Pathways

Price £ 2.50 (Free to members)

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

The New Employment & Support Allowance Test Starts.

The DWP will begin sending out ESA50 (ESA2) forms relating to the new, harsher work capability assessment (WCA) on 14th March. It is not yet clear whether the claimants who receive their letters this week will be sent the new or the current questionnaire. Claimants who receive the current questionnaire will be assessed using the current WCA rather than the new one, which comes into force on 28 March. *More over page...*

Work and Pensions: More on Incapacity Benefit Reassessment

From Hansard http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110125/wmstext/1101\25m0001.htm#11012543000185

The Minister of State, Department for Work and Pensions (Chris Grayling) said that the trial for the reassessment of incapacity benefit customers in Aberdeen and Burnley has been under way since October last year. Over 1,000 customers have now been informed of the outcome of their reassessment.

The trial has tested a new process providing a number of additional support measures for customers as they go through their reassessment journey. At key points, Jobcentre Plus staff telephone customers to inform them about what is happening and to ensure they have access to appropriate help and advice. Customers also have the opportunity to discuss the decision on their case with a decision maker, putting into practice one of the key findings in Professor Harrington's recent review of the work-capability assessment. These additional support measures have been welcomed by staff and customers. In Mr Grayling’s words:

“We want to ensure that the experience gained in the trial is shared across all of the centres that will be dealing with the reassessment of incapacity benefit claimants before we move to the full, national roll-out in April. So we intend to have a limited, introductory phase in every centre carried out in the same controlled conditions as Burnley and Aberdeen. This will ensure the process remains robust and we continue to learn valuable lessons as more customers are involved in more areas across the country.

At the end of February, we will begin this introductory phase. Letters will be sent to 1,000 customers a week nationally, marking the commencement of their reassessment. So a total of around 300 people will be assessed in each reassessment centre over this period. In April, we will step up the implementation and increase the number of cases to around 7,000 a week. From May we will be processing the full case load of around 11,000 cases per week. This steady ramp up of activity will ensure that Jobcentre Plus and its partners are ready and can deal with the volume of cases as it builds. Customers' reactions to the changes will be closely monitored and lessons applied. Our plans are on track. Reassessment remains a key priority for this Government. We cannot allow people to be trapped on benefits, but we will ensure people get the benefits and support that they are entitled to.”

An independent point of view from the Benefits & Work Website

IB to ESA transfer started in earnest today 28th February 2011. The pilots are over. The DWP is sending out the first 1,000 letters to current incapacity benefit (IB) claimants, informing them that they are about to be reassessed to see if they are eligible for employment and support allowance (ESA). .The letters will be followed up by telephone calls to each affected claimant, to confirm the contents of the letter and to check if you need any additional support with the process. A small proportion of claimants will have a decision made to award them ESA just on the basis of information the DWP already holds on them. But the next thing that most people will receive will be an ESA questionnaire to complete and return. The DWP has stated that it will begin sending out ESA50 (ESA2) forms relating to the new, harsher work capability assessment (WCA) on 14th March. It is not yet clear whether the claimants who receive their letters this week will be sent the new or the current questionnaire. Claimants who receive the current questionnaire will be assessed using the current WCA rather than the new one, which comes into force on 28 March. Provisional figures from the Aberdeen and Burnley pilot, using the current WCA, showed that:

30% of IB claimants were found fit for work.
31% were placed in the support group.
39% were placed in the work-related activity group.

Advice is don’t fill in out the forms yourself—use a welfare rights advisor –Mike

You Write

Helen (SYCIL) writes: I have recently received a message from a strategy group based at Job Centre Plus which is looking into problems which ESA claimants have been experiencing with the ESA medicals. They are interested to hear of the experiences of people with hidden impairments like ME/CFS, and those who have scored zero points at the medicals. If you have any information about the experiences of your members which you would like to share, please could you let me know? I will pass on your comments, anonymously if you wish.

Fiona (CMP) writes: Sorry I was unable to arrange to come and talk at one of your meetings. Things have been very difficult here as I'm sure you know that we are finishing at the end of March and staff have been finding other employment and leaving since September last year. With regard to the ESA Zero Point situation, we are finding that the majority of our customers have been classified as 'fit to work' even when they have obvious disabilities, let alone hidden ones!! Anyway I could try to get some details together, I think anonymously would be best and send them to you, if you think that would be useful.

