeds General Infirmary on July 20.

Mr Haigh, of Cottingley, Leeds, says he told a benefits review panel about the operation two days before.

The Department for Work and Pensions is now reviewing his case.

Ross Writes: Here we have another instance of the ESA/DLA maladministration. Although the guy told the DWP review panel about the operation two days beforehand, he has still lost his benefits. This just goes to show that the DWP don't listen to what people say. The fact that is guy has a brain tumour means that he is likely to have absences and epileptic type fits. He will have lost his driving licence. Because he had a major operation he should be classed as sick and way under the major surgery rules, and not harassed. He would certain qualify for DLA and ESA, from the point of view section on remaining conscious.

It is not the responsibility of the hospital or doctors or NHS to tell the DWP. That responsibility lies firmly with the patient.



SCANDAL THAT SHAMES BRITAIN

NO HELP FOR A HERO

EXCLUSIVE

He lost a leg fighting for his country.. now his disability benefit has been cruelly axed

Here is another case. A veteran from Afghanistan who lost a leg has lost his DLA after he reported he could walk 400 metres.

Reading into this more, I bet that he did not put in pain or consequences (as with ME/CFS) of what walking does. He could also have quite a degree of denial or be over estimating his abilities as I quite often see. If he has injuries to his other leg it could result in arthritis further down the line. I think that this guy may have been sent one of the 4 page DLA forms. The Decision Makers for DLA just look at forms in front of them, and don't really look in depth at a case. The only real in depth examination occurs at a tribunal.

Bob Writes: I've just read in the paper that Calcium supplements are linked with heart attacks. Any thoughts on this one?

There has been a flood of news stories in the papers and on TV recently about this. The stories are from a research paper "Effect of calcium supplements on risk of myocardial infarction and cardiovascular events: meta-analysis" recently published in the British Medical Journal (BMJ). The investigators analysed data from a number of trials involving in total approximately 12,000 participants over the age of 40, who took calcium supplements at a daily dose of 500mg or more.

The results suggested that calcium supplements increase the occurrence of heart attacks by 30% and furthermore increase the risk of stroke and mortality. They are not sure why calcium supplements might increase the risk of heart attacks and cardiovascular events, a suggestion is that calcium affects receptor pathways which subsequently increase coagulation and change vascular flow. The investigators conclude that although the risk is not significantly high, the small increase in incidence of heart attacks in the large number of patients taking these supplements could have a major impact on the burden of disease in the population. They also recommend further investigation of these findings and a review of the use of calcium supplements for the prevention and management of osteoporosis. Calcium supplements may be of benefit to many patients where it is clearly indicated and use should be rationalised according to benefits versus risks. Some reports have caused some people unnecessary anxiety.

Personally, I think calcium compounds have been around for years and are found in some over the counter indigestion remedies. I think that supplements are relatively safe. In Doncaster, we have hard water which contains calcium (lime); indications are that calcium has a minor protective cardiovascular effect. Calcium levels are controlled by the parathyroid glands and are kept within narrow limits. Calcium of course is essential for bones, but also essential for proper nerve and muscle function. Many diseases cause high blood calcium levels, which always needs to be investigated. Some people with ME/CFS have high calcium levels which is associated with fatigue and pain which appears not to be linked with any other conditions.

***News from Fairlawns*.**

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

I represent the Leger ME group, along with Michèle Young, from Derbyshire ME Support Group and Ute Elliott from Sheffield ME Support Group. I can't really report everything that goes on at the Sheffield CFS/ME clinic's Local Patient Involvement Group (LPIG) Meetings, but I can give a digest of what is happening in that part of the world and how it applies to us in Doncaster just as an MP would report back to his/her constituents. I attended the last LPIG meeting on 11/6/2010.

Will the current round of NHS funding-cuts affect the Sheffield Clinic?

Leger ME policy is to support the Sheffield ME/CFS clinic in whatever way we can. I have been involved with the service from the early stages in 2003, before many staff were recruited. So my concern was, knowing that the Sheffield Clinic has limited funding, I wanted to know what was the situation with the clinic. When I asked that question the answer it got was that the Sheffield ME/CFS was a service for chronic long term conditions; no cuts are planned; priority money is being diverted from acute services. The buzzword at the moment in the NHS is 'QIPP' for Quality, Innovation, Productivity and Prevention. It's about improving what the service does best; making the best use of what is available and the best use of resources (presumably money-wise).

Use of volunteers within the clinic.

The clinic recruits volunteers in a supportive role, to augment the service. Volunteers are basically unpaid staff who give their free time to the clinic. I have spoken with various volunteers who have been through the clinic's service, 'been there and got the tee shirt'. Speaking to one volunteer, that person's reason for volunteering was that it enables him/her to have something definite to do in a protected environment, and make him/her feel useful. Volunteers have to go through a recruitment interview and training process just like any employee. Usually the DWP has to agree. One of the recently recruited volunteers has attended an "Introduction to Pacing" session, where they speak with patients to pass on their experience and give reassurance before the patient sees the clinic staff. For obvious reasons the NHS is wanting to expand the use of volunteers in the service.

How can Sheffield CFS/ME Clinic help patients with DWP issues?

I asked for that question to be added to the agenda because of the recent massive increase in the reports I have received about Leger ME members locally who had attended the Sheffield clinic and had been refused benefits mainly due to due to the complexity of the forms. I felt that the service should formulate a standard information sheet for patients to use when completing forms for DLA/ESA. I quoted the Benefits & Work Organisation which has downloadable versions for clients to use. Some ME/CFS groups offer this as a service to members. There is however a £95 per year subscription that the service would have to find. Due to time restraints, this matter will be deferred until the next meeting.

Getting patients into the service

We were told 68% of patients are being seen within 4 weeks of acceptance. The is in line with our experience in Doncaster. This figure excludes the lead time needed for the G.P. to send in the necessary test results, and letters to be exchanged. We were asked for any ideas regarding how we could improve the referral of patients into the service. There is a GP Gateway process which includes an internet site which GP's use for forms and documentation. I suggested that an information pack could be put together for all new ME patients to take to the GP for onward referral. There will be opportunities to link in with NHS Sheffield's web site. With the recent NHS reorganisations there should be opportunities for the service to enhance the CFS/ME Service into GP's surgeries and consortia.

Avoiding pitfalls: While you are still working or learning with ME/CFS

Overview. There are two patterns of ME/CFS onset, the first type being acute onset, when a specific event or incident gives a definite start date. The second type is insidious onset, where there is a non-specific gradual onset with ME/CFS only being diagnosed after some major realisation that something is wrong. The people with this slow onset usually have a harder time, usually because they have had ME for years, and have struggled without treatment. There are basically four grades. Grade 1 is 'mild' when you can work part time, grade 2 is 'moderate' when someone can work a few hours in a restricted or protected environment, grade 3, 'severe', is when someone is basically house bound most of the day and 'very severe' is someone mostly bedbound. Most people we see are between grades 2-3 and have had ME/CFS for quite a while. The root cause of ME/CFS is autoimmune damage where the immune system attacks or adversely affects a body system. With ME/CFS there are no known anatomical targets as with motor neurone disease and type 1 diabetes. I see an autoimmune/atopic history or similar family traits with many of the people who contact us. Many will have asthma (40%), diabetes (10%), eczema or coeliac disease. So rather than just pure ME/CFS, most people have other health problems which have to be managed. There are often other complications like irritable bowel syndrome and reactive mental health issues such as anxiety and depression. The latter two are sometimes the obvious treatable symptoms, and it is not uncommon for things like antidepressants, graded exercise therapy (GET) and cognitive behaviour (CBT) therapy to be tried. There are reports that GET and CBT have made people with ME/CFS worse.

The way forward. The first thing to do is get a provisional diagnosis from your GP, followed by a consultant-level confirmation of diagnosis from a hospital clinic. Our recommendation is after that you seek help with management from a NHS ME/CFS clinic e.g. Sheffield or if you can afford it, one of the private doctors but beware—the entry price for the latter is £400-£500.

General guidance. Listen to your body. Keep a diary of your problems (it will be very useful later) Learn as much as you can about ME/CFS, and get to know your condition. Check with your G.P. about any treatments before starting them. Avoid or limit known things that cause stress. Think about your environment. Some people find that certain environments foods & chemicals affect them.

Continuing to work with ME/CFS. The is an ideal outcome, but in practice is not very often achieved. If your grade is mild and you can have a protected or controlled environment that is ideal. Pacing is the only really effective way to deal with ME/CFS. This might include flexible working hours, and provision of a specific parking place. With current working practices, the tendency is to load an employee for maximum output. Some sort of working-to-contract or supervision is needed to avoid stress from excessive workloads and unpaid work or training.

