



Pathways

Price £ 2.25 (Free to members)

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.

Major Social Security Benefit Changes

Out goes Incapacity Benefit and Income Support and in comes Employment and Support Allowance for people of working age. For most, in come less generous state benefits with sanctions to reduce benefits if you do not comply with DWP expectations of work-related activity. What is not quite clear is what the appeal process will be. The most severely ill will receive around £5 extra. The Government promises transitional protection of income for existing claimants, but this has yet to be clarified. Also it is not clear what attitudes will be taken by the DWP with reference to ME/CFS. From the information received at the time of printing, it would appear that the only the only advantage is the 'it varies' on the ESA50 form which replaces the IB50. See page 6.

Olympics '08 Go Britain **MoneySavingExpert.com**
FREE TO USE FREE OF ADS UK CONSUMER REVENGE

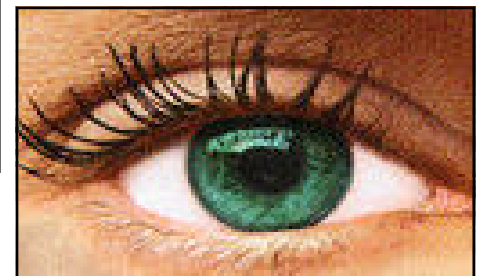
CARDS LOANS RECLAIM £1,000s SHOPPING SPENDING UTILITIES PHONES BANKING SAVING TRAVEL TRANSPORT INSURANCE MORTGAGES HOUSES

The Latest News
DON'T SWITCH PROVIDER!

Aug '08. Time to Switch Traffic Light turned to RED

British Gas and EDF have hiked prices by up to 35% (see [price rise charts](#)); the other four of the big six are almost certain to follow in the next two months. If people say you can save, ignore them: whether they knock on your door; accost you in supermarkets; appear on a comparison site's results page; or even via British Gas's ads.

Any comparisons are now misleading. *Copy from web page*



Gas Energy Prices Up 35% ?

Do they ever come down? There are ways of reducing the costs, with potential savings up to 30%. However there are also potential pitfalls and traps. See page 4.

The Eye and ME

See page 15.



Recipe Corner

See page 10.



Online Fraudulent Emails

See examples received by Leger ME, and advice from Bank Safe Online, the UK banking industry's initiative to help online banking customers stay safe online, run by APACS on behalf of its member banks. See page 11.

BANK SAFE ONLINE

Stay informed...
♦ Types of scams
♦ Spotting scams
♦ Protecting yourself
♦ Frequently asked questions
♦ Helpful sites

Tell us about...
♦ Report a scam
♦ Request advice

Frequently asked questions
Please select a question...

Enter search words... Search

2 August 2008

The UK banking industry's initiative to help banking users stay safe online

Online banking is an enormously popular and safe way to access your bank account, but it pays to be aware of the ways in which criminals can try to gain access to your account and to learn how to protect yourself and your money.

Current warnings
♦ January 2008 - Money Laundering recruitment
New money mule recruitment scams are listed here
♦ January 2008 - Phishing
Find new phishing scams here
♦ March 2008 - Email problems
Our mail server is back up! If you asked us a question please be patient while we

Report a scam →

Helpful sites →

Copy from web page

RCGP Agrees To Stop Classifying CFS As A Mental Health Disorder.

from the ME Association.

The ME Association is pleased to announce that we have been informed by the Royal College of General Practitioners (RCGP) that they will now remove their classification of CFS as a mental health disorder. This follows a prolonged exchange of correspondence with the MEA on this issue and the fact that it was also raised in House of Lords questions to Lord Darzi in June, and at the All Party Parliamentary Group meeting in July. This is an important precedent in that it will now be very difficult for anyone in a position of authority to claim that CFS (or ME or CFS) can be classified or officially listed as a mental health disorder. The MEA will still be meeting the RCGP to discuss the wider issue of diagnosis and management of the illness in primary care. Thanks to both the Countess of Mar for securing time in the House of Lords for questions on ME/CFS to Lord Darzi in June and to Baroness Howe for asking about the RCGP classification. The relevant part of the email from Ruth Palmer, Director of Professional Development and Standards at the RCGP, states:

Dear Dr Shepherd (*Medical Director of the MEA-ed*)

I am pleased to inform you that the Curriculum Development Group and Postgraduate Training Board have now debated the views expressed about the reference to CFS/ME in the Mental Health statement and have agreed to remove the reference from the statement. It was not felt necessary to insert a specific reference to CFS/ME elsewhere in the curriculum, e.g. under Neurological Problems, because the curriculum takes a largely generic approach and does not specify every possible condition. We remain happy to have a meeting with you and I am sorry that it has taken so long to arrange this.

Yours sincerely

Ruth Palmer <http://www.meassociation.org.uk/content/view/427/70>

Thousands 'Wrongly Denied Benefits'

Press Assoc. - Saturday, July 12 08:02 am

Thousands of people unable to work are being wrongly denied incapacity benefit, disability campaigners have said. Charities including the Disability Alliance and Mind say people face months of hardship while trying to get their benefits back, while many more are incapable of appealing. The groups told the BBC the current system of assessing claimants was not working, meaning tens of thousands were missing out. More than 2.6 million people claim incapacity benefit and it was revealed last month that more than 800,000 claimants - nearly a third of all those who claim - have received the allowance for more than a decade. In February the Government unveiled plans for a huge shake-up of the benefits system, with a report arguing that the true number of people in need of incapacity benefit was closer to 700,000. The BBC reports that of the 100,000 people who fail the Personal Capacity Assessment (PCA) each year 25,000 successfully appeal against a decision to deny them incapacity benefit. While they appeal, their benefit is cut by up to £30 a week.

Paul Treloar, from the Disability Alliance, told the broadcaster: "People report to us that the examinations can often feel rushed, they don't feel like they're being properly listened to. And we have had numerous examples where the medical reports contain statements that don't actually reflect the person's home circumstances." The Department for Work and Pensions told the BBC it is developing a new medical assessment which will be much better at identifying the needs of people with mental health problems, and should reduce the number of wrong decisions. Official figures say nine out of 10 of those who come on to incapacity benefit want to go back to work. Many complain of conditions such as back and neck pain, depression or heart and circulatory problems, which the Government believes do not make long-term unemployment inevitable. The Government is set to introduce a new medical test for incapacity benefit claimants in October this year. It will assess what an individual can, rather than cannot, do.

You Write

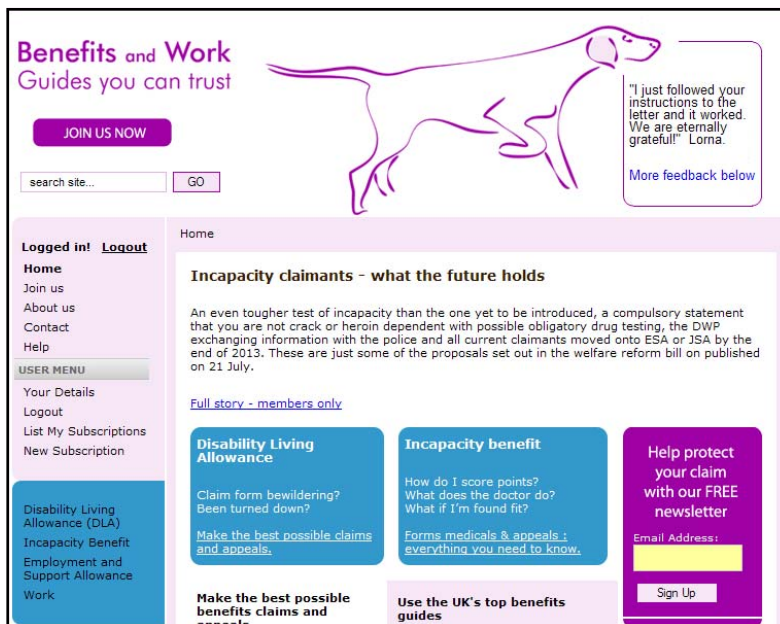
Cloe writes: Here is feature from 5th July's Daily Mail which follows.

Scroungers.com: Website charges £95 for tips on claiming maximum disability benefit

By Tom Harper and Nick Constable (Last updated at 10:33 PM on 05th July 2008)

An internet company is doing lucrative business selling cynical tips on how to squeeze the most disability benefit from the Government – for £95 a time. Customers who sign up are given advice designed to convince ‘snooping’ doctors that patients are sick enough to receive the maximum handouts. Claimants are told to hide any evidence suggesting they may not be eligible for the biggest payouts, such as concealing the fact they are able to travel by public transport or ensuring their walking sticks look well used.....

For your information firstly, www.scroungers.com is a directory website, which is not related to the benefits and work website. Membership costs £18.95 for an individual. I strongly suspect that if I dug deep enough there will be many more examples of *Journalistic Licence*.



A copy of the Benefits and Work front page.