There is no doubt I my mind that there is discrimination against ME/CFS locally at Crossgates House. I did an ESA50 form for a member who was refused, and currently an appeal is in progress. In desperation to get the member some money to deal with a financial crisis I did a DLA form for which surprisingly he got high rate mobility and low rate care. Because this seems odd, usually ESA needs to be awarded before DLA is given, I asked the member to request all his case papers using the Freedom of Information Act. What follows is the text of a letter I sent to the member. I have removed sensitive information, but I have the member's consent to reveal this to any DWP staff or any member of Leger ME before they go for a medical to Crossgates House.

*"With reference to the case papers received. I have reviewed the batch of paperwork that you sent me from the DWP regarding your two recent medical examinations at Crossgates House Doncaster, firstly the one carried out for ESA by * on * August 2010 and the more recent once carried out for DLA by Dr. * on * January 2011. I have also compared these to the report by your G.P. Dr. * on *th December 2010, and the various support letters from myself at Leger ME and Clouds CCS.*

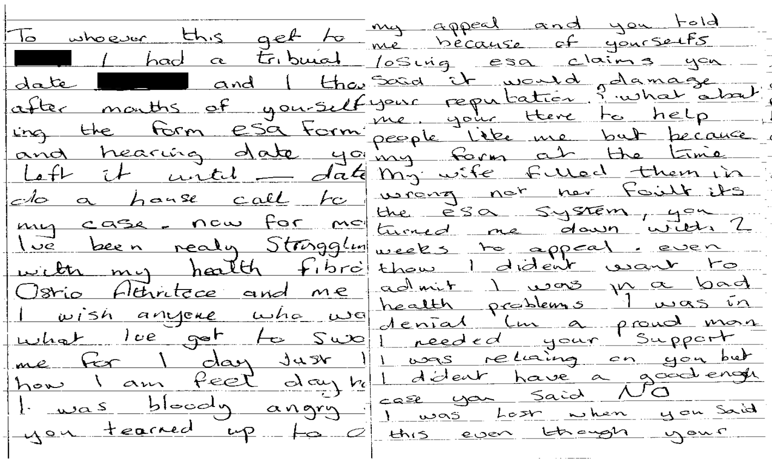
*Within the context of these documents, the case history and taking into account what I have about you on my records. It appears that * is either negligent or incompetent with no understanding about ME/CFS, Anxiety or Mental health problems, and the ability to put things into context. From here I would recommend that you take some sort of legal advice because I believe that that person has or is causing you ongoing harm by her inappropriate actions.*

*Leger ME does not have the resources to pursue this issue on your behalf. From my own point of view as the chairman of Leger ME, this person appears to be working outside their qualifications, because Physiotherapists are not trained to assess mental health problems or medical problems. As * is a registered Physiotherapist, I think that you should consider rising a concern to the professional body the Health Professions Council that regulates her profession. * registration number is PH*. I recommend that you contact the Health Professions Council for help in making a complaint. I also recommend that you continue to dispute the ESA 85, and ESA claim.*

Thank you for allowing me to see these documents. I have had similar reports from other Leger ME group members regarding these persons' activities, but most have been too frightened, ill or intimidated to pursue their cases or seek help or redress. I will be advising Leger ME group members who are invited to Crossgates House to decline any contact with this person and insist on being examined only by a qualified doctor. Please see me at the next meeting to discuss your options."

Of anyone else has any encounters with Crossgates House, favourable or adverse, please let us know.

A Member writes: The following letter was posted through my letter box last summer. The person concerned had applied for DLA, and had been turned down, and was being assisted by **** Doncaster through the appeal process. He had a concurrent application for ESA, which during the DLA case was refused. Because the ESA was refused **** dropped this DLA case two weeks before the tribunal. If you want to know why, just read the letter.