Part time working. In some cases light work may be possible with reduced hours, but it needs a protected environment, supervised to avoid a relapse, as stress of any kind hinders recovery. There are several money problems with part time working. Firstly a history of part time work will adversely affect your credibility with the DWP to claim ESA or DLA. Secondly, working part time you pay a reduced-rate National Insurance stamp which reduces or cancels your entitlement to a state pension and a further ESA claim. Thirdly, if you are on a final salary pension scheme, it will reduce your pension. We frequently find that part time work is only a temporary solution and is often unsustainable in the long term.

Exit Work Strategy. In many cases, the unpredictability is incompatible with what an employer would reasonably expect, as no guarantee can be given about fitness to work at any one time or the quality of work that can be expected. Employers are usually sympathetic at first, but when it becomes clear that the illness may last a long term problems occur. Take careful advice from your union, solicitor and doctor. In most cases an occupational pension or state benefits can be or are paid. No one should resign or accept an offer of employment changes without professional guidance as this could reduce your pension, severance pay or state benefits.

Attend school or college with ME/CFS. Games & physical activity need to be restricted with active guidance from a ME/CFS clinic. Attendance may be limited or a home tutor may be needed. Co-operation of the school, teachers, doctor & parents is essential.

Avoiding pitfalls: PACING vs. WORK: The Impossible Dilemma?

(We used this feature from the Bolton and Bury ME/CFS Support Group Newsletter July 2010 because it gives the personal views of real ME/CFS sufferers.)

In the last issue, Clinical Specialist physiotherapist Peter Gladwell responded to Interaction readers' thoughts and experiences of exercise. He and his colleague, specialist occupational therapist Bev Knops, now turn to a letter from Ed who, like many people with ME., is forced to balance his illness with his need to work.

In an extract from a long, passionate and courageous letter, Ed writes: I work as a head gardener; I manage five staff and an historic garden. I do this work because I enjoy the physicality of it, or I did until a virus flattened me three years ago. I managed to reduce my hours but the job is still at the edge of what I can manage.

Exercise for me is functionality. I do only what I have to do; that was the hardest lesson. I was in a hole, getting up and going to work was like climbing a mountain every day but not doing so was even worse. The aching and lethargy just got worse with inactivity and it was that much harder to keep going if I stopped. Weekends were the worst as my routine ceased, the opportunity and motivation to exercise was absent and I couldn't seem to find an alternative. This would leave me shattered, if with less pain, on Monday morning. As the week progressed I was able to do more until Thursday or Friday when I began to tire, leaving me shattered and in pain on Saturday.

I could walk about 150 yards on flat ground but meeting the gentlest of slopes I would slow and stop like a wave on a beach. I would work for short periods and rest my legs and that is how I coped. In the first year I could sleep for England; my life was work, sleep, cook, sleep, work. I started to get joint-pain which really scared me, mostly wrists and ankles. I would be unable to walk or pick things up or use a knife and fork. Stairs were hard. I used to go upstairs once a day, to bed, and I would take them sitting, one step at a time and then rest. I became selfish, harder to live with, but I coped by saying NO.

I maximised my routine to minimise the unexpected or novel. I find new situations far more tiring. I discovered D-ribose and aching muscles no longer dominated my life! My stamina is better, as is my strength, but some combinations are killers: bending and working, working too fast, overheating (very bad) and allowing my attention to be divided. Progress is pitifully slow but I am now more able; I can jump gates without my legs crumpling and leaving me in a heap on the ground. I have found that a low dose of an SSRI seems to help muscle stamina.

Bev comments:
Despite the struggle Ed has experienced trying to sustain work; he has developed a range of useful coping strategies that may be transferable to others in different occupations. Many of our clients consider either a temporary or permanent reduction in working hours which will minimise the risk of overexertion. This may leave enough energy to participate in other activities or at least avoid collapse on returning home after work. Obviously employees are concerned about a reduction in pay; however, it is possible to negotiate part-time hours with full pay—temporarily, anyway.

Regular rest breaks are so useful. Negotiation with employers for more frequent rest breaks, and timing these according to their own needs rather than a pre-determined schedule, may be possible. Where to take good quality rest breaks in a busy, noisy work environment? I have worked with people who successfully rest in toilets and stairwells. Personally I would prefer to retreat to my car. Use of an iPod or similar can block out background noise, and can also be used to listen to relaxation recordings during a break. Ed writes that he coped by saying no.

Being able to say no to additional work tasks, particularly when you feel pressurised to prove you can continue to work effectively, is difficult. However, we have found that this ability, plus other communication skills are particularly beneficial in sustaining work and working relationships. Good communication with employers, and in particular line managers, is essential. It may be helpful to organise a meeting with your employer to discuss how you are currently coping and what changes may enable you to sustain work. This seems to bring greater understanding than focusing on barriers, or assuming that employers should know how to help. Remember you still have valuable work skills—don't be afraid to discuss those, too. Ed also mentions how important having a routine has been. Pacing in the work place can be a huge challenge but the structure and routine of work can also support pacing. I have several clients who can pace beautifully at work during the week but it all goes to pot at the weekends.

www.direct.gov.uk/en/DisabledPeople has a section on employment rights and the Disability Discrimination Act, with information on reasonable adjustments. The RADAR guide Doing Work Differently has also been helpful for many people. You can find it at www.radar.org.uk in the Campaigns section, or call RADAR on 020 7250 3222.

Peter adds: I agree with Ed that he does not need to be adding extra physical activity, because his job as a gardener is already demanding to the extent that he finds his work more of a struggle towards the end of the week. I would offer Ed the opportunity to learn a gentle stretching program, which can be helpful to maintain a balance of movement and rest at the weekend, but this would be an 'optional extra' for him to consider. I would also encourage him to meet one of our occupational therapists.

We asked other people with ME. How they managed to cope with working. Here is what some of them had to say:

R. L.

I was a single mother when I first became ill and had a house and mortgage. So I couldn't afford not to work. At the beginning I took considerable time off sick and reconsidered my situation. I changed my job. I found easier and less stressful work. As travelling to work was time-consuming and very tiring I decided to work nearer home. In fact, I was lucky to get something on my doorstep. I rested as much as possible before and after work. Unfortunately that was not always possible as there were responsibilities and things that had to be done. Despite all this I still found myself having to take time off more and more until I had a complete relapse again.
I think it's extremely difficult if impossible to work with this illness due to its unpredictable and variable nature. Pushing oneself to work is not good and long term detriment to health is usually the-result.

L. P.

I have two small children so I work weekends from 9am to 6pm. Having to cope with this, sometimes, can all be too much. I do not have a great sickness record but my boss is fantastic.
I told her as soon as I had the diagnosis and she really understands. I am a team manager of 12 people. At first I was coping really well, but then I was getting worse, so I told my team what was going on. I was super nervous, but they were brilliant and really supportive. However, that changed things as I was now known as "that" girl, and I hated this as I already had labels (mum, wife, etc) when I really just wanted to be myself. I found that by letting people in can be hard at first, but then you have that added support network that you can rely on and, when I'm feeling rough, they can help.

K. R.

For several years I worked 18.5 hours a week, but around 18 months ago I was forced to reduce to 12 hours. For the first six months there was no-one to pick up the hours I had dropped, so I was effectively attempting to do the same work in less hours. My employer wants to help, but as it is an extremely small office it is hard for them to be flexible, and as it's a charity, I feel guilty about letting them down. I am now struggling again, but doubt my employer can reduce my hours further as the lady I job-share with can't take on any more hours. My doctor has done a u-turn and is no longer supportive, and the Citizens Advice Bureau has advised me that I would probably be turned down for ESA.

I don't know what to do - I need to give up for the sake of my health but financially I don't know that I can. I also worry that if I was at home all the time I might become lonely and depressed. I would recommend trying some voluntary work first in order to establish how many hours one can sustain, without having the same level of commitment as paid work. If possible, spread the hours out across the week. In paid employment, check out how much holiday you get and plan it in at regular intervals across the year. I also take some unpaid leave each year to top up my holiday allowance. Work gets the best of me, and I have no energy left to see any friends—so don't necessarily work the maximum number of hours you can, as you also need to have time and energy left for doing something enjoyable.

A. C.

In terms of balancing work with my illness, I found that I could work from home from my bed. I struggled to lift my laptop onto my lap a lot of the time because it was quite heavy, so my employer has provided me with a super-light laptop which has made things much easier. I'm lucky because I have a very supportive employer, but you don't get if you don't ask so if there's any equipment you need, there's no harm in asking for it! Make sure you mention the words 'health and safety' and that should start the balls rolling! Most of all I think it's really important that you make sure you are working on something you enjoy, and that you take the pressure off yourself to get back to work as quickly as possible, else it will only take a lot longer!