The many of us who have had dealings with the DWP will know all too well what they get up to, and many of the misleading inferences that they draw from even the smallest things. The Benefits and Work website does appear to make information to scroungers public, but much of the information they give is well known to professional welfare rights advisors, for example the CAB or solicitors, and is available from other respected sources like the Disability Alliance. The actual website contains many references to public information from the various DWP websites, which is publicly available, providing you know where to look. Much of it is technical and difficult to understand for the average person, and needs technical interpretation.

The particular problem with ME/CFS, as many of us know, is lack of hard medical evidence. Because of this, ME/CFS is targeted by fraudsters, of which the DWP are all too well aware; and we are given a hard time because of this. When we get a benefit refusal enquiry, on checking the reason for refusal, most are due to lack of, or wrong information. I always advise that anyone with a DWP form like the IB50 or DLA1 requesting health or disability details should see a welfare rights advisor for help and not do it themselves. We have DIAL, SYCIL, DPFC, CAB and DMBC Welfare Rights who provide free services in Doncaster.

A starting point for a sound application is a diagnosis of ME/CFS from a GP, with confirmation from a hospital or ME clinic like Sheffield. The next thing is proof of ongoing support e.g. involvements of a health professional or treatment e.g. medicines or appliances. Lack of this sort of evidence is the main reason for many refusals.

Carolyn Writes: *I am concerned about the recent 35% price rise by British Gas and 9% rise in electricity prices. The problem is that I'm on basic state benefits and already find it hard to make ends meet. I have had extra loft insulation, and a new efficient condensing boiler. All my lights are the new energy efficient light bulbs, and I have even replaced my free fridge freezer. What irritates me most is the free low energy light bulbs I keep receiving from British Gas; I already have a drawer full to overflowing. Wouldn't it be better if they deducted £10 from all our gas bills? I am also being bombarded with offers of different tariffs and being recommended to change suppliers. I notice that in a recent BBC Money programme they stated that irrespective of the deals, price fixing offers and discounts, the cost of energy for the average household is expected to be around £930 PA, and the bottom line between different suppliers is in the order of about £10 –15. I've looked at Martins Money Website, which is advising that now is not the time to change. I saw in a recent BBC programme that the average energy bill is expected to increase from £588 PA to £846 PA for 2008. Any suggestions?*

Firstly, budget your energy. When you buy energy, it is bought in kilowatt hours (kwh); when you use energy; it has to be budgeted just like money. A kwh from gas costs about half the price of an electricity kwh. Most modern electrical appliances use energy almost to 100% efficiency, and very little is wasted. Most gas appliances burn the gas for heat, and there is always a large amount of waste heat or energy that goes up the chimney, which can be 60-70% of the kwh you've paid for. Avoid using any open flame appliance like a gas hob or open fire. Use things like electric kettles, microwaves, steamers in preference to gas, for small scale applications of heat. Modern condensing gas boilers are about 90% efficient, and are the cheapest way to heat large spaces in the home. For hot water, in small amounts, things like electric showers or heaters are cheaper. Think in terms of a bath full of water costing £1, and a shower costing 10p. Avoid using solid fuel (coal) or gas heating for hot water in the summer months as there is a start-up/running overhead, and consider installing an electric immersion or pipe water heater that may save money in the long term. Consider that a gas boiler needs a maintenance contract between £60-200 P.A. for servicing to keep efficient to avoid waste and ensure safety, whereas electrical appliances need less attention.

Secondly avoid energy waste. Turn off unused appliances. Warm Front is a scheme funded by the Department of the Environment, Food and Rural Affairs (Defra) and forms the cornerstone of the Government's pledge to tackle cold homes and reduce fuel poverty by 2010. To date it is estimated that more than four million people in the UK are living in fuel poverty and are spending at least ten per cent of their household income on trying to keep warm. To receive a benefit entitlement check and find out if you are eligible for the Warm Front Scheme. Residents can call the free phone help line on 0800 072 9006 or log on to www.warmfront.co.uk. The Warm Front grant is a government funded grant, aimed to reduce fuel poverty and decrease carbon emissions. Over 1 million homes throughout England have received a Warm Front Grant to help pay for heating and insulation improvements in their home. Households could receive up to £2,700 to help pay for energy saving measures such as draught proofing, loft insulation, cavity wall insulation, central heating, replacement boilers and heating repairs. Residents over the age of 60 and people who suffer from a long term illness or disability like ME/CFS may qualify. Consider double glazing. Dry clothes outside.



Thirdly, buy carefully. If possible pay by direct debit and avoid coin slot meters. Get dual fuel discounts by sticking with the same supplier for gas and electricity. There may be a small saving by swapping suppliers. Most suppliers provide a discounted tariff to existing customers with DLA or pension credit, but you have to ask, and they don't usually offer this to migrating customers. All suppliers buy energy from the same world market, and the scope for discount is only few percent. They may be able to save in distribution costs, but this is only about 15% of the fuel price, and the scope for this is limited. Salesman and websites promoting a change to another supplier usually get a commission of about £50-60, and this usually is hidden in the tariff to the new customer. There are administrative and billing disputes for new migrant customers which just add to the hassle, and stress of ME/CFS. Personally, I use what appears to be the most expensive supplier, British Gas. I have always found them cheaper; at present I am paying 39% below the standard tariff. —Mike

Eve writes: *I have started taking Niacin and within 15 minutes, get the flushing and rash for about another 20 minutes. I know this sometimes happens. If I persevere, are there any long term effects or dangers and is it something my body would get used to after taking it for some time??*

This is a well known side effect of nicotinic acid or Niacin, and is usually just a minor inconvenience or embarrassment. There is a derivative called niacinamide (or nicotinamide), which does the same job but doesn't cause flushing as much, if at all. Just one thing though; the amide works just as well as Niacin as a vitamin supplement, but if you are prescribed it for cholesterol reduction, the amide will not work. Niacin (vitamin B3) is a precursor of coenzyme Q10, which some people find helps ME/CFS. Enada is another B3 analogue (NADH) but it may be an expensive option.

Hazel writes: *I just spoke to Sally from Clouds and she suggested that I contact you about my latest findings. www.freedomfromme.co.uk is a website for a ME/CFS clinic in London. It was started by an amazing guy who recovered from severe ME after 7 years (using nutrition, psychology etc). The website has lots of free info including audio downloads and PDF files (they seem to really care about people and give away a lot of amazing stuff). I have found it incredibly helpful and inspiring. www.secretstorecovery.co.uk is a sister site. It is a pay/month service (£15/month) and is worth every penny as it is full of cutting edge advice, information and stories from people who have recovered. The clinic also do a free DVD and info pack about ME (the DVD was so touching it made me cry!). To obtain a copy of the DVD/pack go to www.freedomfromme.co.uk and request one. Alternatively you can give the clinic a call. I hope this helps others as much as it has helped me.*

Thanks for the information. We are always interested to hear of people's experiences. I think many 'Pathways', readers will be curious to the contents of these services. In particular, what do they do, what do you get for your money, and how did you find their service. Any chances you could review them for us as a significant number do not have internet access?

Charlotte writes: *I have severe grade 4 ME. Around the time of my most recent deterioration I started to have some emotional problems as well. Since then I have been having about 4 distressing nightmares each night. I take an anti depressant and anti anxiety anti histamine. I also have diazepam for muscle spasms. None of these seem to be helping with the nightmares, however. In addition I take melatonin and don't tend to have nightmares during the first part of the night when this is effective, but sadly it doesn't last that long. I know that they can be triggered by bad M.E. and also by emotional troubles, so it would seem I am a prime candidate especially as I also have bad cognitive problems and experience periods of confusion when I forget where I am or major life events such as the death of loved ones. I am being treated for severe pain. I have delayed release morphine which is topped up by an instant morphine. This works extremely well, but I experience an odd sensation. Whenever I am roused from a rest I find that my limbs are burning and I feel the need to have more rest even though I believe what I had should have been sufficient. As soon as I then start to participate in an "activity" the pain disappears. Any thoughts on what the problem is?*

When you sleep overnight, there are 4-5 definite brain activity cycles of just less than two hours. Dreams, odd thoughts, illusions and nightmares tend to occur during what is known as REM sleep towards the end of each cycle. This explains your experience. Melatonin induces sleep, but our group member's experiences of it have been patchy, and some have reported depressive problems as a result. There are a group of prescription medicines called z-hypnotics available on the NHS, but sometimes availability is limited by area policies (postcode lottery), and they are more often prescribed privately by ME doctors. These tend to produce 'clean' dream free sleep, and abolish the pain sensations which usually are carried to the following day after the hypnotic effect has worn off. I know two people who have found zopiclone helpful, whereas some haven't. Some doctors question the long term safety of these drugs, but this also applies to commonly used TCADS) e.g. e.g. amitriptyline. The morning burning pain you describe is more neurological, and is phantom sensation possibly due to neurological disturbances due to ME/CFS related disturbance (HPA axis delay, pain gating imbalances) of the waking process. All of your brain does not wake up at the same time. Your local NHS pain clinic may be able to help.—Mike

Employment Support Allowance with thanks to the Disability Alliance.