To whoever this get to
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my case. now for me
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with my health fibro
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me because of yourselfs
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Said it would damage
your reputation ? what about
me. your there to help
people like me but because
my form at the time
My wife filled them in
wrong not her fault its
the esa system, you
turned me down with 2
weeks to appeal. even
thow I dident want to
admit I was in a bad
health problems I was in
denial Im a proud man
I needed your Support
I was relaing on you but
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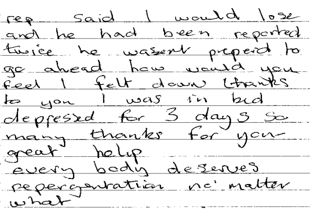
I was Lost when you said
this even though your



rep said I would lose
and he had been reported
twice he wasent preperd to
go ahead how would you
feel I felt down thanks
to you I was in bed
deppresed for 3 days so
many thanks for your
great help
every body deserves
repergentation no matter
what

Earlier last year this case had been referred to me by a local counselling agency because the patient had a diagnosis of ME/CFS. Because **** was on the job, I preferred to let them continue with the job they are paid to do. Once **** had withdrawn their support, I advised the member to continue to the tribunal, which was lost. What was quite clear to me was the members/family had done a DIY job on both the ESA & DLA forms. So really, the refusal did not surprise me. The member was not conversant with the system, and had a high degree of denial, and did not understand the issues involved. We decided to start again, only this time I would do the forms. Firstly I did a case review, and it was quite clear to me that the member did not have adequate pain control, so was necessary to contact the G.P. and get that sorted. The pain required level 3 control using narcotic opiates. Next we started at square 1 with a new DLA form. Over a period of a couple of weeks, that was sorted, and the outcome eventually was DLA high mobility, and high rate care.

The counselling agency then raised a complaint with **** which went through all three levels of the grievance procedure. Ultimately a **** tribunal was convened and I went with the member. Beforehand I had counselled the member and asked what he wanted as an outcome. His reply was that he was looking for an apology; for them to say they were 'sorry'; not for compensation. At the tribunal, the Chairwoman called herself Dr ….. No confident doctor behaves like that, so I asked for her GMC registration number. "I'm not a Doctor; I'm a doctor of education, a PhD." I raised that as a matter for AOB, and then the meeting proceeded. Over a period of 15 minutes our member was treated like a deviant school chid, to the point where I could see stress and anger emerging. At that point I called a halt to the proceedings and we both walked out. None of the people at the tribunal had any health qualifications except me. I gather that I am labelled as 'deviant and disruptive' by **** although really, I fixed some of their mistakes. The issues I have with **** regarding this case are:

1) Inappropriate and misleading use of the title 'Dr' out of context by the chairman. The title 'Dr' is not used in front of patients if the person is not a registered doctor. This is considered a no-no. I have several colleagues who hold PhDs e.g. in nursing, but they do not use the title 'Dr'.

2) Absence of anyone with appropriate medical or nursing qualifications or appropriate training. Even the DWP has a doctor on its tribunals.

3) Subjecting a patient to unnecessary pointless stress through a complaints procedure on a clear-cut matter which clearly could have been resolved by a simple letter, apology or appropriate explanation. This does not happen in a NHS complaint or even at DRI.

4) Causing unnecessary suffering and harm to a patient by putting the interests of the patient last and below that of the organisation. The counselling service has reported that this person's treatment has been set back six months as a result of ****'s action.

There is very little point in pursuing this issue any further. It's really sad to have to report to members this episode with a disability organization when we should be working with them. I deal with other **** branches without any problem. The outcome is no surprise, because from my experience **** in Doncaster has been ME-unfriendly for years.

Karen writes: Am I being watched? I have just received a letter from the Department for Work and Pensions with the following text:

> *We have recently received information which casts some doubt on your continuing entitlement to DLA. We are unable to provide you with further details of the information we have received. This is because the Freedom of Information Act, Section 30, prevents us from disclosing information provided by a confidential source. The Agency receives information from a number of sources, including internal data matching, information from other public bodies and members of the Public.*
>
> *We require some additional information from you to determine whether you are still entitled to the DLA you are receiving. Acting on behalf of the Secretary of State we have the authority to seek information about a person's continuing entitlement to benefit under Reg 32(1) of the Social Security (Claims and Payments) Regulations 1987.*
>
> *Enclosed is a DLA review form which I would like you to complete and return within two weeks of receipt, using the envelope provided. If you have any difficulty in returning the form by this date, please contact us to discuss. Our contact details are at the top of this letter. Once we have received your completed form, we may need further medical information. We may want to request information from people who may have treated you or are currently treating you for your medical conditions or you could be referred for an independent medical examination. Once all necessary information has been received, your claim will be referred to a decision maker who may make a new decision on your entitlement to DLA. I will write to you and inform you of the outcome of our enquiries once they are completed.*
>
> *It is important you return the attached review pack by 15/10/10. If you do not do this, your DLA could be suspended and your payments ended. I must also remind you that it is your responsibility to inform the department of any relevant change of circumstances that have occurred which could affect your continuing entitlement to benefit. If you have any queries regarding this letter please telephone the number above between 8.30am and 5.00pm.*