A. T.

For pacing and work, I find restricting the amount of time I spend on my laptop essential. I do a certain amount then leave it on charge and do something else that doesn't require looking at a screen. Rest breaks even for 5 minutes are essential too.

With our thanks to InterAction

Avoiding pitfalls: Claiming Sickness Pay or Benefits

While working, you will have paid into National Insurance as well as an employer's or a private insurance scheme. So you think your contributions will see you through your sickness comfortably. Forget it! Most employers have a sick pay scheme which will last between a few weeks and 12 months maximum. Be it the state or a private scheme the first few months will be paid on the basis of a doctor's 'Fitness to Work' note without question. After that further evidence is needed by either state or private schemes. There will be questionnaires, forms and possibly medical examinations. There is certainly much anxiety at this point in time and careful financial planning is needed. Golden rules are:

Money Wise

Do not take on any further big financial commitments e.g. a big mortgage or new car.
Avoid any type of debt, and do not take on any extras on credit cards.
Do not take on any new loans to clear debts. Various agencies and banks will offer these, but many of the debt management organisations advise against this.

Doctor Wise

Keep in contact with your GP and keep him or her up to date. The DWP or employers or insurers are the first people that require information from your GP. Apart from a Fitness to Work note, your G.P. will be paid by the DWP or Insurance Company to supply a report. Keep a regular appointment and at least see your GP every couple of months.
Keep a copy of all your sick notes and prescription counterfoils.
Keep a record of your treatments, appointments, or interventions. This will include prescriptions, lab reports, and hospital appointment letters in fact anything to do with your health or sickness.
Keep a record of Medical examinations or Reports. You have a legal right to have a copy of reports made about you.
Keep photocopies of all claim forms

Dealing with DWP & Private Medical Questionnaires and Forms. The most common Leger ME enquiry is from someone who has had a refusal due to filling out a claim form themselves. Most ME's will have, without realising, adjusted their life around ME/CFS limitations, and take things as normal, which is in fact disability adaption. You need to get expert help, preferable a welfare rights advisor. The Leger ME helpline can put you in touch with local organisations with expertise in ME/CFS who can help, and provide the service free so taking away the stress load and hassle.

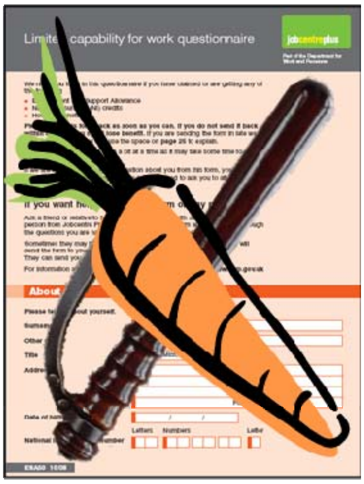
General Guidance Dealing with DPW forms ESA 50 and DLA1a

The forms are illogical and rely on reverse DWP logic. If you experience difficulties in any of the activities mentioned within the various questionnaires you will need to give a full explanation of your problems. The questionnaire gives you space to describe variations in the way symptoms affect you. When completing these, consider how you are at your worst. It is tempting to write an essay, but really you need to answer each question individually, even if this means that you have to repeat the problems of fatigue, aches, pains and flu-like symptoms that can arise. The DWP says that the assessment should not be just a 'snapshot' of a person's health at one point in time, but must take account of conditions that fluctuate over time. (That's what they say, but it is not our observed practice). If you are unable to fill in the entire questionnaire yourself and someone helps you, mention that this is the case, either in the section on memory and concentration or the section on manual dexterity as appropriate. If you cannot give all of the information that you need to in the boxes provided, continue on plain paper and attach to the questionnaire. Make sure that your name, date of birth and national insurance number is included on each of the additional sheets.

Avoiding pitfalls: Completing the ESA 50 Questionnaire

The objective of the ESA 50 is to score 15 points to qualify for Employment and Support Allowance. The questionnaire tries to link reality to the 21 ways (descriptors) that the law requires to be considered. You can score 15, 9 or 6 points by meeting the various listed criteria. How the points are calculated is demonstrated on our website ESA demonstrator. We have covered this in more details in earlier editions of Pathways. At the time of writing there was a proposal to reduce the number of descriptors to 17. The problem is that the ESA 50 is a general disability form and not specific to ME/CFS. Most of the questions require a great deal of interpretation, foresight and imagination. We recommend that you use a professional welfare rights advisor to help you fill out the ESA 50 form, as the way the descriptors are allocated by the DWP will change over time, and your advisor will be up-to-date on the latest guidance and best practice information.

If you find that you have ticked *'no problem with this activity'* on most of the descriptors, then you are most likely wrong, and in denial about your health problems. That is the quickest way to a benefit refusal. Ticking a no problem box means that the corresponding narrative is ignored.
It depends on the individual, but basically for ME/CFS most of the ticks should be 'it varies', and there should be a narrative in each of the appropriate boxes. As an example, and it very much depends on the individual case, most people with ME/CFS have very limited walking abilities, particularly in a morning. There is a Jekyll and Hyde situation, between better days and fatigued days which needs to be explained. Many people are too embarrassed to admit continence problems with ME/CFS which sometimes can be decisive in a borderline case for example.



Here are the main advice points to consider based on Action for ME advice:

- Read the questionnaire through carefully before committing pen to paper.
- Ask our helpline for information about someone who knows how to deal with the questionnaire with you, as they may be able to help you set down a clearer picture of the extent of your illness or disability.
- Draft your answers in rough first. We suggest you photocopy the blank form or print out a copy of an ESA 50 downloadable from our website.
- Be realistic about what you can and can't do. If your bad days happen more often than not, highlight your problems as they are on bad days.
- Use the boxes provided to explain your answers more fully. Explain how performing the activity repeatedly affects you, including the level of any pain and fatigue.
- Include information on ALL of your health problems, not just ME/CFS.
- If you have to avoid an activity because of after-effects or you are unable to complete it, imagine how you would feel if you did carry it out. Answer the questions on that basis.
- If you take medication which affects your ability to perform activities, e.g. because it causes dizziness or other side effects, describe this in full.
- If you have recently attempted work of any kind and have been unable to continue due to problems with your health or disabilities, include this.
- If you are able to provide medical evidence to send in with your ESA 50 questionnaire, then you should do so.
- Keep a photocopy of your completed questionnaire in case you need to attend a medical examination or appeal.
- It is important to return your completed ESA 50 questionnaire before the deadline. If you cannot, contact Jobcentre Plus, explain your problems and ask if they can give you extra time. If they accept your explanation they can give you an extra 2 weeks (especially if you have waited for paperwork from them).

Avoiding pitfalls: DWP Jargon Buster. *(From the Disability Alliance).*

After you apply for ESA or DLA, the DWP uses keywords to asses an application. The meaning that they give may be different from your understanding. What you write may not be clearly understood by the DWP decision-makers. This is why a welfare rights advisor is important when filling out DWP forms. Here is a list and the meaning of the most commonly used jargon.

Attention: This is help of an active nature required to be given in your physical presence. This can include help given to you to wash, dress or to go to the toilet. It can also be more indirect help such as signing, reading aloud or prompting and encouragement.

Bodily functions: These include hearing, eating, seeing, washing, reading, communicating, walking, drinking, sitting, sleeping, dressing or undressing, using the toilet, shaving, shampooing, help with medication and thinking.

Continual: Means regular checking but not non-stop supervision; does not have to be constant.

Cooking test (Sunday dinner test): This is a test of whether or not you can cook a main meal for yourself if you have the ingredients (and regardless of whether you are a good cook or not).

Frequent: Means more than twice.

Needs: This is help that is reasonably needed, not what is given, nor what is medically essential. This is help to lead as normal a life as possible. This includes help you need outside your home. For example you can be given help to do your own shopping or to take part in "reasonable" social activities.

Night: This is when the household has closed down for the night. It is generally the time when an adult is in bed but must be more or less within night-time hours, generally between the hours of 11pm and 7 am.

Prolonged: Means some little time, at least 20 minutes.

Repeated: Means two or more times.

Significant: This is around an hour in total.

Substantial danger: The danger must be real, not just remotely possible.

Supervision: This is watching over, with someone ready to intervene.