Employment and Support Allowance (ESA) is a new benefit that will replace Incapacity Benefit (IB) and Income Support (IS) paid on the grounds of ill-health or disability. The introduction of ESA forms part of Government's welfare reform plans contained in the Welfare Reform Act. Regulations setting out how ESA will work were published in March 2008, with the introduction of ESA proposed for 27 October 2008. ESA will replace both IB and IS which are paid on the basis of incapacity. ESA will have a new structure that has both a contributory element and a means-tested element. The test of entitlement to the contributory element will be similar to that currently used for IB, i.e. sufficient national insurance contributions paid. The test of entitlement for the means-tested element will be similar to that currently used for IS i.e. an income-based assessment. There are no age or dependent additions. Many ESA claimants will receive less benefit than they would with IB currently. IB and IS claimants who transfer to ESA will not experience a drop in their income on transfer. For those migrating from Statutory Sick Pay (SSP), and new claimants who also receive Disability Living Allowance, this appears particularly harsh. It is also possible that such claimants could receive less benefit, due to the difference in rates between SSP and assessment phase ESA, and the lack, in ESA, of an equivalent to the Disability Premium which exists for some current benefits.

Group	First 13 weeks assessment phase	Addition after 13 weeks	Sanction For the first 4 weeks after default	Sanction after first four weeks of default
Over 25	£ 60.50	N/A	N/A	N/A
Work-related activity group	£ 60.50	£ 25.00	£12.50 reduction	All extra payment stopped
Support group	£ 60.50	£ 29.00	N/A	N/A

First work-focused interview. During the 8th week of a claim, all ESA claimants will experience a work-focused interview. A Jobcentre Plus personal adviser will meet the claimant to discuss their ESA entitlement, their aspirations for work, the steps that could be taken to help them to take up a job and the support that is available. This interview can be deferred if a decision is taken that a claimant is so sick or disabled that the interview would be of no assistance to them, or is not appropriate e.g. for terminally ill claimants. Otherwise, attendance at the interview will be mandatory and ESA payments can be reduced or 'sanctioned', if a claimant fails to attend or participate in this interview without good cause. There will be a Work capability assessment In addition to the basic tests of entitlement, ESA claimants will have to undergo a Work Capability Assessment (WCA) within the 13-week assessment phase.

1) **Limited capability for work assessment** will be carried out by a DWP 'health care assessor' who will assess physical and mental health 'descriptors'. A score of 0, 6, 9 or 15 points is assigned to each descriptor. If the total score is 15 points or more, then, as with the existing PCA, the claim will be accepted. This part of the assessment is based on the current PCA, used to assess entitlement to IB and IS. However, the structure of the new WCA has been radically revised.

2) **Limited capability for work-related activity** will be carried out at the same time. This looks at whether it is reasonable for the claimant to undertake any work-related activity. If a claimant demonstrates that any one of 46 descriptors applies to them, they will be put into the 'support group', and will not be expected to engage in work related activity, although they can volunteer to do so. Those in the 'work-related activity group' will have to undertake a variety of work-related activities as a condition of continued entitlement to ESA.

Limited capability for work questionnaire Jobcentreplus
Part of the Department for Work and Pensions

We need you to fill in this questionnaire if you have claimed or are getting any of the following:

- Employment and Support Allowance
- National Insurance (NI) credits
- Housing Benefit

Please send this form back as soon as you can. If you do not send it back within 4 weeks you might lose benefit. If you are sending the form in late we need to know why. You can use the space on page 26 to explain.

You may wish to fill in this form a bit at a time as it may take some time to complete.

If we are able to get enough information from this form, you, your doctor or the person treating you, we may not need to ask you for a medical assessment.

If you want to see a doctor, you should see them as soon as you can.

If you want to see a health care assessor, you should see them as soon as you can.

Ask a friend or relative to help you, or get a friend or relative to fill in the form for you. The person from Jobcentre Plus will have a copy of the form and they will go through the questions you are having trouble with.

Sometimes they may be able to help you. If they do this, you should send the form to you. You should fill it in and send it back to Jobcentre Plus.

They can send you a copy of the form in braille or large print.

For information about the services visit our website www.dwp.gov.uk

As about yourself

Name

Other names

Title Mr/Ms/Ms/Ms

Date of birth / /

Postcode

National insurance (NI) number Letters Numbers Letter

ESA50 10/08

Support group: These people do not have to undertake further work-related activities but may volunteer to do so. They receive a higher rate of ESA and are not subject to conditionality or sanctions.

Work-related activity group: These people will have to participate in a work-focused health-related assessment, as well as further work-focused interviews. If a claimant in the 'Work-related activity group' has failed to attend or participate in the range of work-related activities without good cause, the extra work-related element of their ESA payment may be sanctioned.

3. Work-focused health-related assessment (WFHRA) will be carried out by a health-care professional approved by the Secretary of State. It seems likely that this will be carried out immediately after the two capability assessments, as noted above. This provides additional information about the claimant's residual functional capacity, i.e. what the claimant can do despite their disabling condition, as well as information about any health interventions that would improve their functional capacity. This includes adaptations that might be necessary to support a person going back to work. The advice from the WFHRA, in the form of a 'capability report', will be made available to the claimant and their personal adviser to be used when they have passed the assessment phase and are undertaking further work-focused interviews. A failure to participate in the WFHRA, without good cause, can attract sanctions to ESA payments, except for 'support group' claimants who volunteer to participate in a WFHRA.

Further work-focused interviews: Those placed in the 'work-related activity group' will undergo five further monthly work focused interviews after the 13-week assessment phase has passed. During these interviews, a personal adviser will try to help the claimant back to work. At this stage, the personal advisers will usually be employed by a contracted private or voluntary sector organisation. The capability report produced from the WFHRA will be used to inform actions recommended during the work-focused interviews. The Personal Adviser will draw up an Action Plan outlining activities that the claimant could consider undertaking to move closer to the labour market. They can also give direction about what can and cannot be accepted as work-related activity. This will be optional initially, but in the longer term, the Government intends to make compliance mandatory, with regards to the directions and undertaking some kind of work-related activity. From the introduction of ESA, attendance and participation at the interviews is mandatory, with the risk of sanctions being imposed for failure to attend or participate without good cause. ESA claimants can ask for an interview to be deferred or waived but this is at the discretion of their personal adviser.

Work-related activity. The Government has stated that no claimant will be forced to undertake any work-related activity resulting from their work-focused interview or Action Plan. However, there is a longer-term intention to review this situation, and there will be powers to make claimants in the 'Work-related activity group' undertake some form of work-related activity. Work-related activity can include work tasters, managing health and work issues, improving employability, job search assistance and stabilising life styles.

Sanctions can only be applied to the additional elements of ESA after the 13-weeks, so an ESA claimant will always retain entitlement to the basic or 'assessment phase' rate of ESA, provided they satisfy the other basic entitlement criteria of having a limited capability for work. A sanction will initially halve the additional element for 4 weeks, then stop it thereafter, and it will only be restored on compliance. There will be an appeal process and safeguards, the details of which has not yet been clarified. Private and voluntary sector contractors will be a key element in the system. Their involvement will be centred mainly on employment rehabilitation i.e. helping and encouraging ESA claimants to undertake work-related activity.

Existing IB/IS claimants will move to ESA over time. The most recent IB and IS claimants over to the new ESA system first, as well as those with dependent children. An analysis of current IB claimants suggests that there could be approximately 850,000 claimants who would receive this transitional protection at current rates of payment. Further, there are some 550,000 current IB claimants who have been receiving IB for more than 5 years. It would appear that these people could remain on the 'old' system for sometime to come, until their review is due.

The ESA 50 Form Reviewed

During the first weeks of an ESA claim, a Work Capability Assessment will be actioned. The claimant will receive an ESA 50 form to fill out. It appears that the ESA 50 will be a 'plug in replacement' for the IB50. Almost all of our group members will have encountered the IB50 form with its perils and pitfalls. The main complaint was that the questions asked for definite answers—which for ME/CFS are never clear-cut and always variable. This has caused many members confusion, benefit refusals, appeals and tribunals. Always the questions had to be broadly interpreted and the nearest answer given, which in almost all cases could never be 100% true. The ESA form does have one advantage—in almost all the questions there is a 'varies' option. The mental health section rather than just being a blank box now has choices, and now also even has a 'varies' option. The ESA 50 will be scored, as with the IB50, and a score of 15 will grant the claim. Although the DWP say that as far as possible they will not call claimants for a medical examination, with the new system as with the old, it will be inevitable for ME/CFS patients. They will certainly contact doctors, and other health professionals for further evidence. It is also highly likely that claimant will face a medical examination, and be assessed by a DWP doctor using a variation of the LiMA system, and possibly also an ESA85 report. A specimen ESA50 can be downloaded from:
<http://www.disabilityalliance.org/esa50.pdf>

Walking

We need to know if you have any difficulties walking.
 By walking we mean walking on level ground, using any aid you normally use.