I had my Incapacity Benefit renewed at a Medical PCA last October with no problems. They have also just send me a new DLA form, so does it mean I have to apply again?

We've seen this before, and it has happened to some other members. I think that although you got Incapacity Benefit again, something in the examining doctor's report has suggested that you are no entitled to DLA. This likely to happen more and more, as more ESA medicals are carried out. You will have to apply for DLA again, but before you do, obtain the IB85 from the DWP and let a welfare rights advisor see it. Ross, one of ours members, saw this in a national newspaper which explains things.

The great disability benefit free-for-all

Half of claimants are not asked to prove eligibility

By **James Chapman**
Political Editor

HALF the 3.2million people on disability benefit have never been asked for evidence to back their claims, it emerged last night.

In addition, nearly a million people have been on disability living allowance for at least 14 years, a Government analysis of claims for the benefit revealed.

DLA costs the taxpayer £12billion a year, the same as the Department for Transport's entire annual budget.

But now, in what is likely to be the most contentious of the Coalition's welfare reforms, ministers are preparing a crackdown on the payments.

Cuts to DLA, which is meant to help people who have specific mobility or care needs and cannot do things such as walk or wash and dress themselves, have been criticised by charities and Labour MPs.

However, ministers say figures showing how the benefit ballooned under Labour – and has been paid to people for years with no checks – demonstrate an urgent need for reform.

The Department for Work and Pensions says the number of people on DLA has risen inexplicably from 2.5million in 2003 to nearly 3.2million.

Of those, 31 per cent – almost a million – have been claiming for 14 years or more, while 46 per cent have been on the benefit for more for ten years.

Half have not been asked for evidence to support their claim, having been given the benefit based entirely on their original application form.

The figures also show wide regional variations.

The North West has the highest level of long-term DLA claims, with nearly 160,000 people on the benefit for over 14 years.

London and the South East have the lowest number of long-term claims.

A Government source said: 'DLA was designed to give extra support to disabled people and the Government wants to make sure that continues.

'The problem is there is no system of review. People can be given the benefit and no one checks if they still need it.

'The Government wants a fairer way of reviewing DLA so money goes where it is most needed.'

'Taking us back to the Dark Ages'

More than two million people on DLA have been given indefinite awards, which means they have no further contact with officials about whether they still need the benefit.

The Government now wants all claimants to undergo periodic medical tests to justify the payments. Ministers propose to end the automatic right to DLA, worth up to £70 a week for care and up to £50 a week for travel.

Claimants will be paid a 'personal independence payment' after being tested on their ability to carry out key everyday activities.

A group of 27 organisations for the disabled has warned against plans to axe the mobility part of DLA, which it says will hit 80,000 care home residents unfairly.

The DWP says some residents receive the benefit to pay for taxis even though their care home or local council provides transport.

Mencap chief executive Mark Goldring said: 'We strongly urge the Government to reconsider the proposal to remove the mobility component of DLA.

'Removing this benefit will take us back to the Dark Ages, stripping people of control over their lives and leaving them stuck in residential care homes.'

j.chapman@dailymail.co.uk

Comment – Page 14

Make an appointment to see your welfare rights advisor ASAP for help with filling out the DLA form. Obtain the IB85, and, in the meantime, get reports from your ME specialist and GP.