CLOUDS COMMUNITY COUNSELLING SERVICE LTD

Clouds CCS Ltd has now being working in Thorne, Moorends (and coming shortly to Dunscroft) and this side of Doncaster for over 3 years. Our team has grown and we are expecting to be ten shortly, seven trained counsellors and three final year students who are doing their placements with us. We are a vibrant team with varying strengths and qualities which we are pleased to offer to our clients and do the very best we can to help them resolve the issues that they bring to us.

Clouds CCS Ltd not only responds to the needs of the individual,
but also to that of the community in which we work.

Young People's Service (over 13 years) for one to one Counselling and Bereavement work.
In October we plan to deliver a Bereavement Support Course for Young People which will be creative and imaginative.

Moving-On Workshops for over 18 years and unemployed
In Thorne and Moorends. These will also be delivered at EDDT in Dunscroft at the beginning of September.

We are also looking forward to delivering
The Grandparent Support Workshops
at The Children's Centre Moorends to which a variety of outside speakers will be attending including a solicitor, social services and a hypnotherapist!

The Bereavement Support Group
at the Winning Post Moorends begins at the beginning of September too and will be informally structured encouraging participation as much as or as little as wanted.

Later next year we are hoping to offer Anger Management Courses and Couple Counselling.
Applicants are welcome now to all of our services and you may be assured of a warm and friendly,
but professional and competent service.

IT IS GOOD TO TALK AND WE ARE HERE TO LISTEN

07962 907053

Avoiding the Pitfalls: Crossgates House Medical Ruses

Unless your medical reports and ESA 50 are convincing, you will be summoned to appear at Crossgates House, which is the local DWP examination centre, for a medical examination. Don't be fooled, they are there to save Government money by trying to prove by any means they can, fair or fowl, that you don't qualify for ESA.

The trial doesn't start when you walk into the medical examination room, but as soon as you receive the summons (appointment). A personalised map based on your postcode how to get there by public transport is sent with the appointment letter. Let us suppose you have said you have limited walking ability, less than 200 yards. There are usually no unoccupied parking spaces nearby, within 200 yards. You will be observed walking into the building from the street by concealed surveillance cameras, checking into reception, and walking to the waiting area and examination room. You will be casually asked how you have got to the appointment. There are toilets available, but you have to ask at the reception desk as they are through a locked door. Again this will be recorded. And so it goes on. Experience shows that whatever you have said on your ESA 50 about Walking, Standing and sitting, Speech, Vision, Hazard awareness, Execution of tasks and Getting about is disbelieved. Similarly, if say you are seen reading a magazine, it may go against the descriptors for Vision, Learning or comprehension, Memory and concentration and Personal action.

We think that rather than considering each descriptor in isolation, there are series of observations that are noted and recorded, and each one carries some indexed weighting against five or six descriptors. Most of this information is not public, and is based on evidence provided by ESA 85, reports submitted to tribunals and member observations. One thing that is quite clear is that they do not take to account of fatigue, and base their decisions on snapshots of the day rather than an over all balanced assessment. Also it is quite clear that they consider physical problems first then mental health. They also stop when you reach 15 points, sometimes cutting a medical short.

ESA Descriptors

1) Walking
2) Standing and sitting
3) Bending or kneeling
4) Reaching
5) Picking up
6) Manual dexterity
7) Speech
8) Hearing
9) Vision
10) Continence
11) Remaining conscious
12) Learning or comprehension
13) Hazard awareness
14) Memory and concentration
15) Execution of tasks
16) Personal action
17) Coping with change
18) Getting about
19) Social situations
20) Behaviour
21) Other people

Members also report the examinations have been carried out by specially trained nurses or physiotherapists, and the inference is that a doctor is only used for specific targeted cases. The customer service is reported as terrible. “The chairs were too low with no arms” (we think this is a covert sitting and standing test). We also think that it is rare for them to read your ESA 50 before you are seen as staff at Crossgates House appear to be unaware of specific requirements like the need for urgent access to a toilet or a high seat chair.

So what is the best way to stack the odds in your favour? Firstly, base what you say in the ESA 50 on evidence that can be verified and examples. Ensure that medical backup is sent in with the form ESA 50, if available. You will certainly need a welfare rights advisor to help you with this. Take a taxi both ways to the medical examination, don't walk, and go by bus or drive. Don't go by yourself, take someone with you who knows and understands your condition. You will be placed under pressure and stress in the examination room, and you may need your chaperone's intervention.

Decisions are notified fairly rapidly by post, and are usually buried in the third page of the letter you receive. If you are refused ESA, the payment stops at the day of the medical. At that point you must register with Jobseekers to get any DWP money, and that cannot be backdated. If you win a subsequent appeal or tribunal, than the money is backdated. You certainly need to contact a welfare rights organisation for help with any appeal. Some local ones have waiting lists, and others have qualifying criteria, like they only help their own clients or low income clients. The most effective way to avoid refusals is to ensure a good quality ESA 50 is submitted. This all starts with help from a welfare rights advisor.

Avoiding pitfalls: Disability Living Allowance (DLA) applications

DLA is a cash benefit for people under 65 who need help with personal care or for getting around. DLA does not depend on your income, savings or National Insurance contributions. There are two components to DLA, the care component, which consists of three rates: high, middle and low, is for help with things like washing, dressing and cooking. The mobility component is for those who cannot walk or have difficulty in walking due to their illness and is broken down into two levels, high rate and low rate. Attendance Allowance (AA) is a similar benefit for people aged 65 or over who need help with personal care or supervision to keep them safe, but only has two rates equivalent to the DLA middle and high rate of care.

Claiming DLA. The same general advice applies to the DLA1a form as with the ESA. It is a general disability form and so is ME/CFS-unfriendly. There is no points system, but you have to meet certain unpublished criteria. The legal basis on which DLA is awarded for ME/CFS is based on ‘Commissioners Decisions’, or interpretation of the law which is an opinion and not clear-cut. Many people with ME/CFS receive DLA mobility by being described ‘Virtually Unable to Walk’. Virtual mean something is there, but is not really, like an image in a mirror. While most ME/CFS’s can walk, doing so it is detrimental to health and safety. Most ME/CFS’s receive the low rate care component by the ‘Sunday Dinner Test, which is based on the danger and hazards in an imaginary attempt to make a main meal. Many doctors including those working for the DWP, are unaware of much of the DWP paperwork and unaware of the commissioners decisions as they apply to ME/CFS. Very often DLA is refused, and awards are only made on appeal or tribunal. A welfare rights advisor will know how to fill out the DLA form to avoid this pitfall. With our members, it is almost a right of passage that the first DLA application is refused.

The examining medical practitioner visit (EMP). The DWP may send a doctor to visit you at home, if clarification is needed to assess the claim. The report form is a DLA140 and is completed by the visiting doctor. The first part is usually a verbal interview, which the doctor has to manually write up, and you have to sign. We advise members to have a chaperone present that has knowledge of welfare rights, just to ensure that everything is OK, and to check what the doctor has written. Sometimes the doctors have tried a ruse to get people to sign for something that may invalidate the application, as with ESA medicals. In recent years the DWP has found that an EMP visit does not get the right sort of information they need and is a waste of time and money.

Relationship to Incapacity Benefit (ICB) and ESA. Although DLA is supposed to be an independently assessed benefit under different criteria to ESA/DLA, if you have had a medical examination the past two years and a ESA 85 report or IB 85 report is on file they tend to look at that, and if unfavourable you will have the benefit declined on that basis. ESA/IB 85 reports only go as far as looking for 15 points, and very often the reports are incomplete. People who ‘pass’ these examinations are unaware of this. A welfare rights advisor will get a copy of the ESA/IB 85 prior to submitting a DLA application to check for this pitfall. Increasingly a successful ESA claim is a prerequisite for a DLA application. The stated intention of the Government is to make DLA a points based system like ESA, with a tightening of the criteria at the same time to save money. I am informed from a reliable source that an ESA 50 and medical will trigger a DLA review. These will happen next year (2011) when Incapacity Benefit migration to ESA starts.

DLA Renewals. Members used to receive the 50-page DLA pack which was very similar to the DLA1a. The DWP have introduced a 4 page DLA renewal form, where to renew an unchanged claim all you have to do it tick the correct box and sign it. What actually happens is that the DWP look up your original DLA form and start the assessment process as a new claim. They also write to the doctor(s) you put in the original claim. If your G.P. or Consultant has moved jobs or retired, that doctor will be unavailable to give a report. For that reason alone, many DLA renewals have been refused. One disability rights organisation’s advice members is to use a new claim form rather than the 4 page renewal form.

DLA Refusal. If you get a DLA refusal you need to firstly request a copy of all the information the DWP used and then an inquest is needed. The helpline will signpost you to a welfare rights service that can help with the appeal process. We discourage DIY appeals. Most Leger ME members win on appeal.