Please tick the first statement that applies to you. Tick one box only.

I have no problem walking	<input type="checkbox"/>
I cannot walk at all	<input type="checkbox"/>
I cannot walk more than a few steps without stopping or feeling severe discomfort	<input type="checkbox"/>
I cannot walk more than 50 metres (about 55 yards) without stopping or feeling severe discomfort	<input checked="" type="checkbox"/>
I cannot walk more than 200 metres (about 220 yards) without stopping or feeling severe discomfort	<input type="checkbox"/>
I cannot walk more than 400 metres (about 440 yards) without stopping or feeling severe discomfort	<input type="checkbox"/>
I cannot walk more than 800 metres (about half a mile) without stopping or feeling severe discomfort	<input type="checkbox"/>

Above, the Walking section of a IB50 from demanding a definite answer.

Below, the corresponding section of the ESA 50 allowing a more ME friendly Varies option

1. Walking and using steps

If you normally use a walking stick or crutches, tell us how you walk or use steps with these.

Please tick this box if you can walk and use steps without any difficulty. ☐ Now go to question 2.

Can you walk on level ground?	No <input type="checkbox"/>	Yes <input type="checkbox"/>
Can you walk at least 200 metres (about 220 yards) before you need to stop?	No <input type="checkbox"/>	Yes <input type="checkbox"/>
To give you an idea about distances: A double-decker bus is about 11 metres long, and a football pitch is about 100 metres long.	It varies <input checked="" type="checkbox"/>	

Use this space to tell us how far you can walk and why you might have to stop. For example tiredness or discomfort. If it varies, tell us in what way.

ES&A Draft Tool

Points: Physical Points: Mental 0 Fail

	Descriptor
1) Walking	Cannot walk at all
2) Standing and sitting	Cannot walk more than 50 metres on level ground without repeatedly stopping or severe discomfort
3) Bending or kneeling	Cannot walk up or down two steps even with the support of a handrail
	Cannot walk more than 100 metres on level ground without stopping or severe discomfort.
	Cannot walk more than 200 metres on level ground without stopping or severe discomfort
	None of the above apply
4) Reaching	

Left is an image of the ESA50 demonstrator tool on www.leger.me.uk which is intended to help understanding of the points scoring system. Our advice is that anyone with a IB50 or ESA50 form to fill out should seek the assistance of a welfare rights advisor, and not attempt to do the forms themselves. The DWP have will have their own way of scoring possibly via the LiMA system.

The new EAS50 and old IB50 points system compared.

The physical descriptors are reduced, and the low scoring points are abandoned, scoring 6, 9, or 15. The mental health descriptors are reduced and are now scored as physical. The 1 or 2 scoring is abandoned. These are also directly listed in the ESA50 and directly asked, rather than just a blank box as in the IB50.

<u>ESA 50</u>	<u>IB 50</u>
<i>The physical descriptors</i>	<i>Some merged, reduced from 14 to 11</i>
• Walking.	Walking on level ground. Walking up and down stairs.
• Standing and sitting.	Sitting in an upright chair with a back Standing without the support .Rising from an upright armless chair
• Bending or kneeling.	Bending and kneeling.
• Reaching.	Reaching
• Picking up and moving things.	Lifting and carrying by the use of upper body and arms
• Manual dexterity.	Manual dexterity
• Speech.	Speech
• Hearing.	Hearing
• Vision.	Vision in normal daylight or bright electric light
• Contenance.	Contenance; other than enuresis
• Remaining conscious.	Remaining conscious during day
<i>The mental descriptors</i>	<i>Some discarded, some new, some merged, reduced from 24 to 10</i>
• Learning or comprehension in the completion of tasks.	Frequently finds there are so many things to do that he gives up because of fatigue, apathy or disinterest Cannot answer the telephone and reliably take a message Often sits for hours doing nothing.
• Awareness of hazard.	Agitation, confusion or forgetfulness has resulted in potentially dangerous Overlooks or forgets the risk posed by hazards due to poor concentration Cannot concentrate to read a magazine article or follow a radio or television programme.
• Memory and concentration.	Sleep problems interfere with his daytime activities.
• Execution of tasks.	Avoids carrying out routine activities because he is convinced they will prove too tiring or stressful
• Initiating and sustaining personal action.	Cannot look after himself without help from others
• Coping with change.	Is unable to cope with changes in daily routine
• Getting about.	Is too frightened to go out alone Prefers to be left alone for 6 hours or more each day
• Coping with social situations.	Needs encouragement to get up and dress Mental problems impair ability to communicate with other people Cannot use a telephone book or other directory to find a number
• Propriety of behaviour with other people.	Gets upset by ordinary events and it results in disruptive behavioural problems Is frequently distressed at some time of day due to fluctuation of mood.
• Dealing with other people.	Mental problems impair ability to communicate with other people Frequently feels scared or panicky for no obvious reason
(no equivalent)	Gets irritated by things that would not have bothered him before he became ill Is scared or anxious that work would bring back or worsen his illness Mental stress was a factor in making him stop work Needs alcohol before midday Mental condition prevents him from undertaking leisure activities previously enjoyed

Recipe Corner

Lazy Chicken and Rice

An all in one pot recipe for the cooler days

Preparation Time: 30 minutes, Cooking Time: 45-55 minutes,
Serves 4/6 depending on appetite

Ingredients:-

4 Chicken thighs, 4 chicken drumsticks, Salt and black pepper, 2 tbsp light oil, 1 small onion, chopped, 1 red or yellow pepper, deseeded and chopped, 250g mushrooms, sliced, 2 cloves garlic, finely chopped, 1 teaspoon mixed dried herbs, ½ a teaspoon crushed chillies (optional) 250g Basmati rice or, long grain rice, 850 ml boiling chicken stock, (a cube is OK but reduce salt if using), juice of 1 juicy lemon or lime



Method:-

- Preheat oven to 200/400F/gas mark 6, and lightly oil a large ovenproof baking dish.
- Heat the rest of the oil in a large frying pan over a medium high heat, season the chicken pieces with salt and pepper and fry until the skin is golden, about 5-7 minutes.
- While the chicken is frying, scatter the chopped onion, peppers, mushrooms, garlic, herbs, chillies (if using) and rice over the bottom of the baking dish. Lay the browned chicken pieces on top, skin side up.
- Pour the lime or lemon juice into the hot stock, place the baking dish with the chicken and rice onto the middle shelf in the oven and carefully pour over the boiling stock.
- Bake uncovered for 45 minutes. Check for 'doneness' – the chicken should be thoroughly cooked and the rice tender. If not, cook a little longer, checking after 5-10 minutes.

Note: - If using a fan assisted oven, check half way through the cooking to make sure the liquid hasn't evaporated. Top up with some water if necessary.

Christmas Style Baked Clementines

Yes, I know, Christmas is a long way off but this is so easy and yet 'different' that I wanted to be sure you all had the recipe before Christmas time arrives, so here goes:-

Ingredients:-

Whole Clementines or Oranges. Kirsch, or your favourite spirit/
Vanilla pods, Good Vanilla Ice-Cream

Method:-

- Blanch the clementines in boiling water for 30 seconds. Pierce the top of each clementine and insert a vanilla pod in each. Gently place the clementines on a baking rack on a baking tray. Place into a very hot preheated oven, turn off the oven, and leave to dry overnight.
- Once the clementines are dry, make a hole in the top and spoon some Kirsch or your favourite spirit into each one. Place back into the oven for 15 minutes.
- Prior to serving, slice the clementine into two halves, and top with the vanilla ice-cream, and any other decoration you wish to add.
- Scoop out with small spoons to eat.....



How you got any favourite Christmas recipes? Let us have them for the November issue. Carolyn.

For countdown fans: 11+2 = 12+1, i.e. ELEVEN PLUS TWO = TWELVE PLUS ONE.

The letters in the sum are anagrams, which are the same letters rearranged!

Online Fraudulent Emails

A compilation from personal experience through Leger ME and APACS advice.

Around 15 million people in the UK bank online, and it is a very secure and convenient way to access your bank's services. Many ME/CFS sufferers find that online banking services a convenient way to deal with their finances, and help manage their pacing. However, wherever money is involved there is a criminal element at large all too ready to exploit any weaknesses in security. Users have to be on the lookout for scammers who may try to gain access to your account, usually by trying to fool you into handing over security information such as user names, passwords and memorable information. Users must learn how to recognize the danger signs of online fraud. Most scams have similarities to offline schemes that targeted consumers and investors many years before the creation of the Internet. The main scams are 'Phishing', 'Trojans', and 'Money Mules'.