Lynn Writes: Is there anybody there? Last week I had to visit the doctor's surgery for the first time in a while. I did what I always do, walked in, went to the Reception desk and announced I was there and which doctor I was to see, but my flow was interrupted by a pointing finger from behind the glass, aimed at some screen in the corner and the words 'sign yourself in'. I turned around in the direction of the now wagging, pointing, finger whilst 'she' went back to her coffee and biscuit. A small queue of people were lined up in front of the screen and the one at the front was stood clearly trying to puzzle out what he was supposed to do. He eventually gave up and made his hesitant and apologetic way back up to Reception. The next in the queue got "told off" by the screen for being ¼ hour late and went shamed face to Reception!

Eventually it was my turn and I was thinking to myself "thank goodness I can use a computer" as I looked at the screen. Gender, (now that's debatable for some isn't it but there are only the two choices), date of birth, name of doctor to be seen, and time, were all touch buttoned onto the screen, oops, finger slipped made a mistake, (comes of worrying if it would tell me off for being early or late) start again, and suddenly, there it all was and I was officially signed in, except…….where might the doc be……..upstairs waiting room or downstairs waiting room today – I hadn't a clue. Better not bother the dragon on the desk again with her face full of yet another biscuit, so I took a chance on 'upstairs' and went to sit in the waiting room.

Up in the waiting room, still not sure if I'd picked the right one, all the chairs had changed. Everything was now in neat rows like in the cinema and all facing the front wall of the room. No toy box for the children to sit on the floor and unpack and delight in; magazines on some rack on a wall you can't easily reach. I sat down on the front row and waited.

Silence, except for the odd cough and sniffle coming from the back of me somewhere. I drifted into pleasant thoughts of walks in the countryside to cheer myself up in this silent place, when suddenly beeeeeeeeeeeeeep accompanied by red flashing lights moving across a screen high above us on the wall and someone's name and address and the doctor and room number came up. Mrs. Catherine Park of 19, Somerset Road, etc., etc., disappeared out of the room to see Dr. Sharp who I know is always very slow with his patients and usually running late. Well I now knew she was out and about and if I'd had burglary on my mind could have quickly checked her house was empty with a call from the mobile and have nipped around to her house to get into some mischief!! I sat contemplating whether to take up burglary as my new hobby, when the same scenario happened again and Mr. John Hartington, you know who, of you know where, disappeared into the ether. Ah! Now his address is in the leafy area and he definitely has a more up market home, I'm sitting thinking, maybe I should nip around to his!

Doing all this thinking about your possible new life of crime takes up time and yes, you guessed, suddenly 'beeeeeeeeeeep' and there was me and my life (thank the Lord my weight isn't up there) moving along the screen. Right then, room 5, where on earth is that. It's like a rabbit warren with so many corridors and corners these days. Ah, found it, knock gently on door and poke head tentatively around door. Anybody in – oh, there you are sat behind your screen. A voice says 'come in' /'sit down' and goes straight back to the screen searching madly. Now I'm sitting there thinking 'I wonder if he's got the right record up on the screen, does he know it's me?' (This dear reader may sound a bit paranoid, but you can understand that by now I'm feeling very alone this world). Decide to announce my name to him 'cos I like to be helpful; ok, ok, I just needed to make sure! Having got the necessary prescription, made my way out of his room in the allotted 5 minutes flat, and hobbled back downstairs as fast as my M.E. aching legs will let me, and out, out into the fresh air.

Yes, I should have gone back to reception to arrange an appointment with the nurse for a routine thyroid function test but, hey, wasn't it the doc used to give me a nicely filled in form in his special handwriting which I loved and could never read, to take down with me for that? And anyway, will the nurse exist on the sign in screen?

So, what's happened…………no friendly receptionists, just a do it yourself sign in system; no chatter in the waiting room where once you sat beside and opposite people and listened to all their woes whilst the children played in the middle of the room with the toys that overflowed the toy box. Everyone seeing all our details on screens and up in lights; no friendly doc with a smile and a chair for me to sit on beside his desk, just a busy doc, eyes fixed on reading a screen, barely lifting them to see the person sitting at the other side of the desk, no real communication at all. It has a name this thing that's happened. 'Technology' is the one who has come and carried all the human contact away.

Mmmm, well I've got news for you dear readers and it ain't good. I went to the dentist the other day and suddenly I realised that life will never ever be the same again. This guy 'Technology' is in there too; seems this guy is hell bent on taking over the world and I'm not sure I like him all the time, do you?

Next, the old and the new ?