Avoiding the Pitfalls: Standing your ground.

***ESA Appeal Upheld** by Leger ME Member Anne Fisher*

January 2009 I began the saga of applying for ESA and was informed that it would take a few months to sort out but they started me on a reduced rate of payment immediately. My husband and I spent hours writing out draft answers to the questions, Mike chipped in with his ideas and observations of my illness and eventually the form was submitted. Seven months later I was called to Doncaster for my medical. It wasn't a good day for me but I managed to sit upright for the length of time the appointment took and of course suffered later for this amount of effort but there was no way I was going to cancel this appointment after waiting for so long.

By October I had been denied the benefit and told that I was well enough to return to work in 3 months' time. At this news I didn't know whether to shout, scream, cry or just get depressed! I felt I didn't have the strength to fight this, but after shedding a few tears and feeling very angry for a day or two I got my fight back and got down to appealing against this decision. With advice from Mike and DIAL I began over a number of days to scrutinise the reports I had asked for, to see where I felt the medical had been interpreted incorrectly or where information had been omitted, then began to write my findings down, the effort that this took brought on migraines and increased my general fatigue over a number of days but I was now very determined to do this. I retuned a very detailed report and further evidence after about two weeks and then sat back to recover from the effort. As expected the review was also denied and so the decision to go for the Tribunal was confirmed in my mind, I had already applied for this when the appeal papers had been returned.

There were many times over the next few months that I just felt that I didn't want to fight this. I didn't have the courage or the energy but I hate injustice and felt that I had been unfairly denied this benefit. So I had to be very determined to continue. My husband was willing to support me whichever way I decided to go, so I had to continue for myself and the ME cause.

During June 2010 I received my date for my Tribunal, in July, eighteen months after beginning the process. I informed Mike and DIAL and proceeded to try and get a little more new evidence to send in; Dial did some of this for me which was helpful. The day finally arrived. I had spent a month trying not to allow myself to become anxious, and although I knew if this went against me I would have to start to look for work, I also knew that I was still unemployable as the amount of time each day I can give to any form of activity is very unreliable. So I went in believing that whatever the decision I was still a winner, but I knew I would get the decision if I could talk to someone rather than just tick the boxes (sometimes I think I may be too optimistic).

After being asked about my illness and the treatment received from my GP and what other treatments were available he read through the work history that I had provided and then went on to ask me if I know about depression and wondered if I was depressed. I explained that I knew the difference and that I wasn't depressed but that I did get low at times due to the illness, but that I am a generally optimistic person and always look for the minute good things that happen in a day. We then moved on to going through the descriptors (questions) on the original ESA form. He asked me in detail to explain what I could do for the first three descriptors of walking, going up 2 steps and then standing. All the time he was listening to me he was taking notes, so make sure you continue talking to give him all the information. After these three questions we were asked to leave the room. I didn't want to get too excited at this point but I knew I had got it. After a few minutes we were called back in and informed that the appointment didn't need to continue as my appeal had been upheld. I wanted to hug and kiss him but didn't feel this was appropriate so a thank you had to be enough.

So what happens now? Eighteen months back-money, and I can relax knowing that for a while I don't have to think about going back to work. I would of course love to be well enough to return to work as I enjoyed my profession. But for now I can concentrate on pacing all my activities and getting better. I will probable get another form later this year to see if my condition has changed from a year ago but I will cross that line when it comes, it's not worth worrying about yet. So take heart this system may be hard to get through but it is possible. *Ann*

A Theft of French Art

Louis et ses amis, voleurs de l'art in Paris planned to steal the Mona Lisa from the Louvre.

After careful planning Louis and amis got the past the security guards, stole the painting, and made it safely to their getaway van.

BUT the French police quickly pursued them and they were captured two blocks away.

The getaway Van Goghed

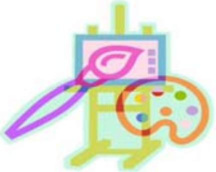
and ran out of Degas.

When asked how he could mastermind such a crime and then make such an obvious error, he replied, 'Monsieur, that is the reason I stole the paintings.' I had no Monet ….

to buy Degas to make the Van Gogh! So we couldn't meet De Gaulle

to send this on to someone else Toulouse !!!

Merci Bien to Colin Artist



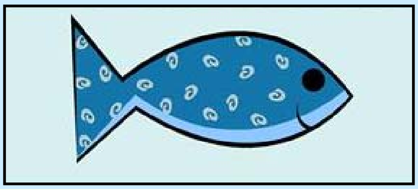
Recipe Corner <u>Smoked Haddock Fishcakes</u>

Homemade fishcakes are a real treat for all the family. For a more luxurious version replace the smoked haddock with salmon and add a few chopped, peeled, prawns. To make little fish nuggets that the children will love, shape about 4 balls from one quantity of fishcake and coat in the same ways. Fry for only 2-3 minutes.

Makes 8 fishcakes, Ready in one hour (30 minutes of the time is for leaving each of the 8 fishcake to chill)

900 (2lb) floury potatoes, peeled and cut into chunks
450 (1lb) smoked haddock fillet
6 tbsp canned sweetcorn kernels
2 tbsp each fresh chopped parsley and chives
2tsp finely grated lemon rind
2 tbsp seasoned flour
1 large egg, beaten
75g (3oz) fresh white breadcrumbs
Oil for shallow frying
Salad and lime wedges to serve

Boil the potatoes in a large pan of lightly salted water until just tender. Drain and mash. Transfer to a bowl, leave to cool. Place the haddock in a frying pan, cover with water and simmer for 8-10 minutes until just cooked. Remove with a fish slice and flake the fish, discarding any skin and bones. Add to the mash with the sweetcorn, parsley, chives and lemon rind. Season with salt and freshly ground black pepper and mix well. Using floured hands, divide and shape the mixture into 8 fishcakes. Coat each fishcake in seasoned flour, then dip in beaten egg and coat in the breadcrumbs. Chill for at least 30 minutes. Shallow fry the fishcakes in hot oil for 3-4 minutes on each side until golden. Drain and serve with salad and lemon wedges.



Lightning Process Study in Children 'Unethical'

Joint Statement with the ME Association & the Young ME Sufferers Trust

The ME Association and The Young ME Sufferers Trust are issuing this joint statement due to widespread public concern, together with our own serious reservations, about a forthcoming study of the psychologically-based Lightning Process on children. The pilot study, scheduled to start in September, will look at the feasibility of recruiting children aged eight to 18 with ME/CFS into a randomised controlled trial (RCT) comparing the Lightning Process with specialist medical care. It is planned that over 90 children aged between eight and eighteen and their families will be involved in the study.

The Medical Research Council (MRC) produces specific guidelines for research involving vulnerable patient groups. The document 'MRC Medical Research Involving Children' is quite clear on this issue. It poses the question: 'Does the research need to be carried out with children?' In answer, the MRC states: 'Research involving children should only be carried out if it cannot feasibly be carried out on adults.' The ME Association and The Young ME Sufferers Trust do not believe that it is ethically right to use children in trialling an unproven and controversial process such as the Lightning Process. A survey of 4,217 people carried out by the ME Association on the management of ME/CFS found that over a fifth of those who had tried the Lightning Process were made worse (7.9% slightly worse,12.9% much worse). If any trial is to be held, it should first be on adults, who can give informed consent. No rigorous 'randomised controlled trials' (RCTs) into the application of the Lightning Process have ever been undertaken.

Despite many years of scientific research there is not still any single diagnostic test for ME/CFS, nor is there a curative treatment. The theory upon which the Lightning Process is based, together with the claim by its proponents that the prolonged nature of the illness is caused by 'the adrenaline, nor-adrenaline and cortisol loop' is not scientifically proven. Moreover, the Advertising Standards Authority recently ruled that an advertisement in an internet sponsored link containing claims of its effectiveness by a Lightning Process practitioner should be removed. We understand that the practitioner will be involved in this study and we find this concerning.

The Trading Standards Departments of two local authorities have also taken action over therapeutic claims by Lightning Process practitioners following referrals by Dr. Charles Shepherd of the ME Association. The Lightning Process calls itself a training programme, not a medical treatment, combining concepts from Neuro-Linguistic Programming, Life Coaching and Osteopathy. It claims to be effective for ME/CFS and psychological problems such as anxiety, stress, depression, guilt and low self esteem. Any evidence for this effectiveness on ME/CFS is purely anecdotal.
ME has long been classified by the World Health Organisation as a neurological illness, not a psychological condition. We cannot approve of a study involving children as young as eight when no rigorous trials have first been undertaken into the safety, acceptability, long and short-term effects of the application of this controversial and unregulated 'process' with adults.