'Phishing'

Phishing is the name given to sending emails at random purporting to come from a genuine company operating on the Internet, in an attempt to trick customers of that company into disclosing information at a bogus website operated by fraudsters. The emails are sent out completely at random in the hope of reaching a live email address of a customer with an account at the bank being targeted.

Mechanism: These emails usually claim that it is necessary for users to "update" or "verify" customer account information and they urge people to click on a link from the email which takes them to the bogus website. Any information entered on the bogus website will be captured by the criminals for their own fraudulent purposes.

Prevention: Be suspicious of all unsolicited or unexpected emails received, even if they appear to originate from a trusted source. Although a customer's bank may contact the customer by email, they will never ask users to reconfirm their login or security password information by clicking on a link in an email and visiting a web site. Think about how the bank normally communicates with you and remember never to disclose a password in full or any of your personal information.

What to watch for: Banks will never contact users by email to ask users to enter their password or any other sensitive information by clicking on a link and visiting a web site.

1 –Emails can look like they come from a real bank email address. It is relatively simple to create a fake entry in the "From:" box. The displayed address is NOT a guarantee that it came from the person or organisation that it says it did. They do not originate from the bank's own systems.

2 - The emails are sent out at random to bulk email lists and the fraudsters will almost certainly not know the users real name or indeed anything else about users, and will address users in vague terms like "Dear Valued Customer".

3 - Banks will never write and ask users for passwords or any other sensitive information by email.

4 - Odd "spe11ings" or cApitALs in the "Subject:" box (an attempt to get around spam filter software), as well as grammatical and spelling errors.

Trojans

Trojans take their name from the term 'Trojan Horse' and are a type of computer virus which can be installed on a computer without users realising. Trojans can be capable of installing a "keystroke logger", which captures all of the keystrokes entered into a computer keyboard. Some specifically seek to capture passwords entered at certain web sites, by capturing keystrokes or taking screen shots of sites users visit. This information is then sent to the fraudsters over the Internet.

Mechanism: Typically the fraudsters send out emails at random to get people to click on a link from the email and visit a malicious web site where vulnerabilities in the web browser are exploited to install the Trojan. The emails are not normally related to Internet banking and try to dupe people into clicking on the link to the malicious web site with a variety of excuses. Firewalls, up to date antivirus software and anti-spyware programmes all provide the best defence from Trojans, so it is important that surfers use these to protect their computer.

Prevention: Most Trojans exploit vulnerabilities in Internet Explorer. Users should ensure that they are using the latest software version and it is essential that users download all of the Internet Explorer Critical Updates (also known as "security updates" or "patches") from the Windows Update

site. Consider using a different kind of web browser. It is essential that users protect their computer by using up-to-date anti-virus software, doing regular scans of the computer to check for viruses, installing a personal firewall and also the latest security updates for their web browser and operating system. Treat all unsolicited emails and those from unknown senders with caution and never click on links from such emails to visit unknown web sites. Some Trojan emails contain code to download the Trojan when the message is previewed or opened using 'HTML view' in users email programme. It is always safer not to open messages from unknown sources and to read messages in 'plain text' setting of the browser.

What to watch for: Emails masquerade as almost any kind of message. Treat all unsolicited emails with caution, but the main similarity is that they try and get users to click on a link by alarming users (e.g. "Your credit card will be charged"), or by tempting users with some dramatic information (e.g. "Osama Bin Laden captured", "Terrorists target Olympic Games", "Someone sent users a private message"). Use an anti-spam product to help to filter out such unsolicited emails. A malicious web site contains code which installs a harmful programme such a Trojan, computer virus or adware onto user's computer. If visited, the web site may appear to be completely ordinary, but behind the scenes it will be installing the malicious code and this may not be apparent, although sometimes a programme will launch unexpectedly, or users may notice a lot of activity on user's internet connection as the files are downloaded. Malicious code may be disguised within the page, so cannot be easily being identified, unless users have specialist knowledge. Even the plainest looking page can conceal malicious code behind the scenes.



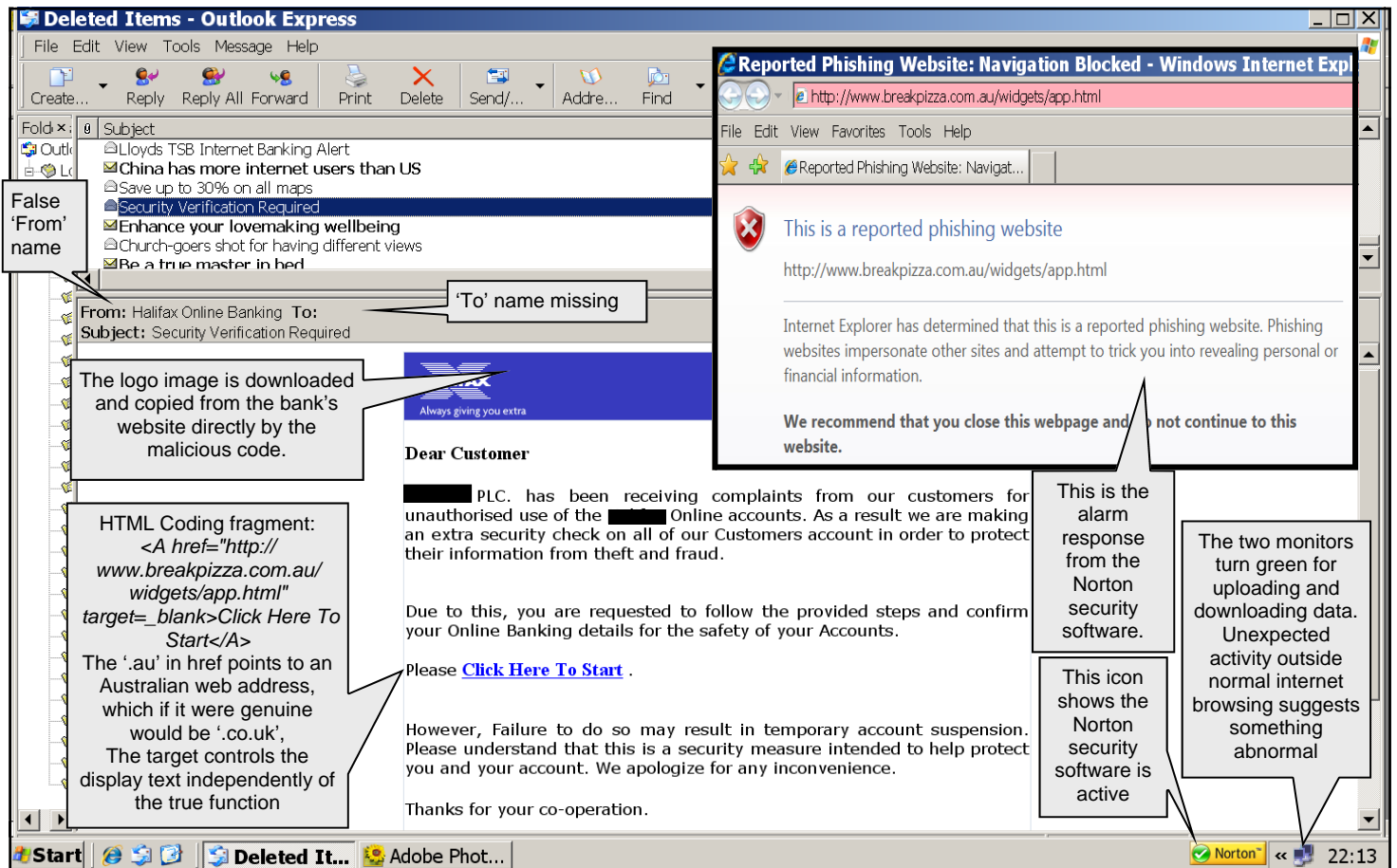
Two online security devices issued by the major banks to vary the access codes, thereby adding another layer of security, in addition to passwords and pin numbers. The first is a key fob style device that supplies a different access code every time the button is pressed. The second is calculator style, with it's own pin & card security. When a request access inline is received, a number is issued, which is then keyed in, a response is displayed by the device, giving the access code.

Money mules?

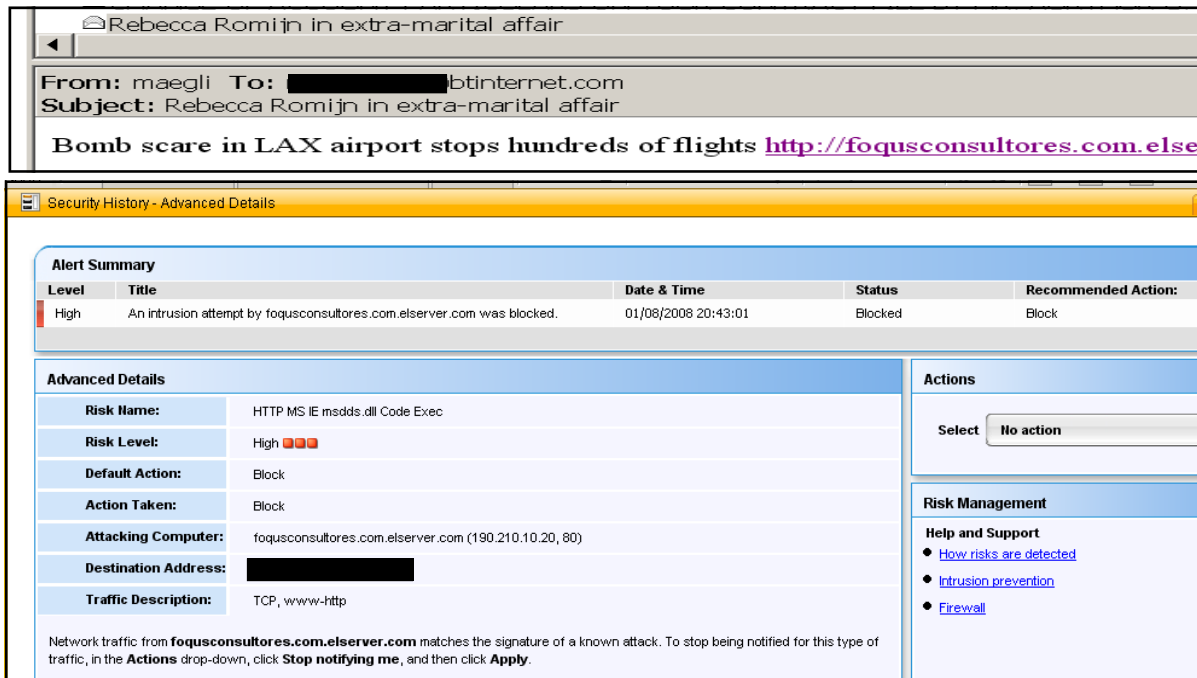
As most of the fraudsters behind these scams are located overseas and it is not possible to make cross-border transfers out of UK online bank accounts overseas, a "money mule" or "money transfer agent" is required to launder the funds obtained as a result of phishing and Trojan scams. After being recruited by the fraudsters, money mules receive funds into their accounts and they then withdraw the money and send it overseas using a wire transfer service, minus a certain commission payment. Money mules are recruited by a variety of methods, including spam emails, adverts on genuine recruitment web sites, approaches to people with their CVs available online, instant messaging and adverts in newspapers.

Mechanism: Potential victims are contacted with "job vacancy" adverts via spam emails, letters, newspaper job adverts, Internet chat rooms or job search web sites. Jobs are usually advertised as a "financial manager" and suggest that no special knowledge is required. The victim is convinced to come and work for their fake "company". Some even ask to sign official-looking contracts of employment. Once recruited, money mules will receive funds into their accounts; which will have been stolen by the fraudsters from another account that has been compromised. Mules are then asked to take these funds out of their account and to forward them overseas (minus a commission payment) typically using a wire transfer service. Acting as a mule is an illegal activity. If caught, mules often have their bank accounts suspended. Positions on offer can include "UK representative", "shipping manager", "financial manager" or "sales manager". They offer some easy money for a few hours work each week, usually just requiring that users have access to the Internet. Although easy money may appear attractive, any "commission" payments will be recovered as they are the proceeds of fraud and users may become embroiled in a police investigation. Users will be the easiest part of the chain to track down and supplying any information to the fraudsters may also put users at risk from identity fraud.

Examples of Malicious Phishing, Trojan and Money Mule emails



Anatomy of a bad 'Phishing' email received by Leger ME viewed in Microsoft's Outlook Express browser with Norton Security. Leger ME do not use this particular bank, so it was deleted. The subject list contains 'Phishing' and Trojans.



Upper.

A single line email which appears to link to a pornography site appears to download a video file.

Lower.

The link download was blocked by the Norton security software, this is the alarm screen response which is generated when a security alert is triggered.

Dear Friend,

(TOP SECRET)

I have decided to contact you on a business transaction that will be very beneficial to both of us at the end of the transaction. I will not fail to inform you that this transaction is 100% risk free. On smooth conclusion of this transaction, you will be entitled to 30% of the total sum as gratification, while 10% will be set aside to take care of expenses that may arise during the time of transfer and also telephone bills, while 60% will be for me. Please, you have been advised to keep "top secret". All other necessary vital information will be sent to you when I hear from you.. I look forward to receive your phone number and email to enable me finish you with more details. Trusting to hear from you immediately.

Yours Faithfully,

This is an example of text from a received email which appears to originate from East Africa which could be construed as a Money Mule scam. Note the odd language, spelling (underlined) and grammatical errors.

Prevention: Be cautious about any unsolicited offers or opportunities offering users the chance to make some easy money. Be especially wary of offers from people or companies overseas as it is harder for users to find out if they really are who they say they are. Take steps to verify any company which makes users a job offer and check their contact details (address, phone number, email address and web site) are correct and whether they are registered in the UK. Never give bank details to anyone unless they are known and trusted.

What to watch for: Be wary of any unsolicited offers or opportunities for work, especially if the company is based overseas. They should verify the details of any company that users are consider dealing with and never give bank account details to someone they don't know or trust. Users should contact their bank immediately if they think that they may have become involved in a money mule scam. Money mule adverts or offers can take a variety of different forms and they may even copy a genuine company's web site and register a similar web address to add authenticity to the scam. These adverts will normally state that they are an overseas company seeking "UK representatives" or "agents" to act on their behalf for a period of time, sometimes to avoid high charges for making payments, or local taxes. The advert may be written in poor English with grammatical and spelling mistakes and they may urge users not to inform the bank or the police about the reason for making the payments. The adverts may seek people with accounts at certain banks, or Internet payment systems. Remember that even if users have nothing to do with the actual extraction of funds from another person's account, by allowing an account to be used to receive and transfer such funds, users will be acting illegally.

I have been using the internet heavily for about 9 years. I have seen many scams, and been caught out once after browsing some obscure USA websites. I didn't realise anything was wrong until I went to my bank accounts. Extra fields had been inserted in the sign in page calling for full details of password and security information, rather than just several random characters. I immediately rang the bank and confirmed that no signing in changes had taken place, and stopped all the accounts.

The Trojan somehow disabled the Windows OneCare security package. I had to use several free downloads from the internet, to find the offending Trojan code, but they couldn't remove it. It was a version of a 'backdoor virus' that was a keystroke logger, sending my keystrokes to another website, but it also intercepted and modified the banks website display. I informed the bank, but they were unhelpful. Once identified, the malicious file was erased, but kept replacing itself. So it was obvious that the Trojan file has one or more backup files, and these had somehow interfered with the erase process. It was obvious that the originator of this Trojan has an intimate knowledge of the banks' systems, Windows, HP computers, and how to override the various security features. I did clear it out eventually. It took about two weeks before things were back to normal. I personally think the bank knew more than they were willing to admit for fear of loss of public confidence. Not long after, the bank did offer a free Norton security package subscription and an electronic gadget to produce different security access numbers rather than fixed ones.

Unless you are a software engineer, you have to rely on the various available security packages. I consider it good practice to:

- 1) Use the package offered by your bank or internet service supplier. For example BT level 2 offers free Norton. Cable companies have similar deals with other suppliers. Go for the complete package, rather than components. Some 'free' internet security software downloads contain Trojans or viruses. Use only store-purchased or service supplier-sourced security packages.*
- 2) Set up your computer to regularly update your operating system e.g. Windows on a weekly basis. Set up your security software to update at least once weekly and do a full system scan.*
- 3) Get to know your system, and watch out for anything unexpected. If you are not sure, check it.*

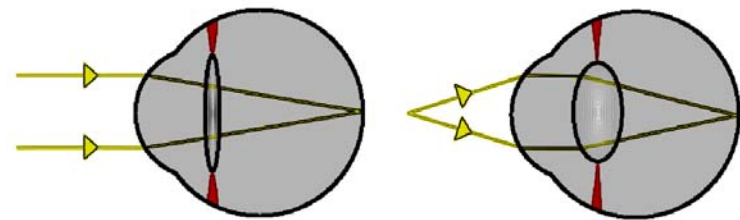
Internet service suppliers are now installing virus and Trojan checkers on their servers. Many offer an anti-spam service. Recently my emails to the Sheffield group and also their Chairman's were blocked because of an error made by an internet security company. There is no doubt that as security gets more sophisticated so will the skills of the scammers. In the early days, most of the malicious computer software was nothing more than a prank, causing inconvenience. Now, with more business done over the internet, most of it has a more sinister purpose. Mike.

ME/CFS, the Eye, the Brain and Vision.