Trust wins Queen's Award

Tymes Trust

The Young ME Sufferers Trust has won The Queen's Award for Voluntary Service, the MBE for volunteer groups. The Trust has received the Award for pursuing the educational rights and advancing the care of children with ME.

The Tymes Trust will receive a certificate signed by the Queen and an exclusive commemorative crystal, presented by Her Majesty's representative in Essex, Lord Petre, at a special ceremony. The Queen's Award for Voluntary Service Main Award Committee Chair and former broadcast journalist Martyn Lewis CBE said: "It's a great pleasure to celebrate the efforts of The Young ME Sufferers Trust with The Queen's Award for Voluntary Service and help raise awareness of all they do for the benefit of others."

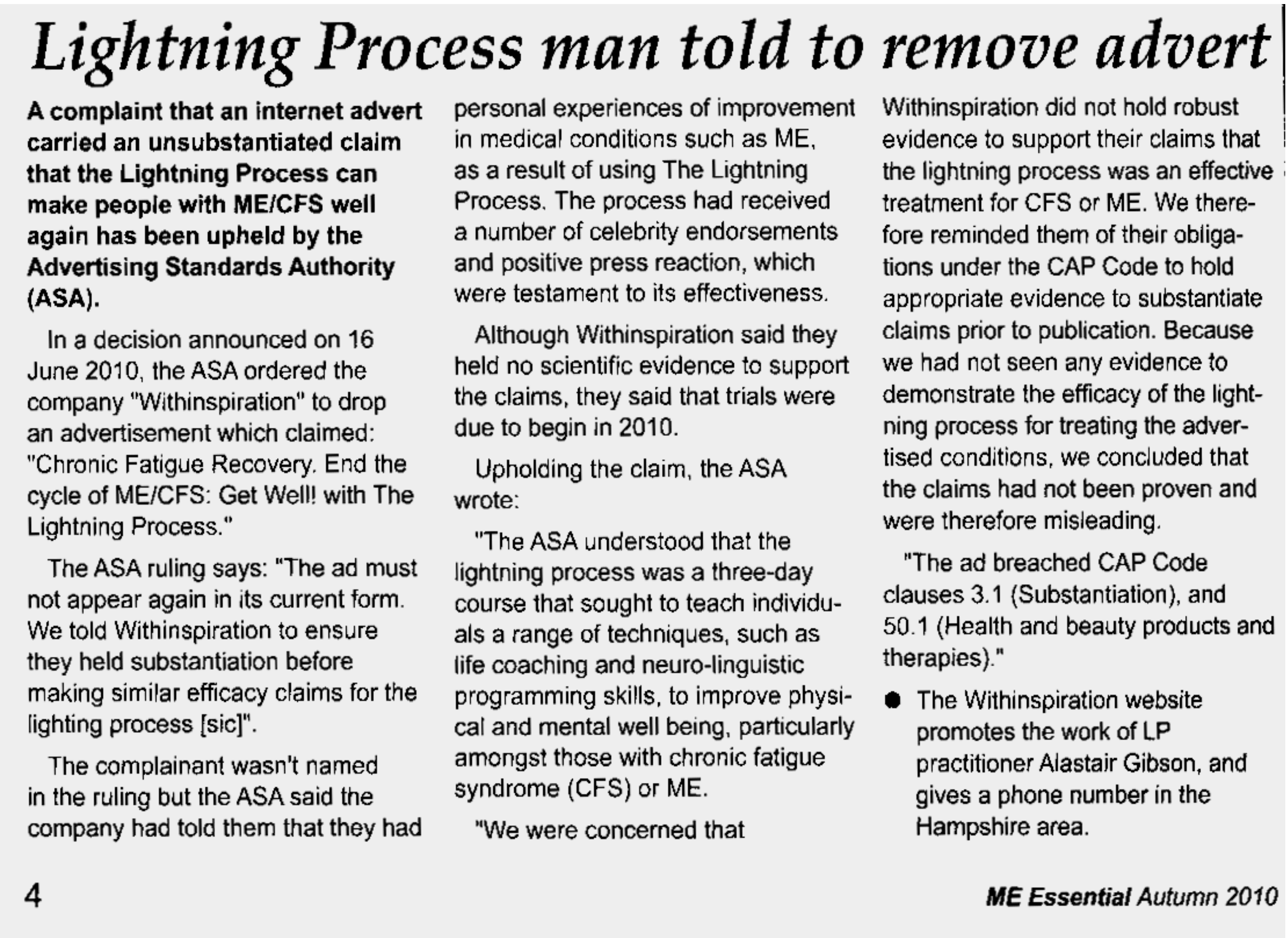
The Queen's Award for Voluntary Service
The MBE for volunteer groups

Furthermore, we have serious concerns about the primary outcome measure, which is school attendance after six months. Children have a legal right to 'suitable education' for their particular needs, which may or may not include school attendance. The statutory guidance 'Access to Education for Children and Young People with Medical Needs' explains that whilst it is desirable for children to be educated in school, other forms of education must be provided for those who need it.

The Chief Medical Officer's Working Group Report on CFS/ME (DOH 2002) stated that most children with ME will need education in their homes at some time, potentially for a considerable period. In 2009 the Education White Paper '*Back on Track*: *A strategy for modernising alternative provision for young people*' included virtual education. Chapter 7, 'Learning from the best and supporting innovation', spoke of 'e-learning and virtual provision, particularly for pupils who cannot attend school due to health needs.' Accessible education is also provided for in disability discrimination law.

If school-attendance is the primary outcome measure of this study, families involved may then feel pressurised into avoiding alternative forms of education which would benefit their children and to which they are legally entitled. For all these reasons, it is our considered opinion that this study of the Lightning Process in children is unethical and should be abandoned.

Jane Colby Comments: It is of course everyone's right to take up whatever treatment or training programme they wish. This statement addresses a different issue: the ethics of experimentation on children when there are legal issues of informed consent and suitable education, and when research on adults has not been done. I discussed the Lightning Process in The Brief 2008-1 (page iv), at www.tymestrust.org/tymesmagazine.htm. Jane Colby, Executive Director, The Young ME Sufferers Trust, PO Box 4347, Stock, Essex, CM4 9TE, www.tymestrust.org,
Tel: 0845 003 9002



Lightning Process man told to remove advert

A complaint that an internet advert carried an unsubstantiated claim that the Lightning Process can make people with ME/CFS well again has been upheld by the Advertising Standards Authority (ASA).

In a decision announced on 16 June 2010, the ASA ordered the company "Withinspiration" to drop an advertisement which claimed: "Chronic Fatigue Recovery. End the cycle of ME/CFS: Get Well! with The Lightning Process."

The ASA ruling says: "The ad must not appear again in its current form. We told Withinspiration to ensure they held substantiation before making similar efficacy claims for the lighting process [sic]".

The complainant wasn't named in the ruling but the ASA said the company had told them that they had personal experiences of improvement in medical conditions such as ME, as a result of using The Lightning Process. The process had received a number of celebrity endorsements and positive press reaction, which were testament to its effectiveness.

Although Withinspiration said they held no scientific evidence to support the claims, they said that trials were due to begin in 2010.

Upholding the claim, the ASA wrote:

"The ASA understood that the lightning process was a three-day course that sought to teach individuals a range of techniques, such as life coaching and neuro-linguistic programming skills, to improve physical and mental well being, particularly amongst those with chronic fatigue syndrome (CFS) or ME.

"We were concerned that Withinspiration did not hold robust evidence to support their claims that the lightning process was an effective treatment for CFS or ME. We therefore reminded them of their obligations under the CAP Code to hold appropriate evidence to substantiate claims prior to publication. Because we had not seen any evidence to demonstrate the efficacy of the lightning process for treating the advertised conditions, we concluded that the claims had not been proven and were therefore misleading.

"The ad breached CAP Code clauses 3.1 (Substantiation), and 50.1 (Health and beauty products and therapies)."

- The Withinspiration website promotes the work of LP practitioner Alastair Gibson, and gives a phone number in the Hampshire area.

4 **ME Essential** *Autumn 2010*

Irritable Bowel Syndrome (IBS) and ME/CFS compared.