ME/CFS is a neurological disease. The camera components of the eye are under neurological control. The imaging proceeding of eye is neurological, involving the brain, retina and optic nerve, and not surprisingly is affected by ME/CFS in certain ways

The eye as a camera. The optical part of the eye is to project an image of the outside world into a sensitive medium. For a camera, this is film or a CCD array; for the eye it is the retina. In order to focus the image, a lens needs a device to focus.

In cameras adjusting mechanically, adjusting the lens distance from the film/CCD achieves this, while in the eye, the lens is set at viewing distance, but in order to focus close up, (this is called accommodation) the ciliary muscles, in a ring around the lens contract, and squeeze the lens to a rugby ball shape to achieve

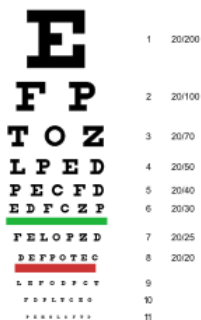


focus. This process takes energy, and the ciliary muscle can

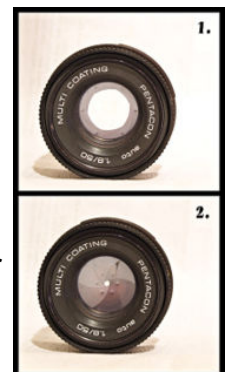
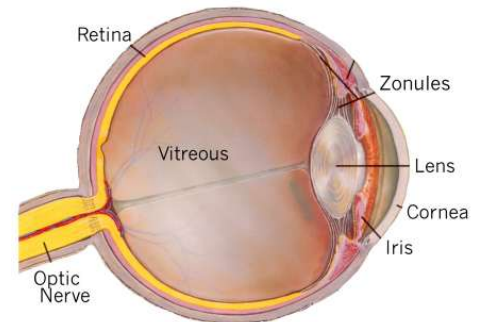
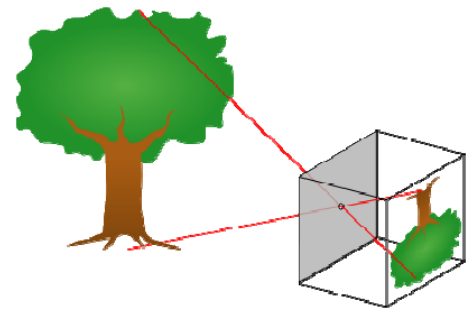
become exhausted as can any muscles with ME/CFS. This is why when some ME's become fatigued, they are slow in focusing or they cannot

focus close up, and need many hours rest before accommodation is restored. Many ME/CFS patients visit their opticians in the hope find a solution to this problem, and very often nothing wrong is found wrong with the optics. This mechanism is under neurotransmitter control. Drugs with anticholinergic activity e.g. TCADs can cause a similar effect.

The pupil is the hole (aperture) through which light enters the eye. The iris is like a tap, it controls the amount of light entering the eye in the same way as that of a camera, opening wide for dim light and shrinking for bright light (right). As with the lens, this mechanism is under neurotransmitter control. Drugs with anticholinergic activity e.g. TCADs and adrenalin (stimulant type drugs) can cause the iris to dilate producing light-sensitivity and focus problems.

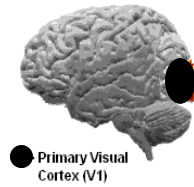


Opticians commonly use a Snellen chart (left) to measure the defects of the optics of the eye and supply corrective glasses. Myopia is the name for being short sighted, for which reducing lenses are used for correction. For hypermetropia (long sightedness), magnifying lenses are used. The ability of the eye's lens to focus close up decreases with age, necessitating the use of magnifying reading glasses.

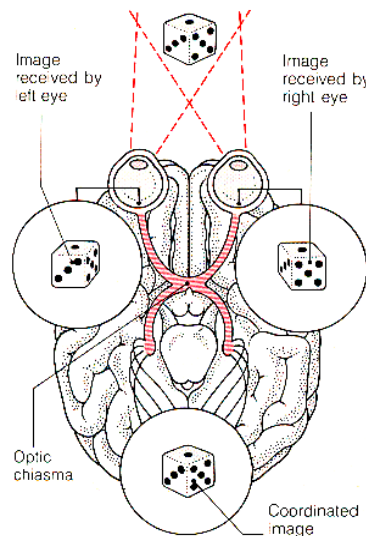


The eye as a photoreceptor. The retina contains the rods which detect brightness, cones for colour in three types (red, green and blue) and non-imaging ipRGC (intrinsically photosensitive retinal ganglion) cells. IpRGCs are light meters and enable resizing of the pupil and suppression of the pineal hormone melatonin, which is used to control sleeping and the body clock. In ME/CFS, this body clock is usually late, and sometimes Melatonin is prescribed in an attempt to resynchronise the (circadian) clock, and induce a normal sleep pattern. The fovea (macula), directly behind the lens in the central field of vision consists mostly of densely-packed cone cells, which gives highly detailed central colour vision. Rod cells are around the remainder of the visual field except the macula. These give light sensitivity. As the light level drops, vision is shifted from cone vision to rod vision, which is why, in darker conditions, colour seems to fade. The visual information collected by the retina is processed (compressed) by a series of ganglions into a recipe to recreate the image that the brain can understand, e.g. as with digital cameras, rather than sending the whole image down the optic nerve.

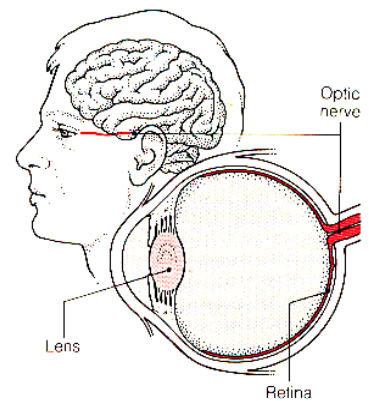
Processing the image information. The output signals from both eyes are sent along the optic nerves to the optic chiasma. There, most cross and are passed to the primary visual cortex at the back of the brain. Some signals are not crossed enabling overlapping of the visual fields and stereo vision. The image from the retina is upside down, and the left hand part of the brain processes the output from the right eye and vice versa. The cognitive problems in some ME/CFS patients may be due to abnormal visual processing.



Each optic nerve is a bundle of long fibres originating from nerve cells in the retina and passing to the back of the brain. Because of the arrangement of the nerve fibres,



disease or injury at any point causes a unique pattern of visual loss. Charting the pattern of visual loss allows accurate location of damage to the nerve.



Binocular vision

Because the eyes are a distance apart, they form slightly different images of a nearby object. The fusion of these two images into one provides the illusion of solidity. This is called stereopsis.

Common ME issues

Photophobia, this dislike of bright lights is quite common in ME/CFS, and can be quite disabling. Darkened rooms or dark glasses sometimes help, but not always, and sometimes the fatigue induced can only be relieved by total darkness or rest. Low doses of the antipsychotic drug olanzapine are used in some London clinics. The problem is hypersensitivity of the brain, and is common to some other brain disorders like meningitis and metabolic disorders e.g. porphyria. Eye Pain (retinal orbit pain) can be severe, and doesn't usually respond to drugs; quiet rest is the only answer. This has to be distinguished from migraine which also may include nausea & vomiting and visual field disturbances like red flames or scintillation.

Nystismus is involuntary rolling of the eye, sometimes seen as a sign of fatigue or worsening of ME/CFS

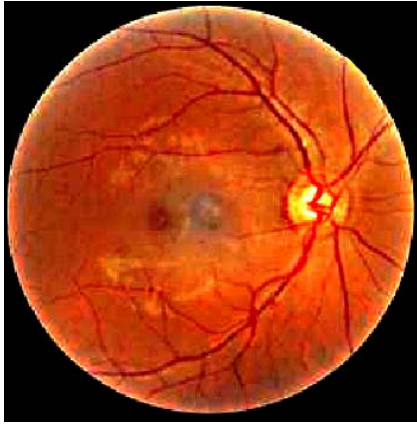
Blepharospasm is involuntary movement of the eyelids due to muscular spasm and is similar to fasciculation. It is usually a sign of fatigue or bad pacing.

Dry eye may be an indication of a connective tissue disease like Sjogrens syndrome, which needs medical treatment.

Visual field disturbances

In a survey of patients, Action for ME found 62% of the patients surveyed suffered with this problem. Many are neurological in origin. Common causes of scotomata include demyelinating disease such as multiple sclerosis (retrobulbar neuritis), toxic substances such as methyl alcohol, ethambutol and quinine, nutritional deficiencies, and vascular blockages either in the retina or in the optic nerve. Scintillating scotoma is a common visual aura in migraine. Less common, but important because sometimes reversible or curable by surgery, are scotomas due to tumours such as those arising from the pituitary gland, which may compress the optic nerve or interfere with its blood supply. Rarely, scotomas are on both sides. One important variety of bilateral scotoma may occur when a pituitary tumour begins to compress the optic chiasma (as distinct from a single optic nerve) and produce a bi-temporal hemicentral scotomatous hemianopia. This type of visual field defect tends to be very eloquent symptom-wise but often evades early objective diagnosis. In a pregnant woman, scotomas can present as a symptom of severe pre-eclampsia, a form of pregnancy-induced hypertension. Similarly, scotomas may develop as a result of the increased intracranial pressure that occurs in malignant hypertension.