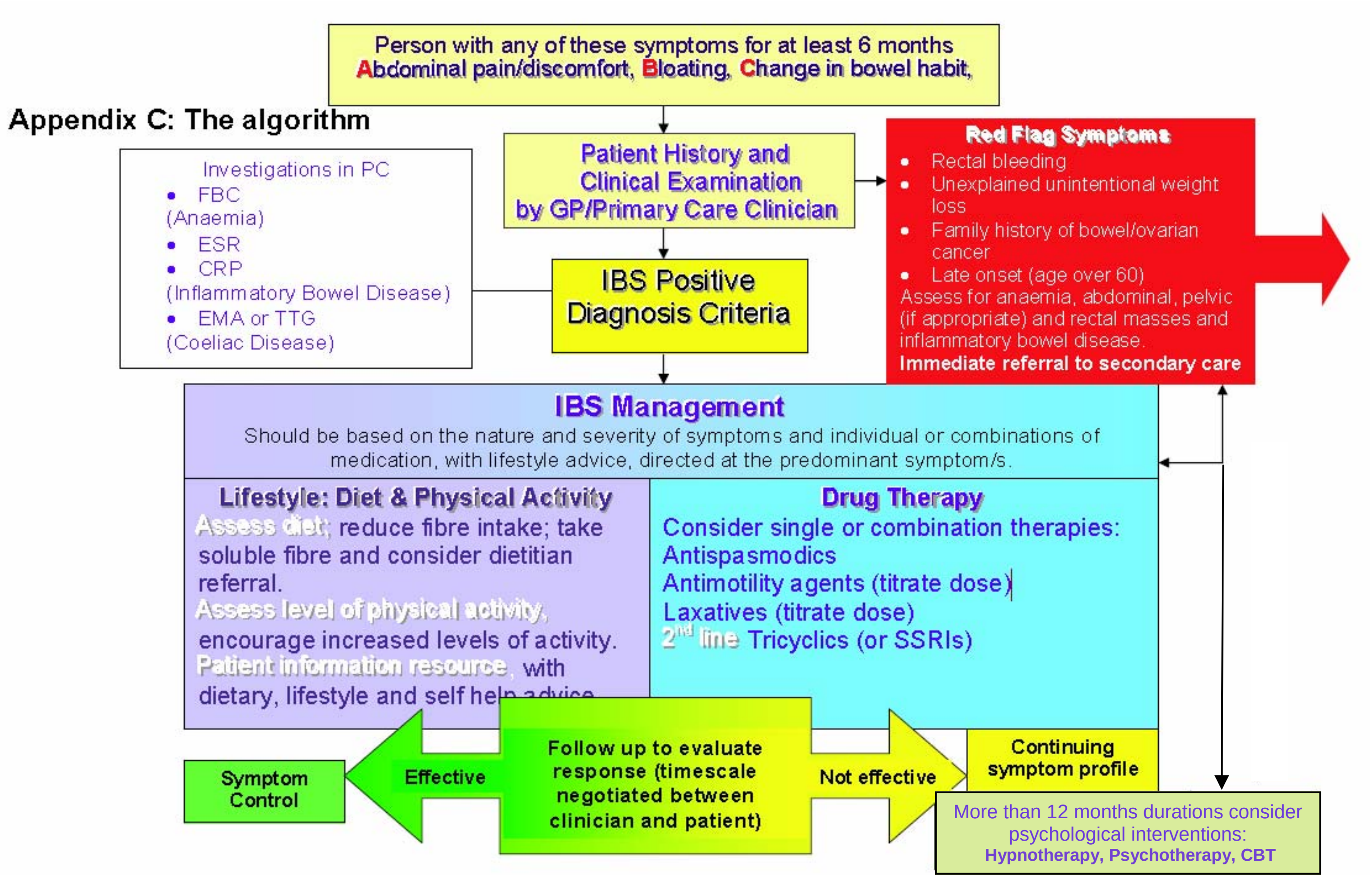
There are a lot of parallels between IBS and ME/CFS. The condition is separate to CFS according to the NICE guidelines and the local NHS ME/CFS clinic. Personally, I see it as part of the clinical spectrum of ME and it is present in the vast majority of ME people I meet. IBS most often affects people between the ages of 20 and 30 years and is twice as common in women as in men. Prevalence is at about 10% to 20% of the general population, with an increase in older people. IBS or spastic colon is a diagnosis of exclusion. It is a functional bowel disorder characterized by chronic abdominal pain, discomfort, bloating, and alteration of bowel habits in the absence of any detectable organic cause. In some cases, the symptoms are relieved by bowel movements. Diarrhoea or constipation may predominate, or they may alternate. IBS may begin after an infection, a stressful life event, or onset of maturity, without any other medical indicators. Although there is no cure for IBS, there are treatments that attempt to relieve symptoms, including dietary adjustments, medication and psychological interventions. In IBS as in ME/CFS, routine clinical tests yield no abnormalities, though the bowels may be more sensitive. The exact cause of IBS is unknown. The most common theory is that IBS is a disorder of the interaction between the brain and the gastrointestinal tract, although there may also be abnormalities in the gut flora or the immune system. IBS is a diagnosis of exclusion and as in ME/CFS the absence of other conditions needs to be checked. The NICE guidelines give the following red flag indicators needing further investigation: unintentional and unexplained weight loss, rectal bleeding, a family history of bowel or ovarian cancer, a change in bowel habit to looser and/or more frequent stools persisting for more than 6 weeks in a person aged over 60 years. Several conditions may have the same symptoms as IBS including coeliac disease, fructose malabsorption, mild infections, parasitic infections like giardiasis, several inflammatory bowel diseases, functional chronic constipation, and chronic functional abdominal pain. Any abnormalities in blood test need to be taken into account.

Essential IBS Facts *from the Gut Trust*

- IBS can only be diagnosed by a qualified medical professional - please do not attempt to self diagnose - see your GP if you think you might have it.
- There is no cure for IBS, but it will not develop into anything else, and does not mean that you are more likely to get another illness.
- Treatment for IBS is based on your symptoms - there is no magic pill, but treatments for each individual symptom can be very effective.
- Self management is the best way of improving the symptoms of your IBS. Understanding how your lifestyle and diet can make your symptoms better or worse can be of real benefit. The Gut Trust has a unique self-management programme for IBS on the members’ area of its website.
- You can help by cutting down the amount of insoluble fibre in your diet (insoluble fibre is bran and the like), and by avoiding spicy foods. If you have diarrhoea, you might want to cut down on the amount of fruit and vegetables you eat, and avoid artificial sweeteners. If you have constipation, increasing the amount of water you drink is often helpful.
- Complementary therapies can be very beneficial, but check our advice first.
- Probiotics can be helpful in managing your symptoms. The important factor is the type of probiotic and the amount of active ingredient it contains. If you taking a specific probiotic and it is not helpful within a month, you may want to try a different one.
- There is a lot of advice available on the internet. Be careful where you get your advice from. There are also many treatments and therapies which say that they can "cure" IBS. This is impossible - be wary of quack cures, particularly ones that cost a lot of money.
- Understanding your illness helps you have an informed discussion with your GP and make good choices in your own life. We recommend reading the NICE information for patients, and the information available on this site.

The Gut Trust Gut Trust and its network of self-help groups make a real difference in understanding and living with your symptoms, overcoming anxiety and building your self-confidence. You can contact us in a number of ways. Our main office details are: The Gut Trust, Unit 5, 53 Mowbray Street, Sheffield, S3 8EN. Telephone: 0114 272 32 53. E-mail: info@theguttrust.org

NICE Guidelines for Irritable Bowel Syndrome



Person with any of these symptoms for at least 6 months
Abdominal pain/discomfort, Bloating, Change in bowel habit,

Appendix C: The algorithm

Investigations in PC
- FBC (Anaemia)
- ESR
- CRP (Inflammatory Bowel Disease)
- EMA or TTG (Coeliac Disease)

Patient History and Clinical Examination by GP/Primary Care Clinician

Red Flag Symptoms
- Rectal bleeding
- Unexplained unintentional weight loss
- Family history of bowel/ovarian cancer
- Late onset (age over 60)

Assess for anaemia, abdominal, pelvic (if appropriate) and rectal masses and inflammatory bowel disease.
Immediate referral to secondary care

IBS Positive Diagnosis Criteria

IBS Management

Should be based on the nature and severity of symptoms and individual or combinations of medication, with lifestyle advice, directed at the predominant symptom/s.