In the following page we have created images to try explaining and help—obviously if anything abnormal happens, you need to discuss it with your doctor - *Mike*.



A natural visual blind spot. This is a view of the optic disk which opticians and doctors see during eye examinations. The dark area in the middle is the macula, the area of most acute vision. The orange/yellow spot is known as the blind spot, and area where the optic nerve and blood vessels enter the eye and radiate to supply the retina. This the only place in the body where blood vessels can be seen without being invasive, and is a useful diagnostic tool. High blood pressure causes silvering, or high optic nerve pressure causes changes in the shape of the arteries and veins. You can demonstrate the blind spot with your 'Pathways'. Keeping the dark line horizontal, close your right eye and focus on the black spot. Bring Pathways closer to your eye, and at about 18" away the star will disappear, and reappear when it come closer. This is because the star part of the image is focused on the blind spot. Put pathways upside down, and try it with you other eye. This sometimes make people dizzy.



Visual Field Anomalies & ME

Scotomas are temporary or permanent losses in visual acuity which usually map to a lesion (something abnormal) in the brain, optic nerve or eye. Temporary scotoma may be due to vascular spasm as in migraine or abnormal brain activity or permanent damage as with a blood clots, tumours, inflammation or injury.

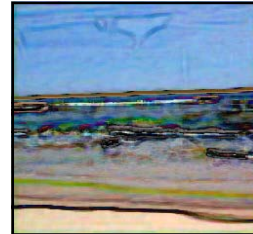
Eye Based Scotoma examples



A central Scotoma may be caused by macular degeneration, injury, or other lesions.



A peripheral ring scotoma, as may be caused by retinitis pigmentosa or glaucoma damage. Glaucoma can be screened for and treated.



Raised pressure in the eye can cause a rainbow effect over the visual area, which requires urgent medical attention.



Neurologically based in optic nerves or brain



A scintillating scotoma can be caused by cortical depression, TIA, Migraine or vasoconstriction. It is usually temporary, moves around the visual field, changes colour and texture and can take the form of flames or fireworks.



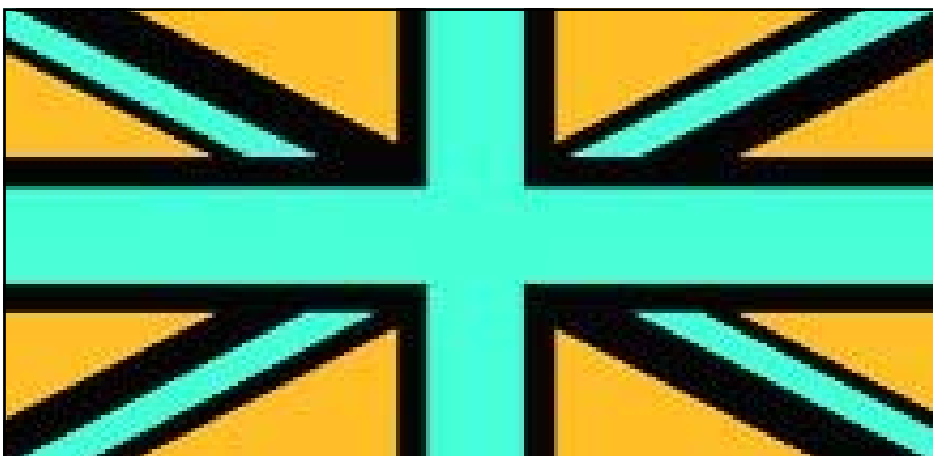
A simulation of a scintillating visual field disturbance affecting both fields experienced by an ME patient,. This can also be caused by a space occurring on the pituitary gland putting pressure on the optic chiasma, but MRI scans found nothing abnormal in this patient.



A simulation of a disturbance experienced by a ME patient, which occurred when the patient became emotionally stressed or on waking. The tree like structure is similar the retinal blood vessel pattern. Something similar is seen with point source light, e.g. using an ophthalmoscope.



A simulation of a disturbance experienced by a ME patient, which occurred just prior to exhaustion. Areas of bright colour smear with motion to the opposite complementary colour.



Negative Union Jack. No, it's not a printing error. It just exploits something known by photographers and artists. Stare at the flag, then blink several times or flash it. When the image disappears or your eyes are closed you should see an after image in the right colour. It commonly occurs when someone is fatigued, and is possibly a quirk of the ganglion image processing in the retina of the eye. It may partially explain the poppy field image above.

Please be careful if you are prone to dizziness or are epileptic.

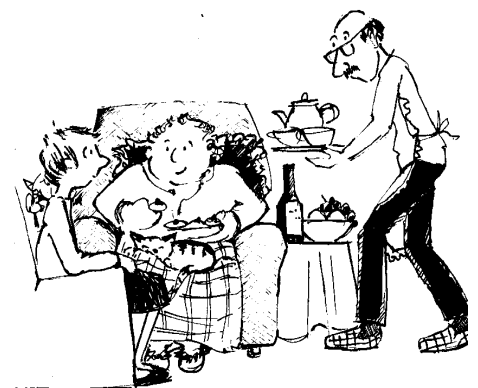
North of Doncaster *Personal Comment by Trevor Wainwright***HIV – ME – A PARALLEL: Part 1**

Many of you may have read the poems I have used to promote ME Awareness but how many are aware of the controversy they caused when trying to get them published, all because some of them were adapted from AIDS poems. It was 1996 and I read a letter in a local paper asking for poems for an HIV/AIDS Awareness Anthology. Having attended an HIV Awareness course and being aware of how not to catch AIDS I put pen to paper, what followed next was truly inspirational as I ended up writing about seven poems all of which were published. The HIV/AIDS support group was called ISIS and I became a reader in their poetry awareness team, seeing first hand how poetry could be used to effectively promote awareness, and, if put into a book, sold to raise money for the cause.

Following an interview in a local paper about my Bosnian Aid Missions, it was made public that I had a daughter who suffered from ME. The theme of the article was that this was what drove me in my aid work in as much that when I took aid to Bosnia I knew that someone was going to be helped, but when it came to ME there was no help available at all, even local doctors did not believe in it. Afterwards the phone began to ring as local groups and sufferers got in touch. I was invited to a fund raising event by a group of people who had recently begun to raise funds for ME Research at St James Hospital, Leeds, and an idea took shape could I use poetry to promote ME Awareness. Taking the poetry book to the event I met one of the people involved, she was impressed by the poems and it was decided to adapt and read a few, this was done to great applause, we would do it again, we eventually became a group it was decided the poems would be published having first obtained permission from the authors to adapt them. So the book took shape and was initially desk top published, a local writer lauding it saying how excellent it was, another local group offering to sell the books, and give the money to the St James Research Project, things looked good, at last I was able to start doing something or so I thought, as I sent a letter to the doctor behind the research, offering her the proceeds.

A letter came back from the doctor; she was reluctant to take the money and asked if I would prefer to give it to a newer project, no good that when I didn't even know of one, so what had I got myself into, a research project wanting money then turning it down. I went ahead with it anyway, I knew the woman that paid the money raised into the projects account, and I would give it to her, and told the doctor so. Shortly afterwards I was to get a message from the local group that they did not know some of the poems had been adapted, and the AIDS link, once they found out they dropped it like a hot brick, adding that the poems weren't uplifting enough. It was strange though when a sufferer had found them beautiful and comforting. There was also the fact as they said that people with ME did not lose weight, shame they never saw my daughter, how she was wasting away, losing weight, losing hope, until a chance remark swayed the balance in her favour and she began to get some form of recovery. This was mentioned but no they said, they were the experts, and they said that due to lack of exercise people with ME put on weight.

I explained about my daughter, but they would not be swayed and as such the woman who would eventually become Chair of a Castleford Group said the book should be withdrawn, and she was behind it in the first place. One of the poems was actually dedicated to her as the inspiration behind it. I was having none of it though and said I would publish it myself. So I did and the few that bought the first few copies loved it, one person even saying it was the best pound he'd ever spent.. It seemed like I was able to do something after all. The book was eventually published under the name of the Castleford Group I had helped form, and would later bear the name of another Castleford Group I would form. Not only that it would receive good reviews from prominent people both involved with ME and not.



ACTUALLY I RECOVERED TWO YEARS
AGO - BUT HE'S HEAVILY INTO
COMPULSIVE CARING

So what were the poems, who supported the book and what is the parallel between two of the most devastating illness in the world? See next issue and HIV / ME A PARALLEL: Part 2.