Lifestyle: Diet & Physical Activity

Assess diet; reduce fibre intake; take soluble fibre and consider dietitian referral.
Assess level of physical activity, encourage increased levels of activity.
Patient information resource, with dietary, lifestyle and self help advice

Drug Therapy

Consider single or combination therapies:
Antispasmodics
Antimotility agents (titrate dose)
Laxatives (titrate dose)
2nd line Tricyclics (or SSRIs)

Symptom Control

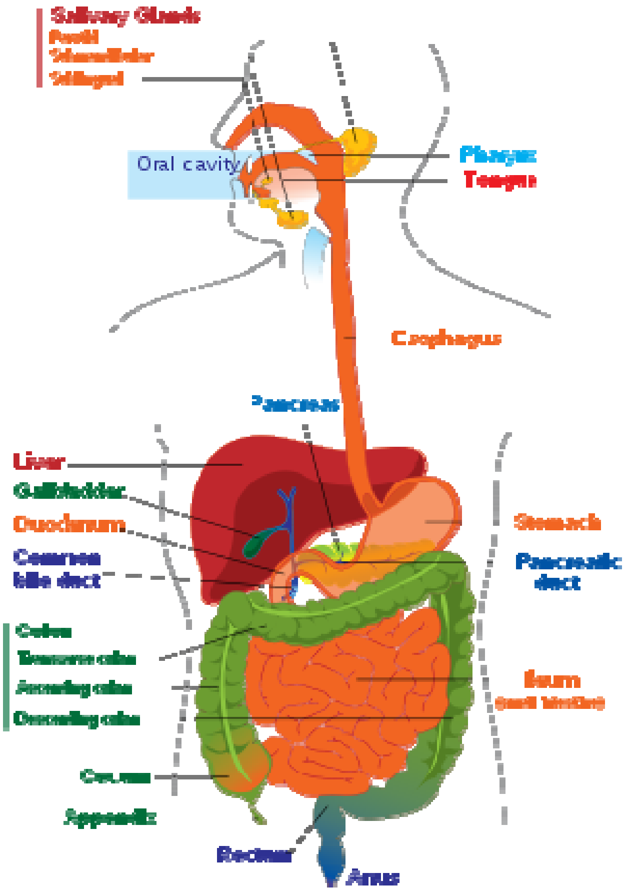
Effective

Follow up to evaluate response (timescale negotiated between clinician and patient)

Not effective

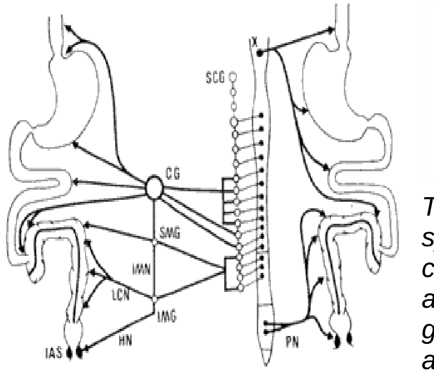
Continuing symptom profile

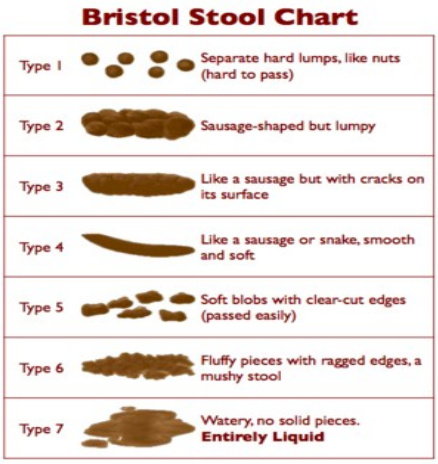
More than 12 months durations consider psychological interventions:
Hypnotherapy, Psychotherapy, CBT



The digestive system, or Gastro Intestinal Tract (GI)

Irritable Bowel Syndrome is thought to be a disorder of the GI tract. Anatomically this corresponds to the Colon and Rectum.





Bristol Stool Chart

Type 1	Separate hard lumps, like nuts (hard to pass)
Type 2	Sausage-shaped but lumpy
Type 3	Like a sausage but with cracks on its surface
Type 4	Like a sausage or snake, smooth and soft
Type 5	Soft blobs with clear-cut edges (passed easily)
Type 6	Fluffy pieces with ragged edges, a mushy stool
Type 7	Watery, no solid pieces. **Entirely Liquid**

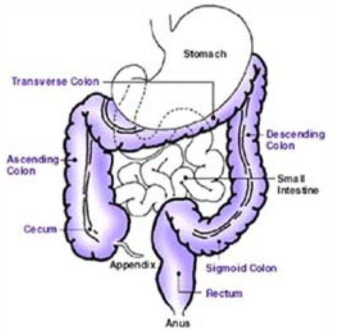


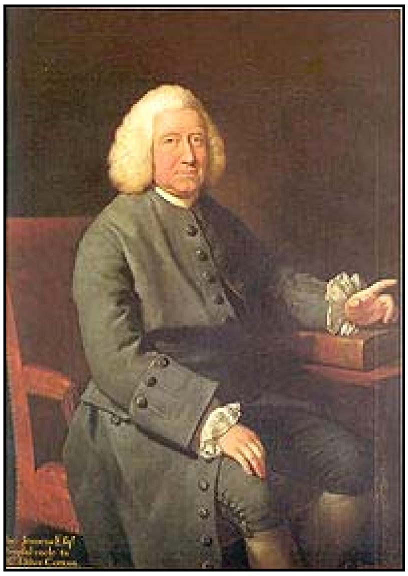
Diagram of the Colon and Rectum

The Gastro–intestinal control system wiring is via the coeliac plexus, an arrangement of nerves and ganglia in the lower abdomen which behaves like a second brain controlling the GI system. The spinal cord is involved ultimately the brain is involved in a modulatory way. This is why drugs like antidepressant and other neurologically active drugs are effective in helping to control symptoms Patients are asked to report symptoms using the Bristol Stool chart. This, with a description of the symptoms, does enable doctors to monitor treatment progress.

North of Doncaster.

Personal comment by Trevor Wainwright

I think everyone from my generation knows of the ‘Hallelujah’ Chorus. Most younger people will know it as one of the most frequently used musical fragments heard often in TV programmes. It is part of one of those pieces from Handel’s Messiah, which some believe is The Greatest Oratorio ever written. An oratorio is a collection of musical pieces, instrumental, solos, voices and choruses which tell a religious (usually biblical) story without costumes, scenery, or dramatic action. The most well known is The Messiah, but other examples are Elijah, and Belshazzar's Feast. There are various stories and theories behind Handel’s Messiah as to where the idea originated; one such is that it he composed it in the temple at Gopsall Hall the home of Charles Jennens, the man who chose the words from the bible. Experts say the time factor renders this impossible. However the following story uncovered during some research into the history of the Christmas Carols for Hospital Radio may well bear fruit.



George Fredrick Handel. In his time, he was as popular as Andrew Lloyd Webber is today

When he was 53 George Frederick Handel, suffered a stroke, doctors held little hope he would recover; through his own determination he did and lived to be 74. It is said that all his great oratorios were written after he was 53. In 1741, nearing 60, he had fallen on hard times, once the toast of Royalty and the aristocracy he was deeply in despair and debt. Returning to his lodgings (now the Handel House Museum) one evening he found on his desk a libretto "A Sacred Oratorio" from the poet, patron of the arts and collector of musical manuscripts, Charles Jennens whom Handel thought second rate and pampered. As he leafed through it listlessly, two passages caught his eye; "He was despised and rejected of men” and “He looked for some to have pity; neither found He any to comfort him". Handel could feel something of his old self returning, melodies formed in his mind, as the words from the Bible seemed to come alive and glow with meaning. Handel began to write page after page. For 24 days he laboured like a fiend, with little rest or sleep, writing all the while, jumping up and running to the harpsichord, shouting hallelujah, tears running down his cheeks. After 24 days he fell on his bed exhausted, on his desk lay the score of the Messiah, the greatest oratorio ever written. Handel slept for 17 hours after its completion. London would have nothing to do with the Messiah so he took it to Ireland. On April 13th 1742 it premiered in Dublin, it was a success, all the proceeds going to charity. London then was anxious to hear the work.

Charles Jennens, source of inspiration and selector of the biblical verses.

The first London performance was on 23rd March 1743, in the presence of King George II for whose coronation Handel composed the anthem ‘Zadok the Priest’ which has been at the coronation of every English Monarch since. At the Hallelujah Chorus the King rose to his feet and remained standing for the duration of the piece. This may have been a touch of cramp or as some say, a gesture of recognition, demonstrating that his earthly kingdom was subservient to the Kingdom of Heaven. As no one could remain sitting whilst the King stood, the entire audience also stood and stayed standing for the duration of the piece. It has since become tradition for audiences to stand for the piece and this is frequently observed even if there are no royal personages present. Handel presented the Messiah yearly.
In 1750 performances were in aid of the Foundling Hospital like charity concerts today. Handel died in 1759 but not without ensuring the hospital continues to benefit from annual performances of what some call “The Greatest Oratorio Ever Written”.