This reminds me of a school toffee nosed headmistress. I suppose it's a bit like you lose three house points and get a detention if you're late. To be quite honest I don't think that names and addresses should be publically displayed, in fact I would say that it is breaking the data protection act somewhere. There are issues with many self check-in terminals. They are often just stuck to the wall and anyone can see what you push in. You date of birth is used a security feature of many financial & banking systems, and some people unwisely, even use their date of birth as their PIN. You get better privacy in banks or street cash machines.

Sally Writes: Clouds Community Counselling Service Ltd is shortly moving into The Bridge Street Centre, Bridge Street Thorne. This has been made possible by the kindness of TMRP. Clouds is a team of 9 and we offer 30 counselling appointments per week and also a number of courses and Groups. The next course is about building up self-esteem and confidence and is free to those over 18 and unemployed and will be based at The Croft Children's Centre Dunscroft from the 2nd March 1pm to 3-15pm to the end of March. Recently we have supported "Grandparents Together" a Group meeting at The Belmont Hotel, Thorne to support Grandparents caring for their Grandchildren. New members are welcome. Altogether we have been working with over 50 people per week. Clouds also sees a number of clients with CFS/ME and we are happy to offer support to these clients. Contact the Client Message Line on 07962907053 and leave a message. You will be contacted without 24 hours by a member of the Clouds team.

Carolyn Writes: I have just seen the following in the Bury/Bolton ME/CFS support group newsletter regarding tax refunds.

Have you stopped working within the last 6 years? If so, did you check if you are due a tax refund? If you have finished work part way through the tax year, you may have paid too much tax. This is because of the way the tax is automatically deducted on the assumption that you will continue earning a similar amount for the whole year. Do not assume if this is the case that the tax office will let you know, you may need to get in touch with them and ask. A member of Bury and Bolton ME/ CFS group was in this situation, having finished work 4 years ago and has just received a £1250 refund. There is a simple (and anonymous) tool for calculating if you are owed a refund on the HMRC website: http://stccalculator.hmrc.gov.uk To claim your refund, phone the tax office on 01355 359022. There are no forms to fill in and it really is a very simple process that can be sorted out with a quick phone call.

Sounds useful— it's always a good idea to check the taxman, but any tax refunds should have been cleared by the June after the end of the tax year.

Carers Corner (from Doncaster Carers Newsletter)

The Doncaster Carers Emergency Contact Card Scheme

In case of emergency

I care for someone and they may need me.
Please call the number on the back of this
card and quote my pin number.
Thank you.

Doncaster

www.doncaster.gov.uk/carers

Ever wondered what would happen if you were involved in an accident or emergency. ?
Carers can worry about what would happen to the person they look after if the Carer is involved in an accident or emergency. Joining the Carers Emergency Contact Card Scheme can offer reassurance and peace of mind to help you know that if anything happens to you, any time of the day or night, a personalised emergency plan will be put into action.

What information is on the card? There is no personal information on the card. Details from the application form will be sent to Doncaster Councils Corporate Alarm Monitoring Centre, entered onto a database, and a small credit card sized card will be issued with the emergency phone number and a unique PIN number.

What happens in case of an emergency? If the Carer is involved in an accident or emergency, the phone number on the card is phoned by whoever is present. The Corporate Alarm Monitoring Centre then phone the nominated contacts given on the application form. If the nominated contacts are unavailable or unable to provide support the Carers Emergency Respite Service (CERS) will be contacted and an agreed contingency plan will be put into place.

How will the CERS know what care is needed? After registration with the scheme, the Carer will be contacted by housing 21 who are providing CERS. They will arrange a home visit to include the Carer and cared for person. This visit will establish a contingency care support plan based on the level of care the Carer normally provides.

Caring

If I was not a Carer I'd do a normal job,
I would work from 9 to 5, to earn an honest bob,
But as I am a Carer, my job never ends,
I work all day and all night and never have any spends,
Is my job satisfying? I hear the people say,
Well every day I wake up and deal with another day,
I care for many people, my own needs are ignored,
But we always carry on and never can be bored,
There is always something to be done of that there is no doubt,
And when voices need to be heard it's us that you hear shout,
Our lives' get over taken; we do what we have to do,
But it's very often they forget the main person YOU !

by Angela Prince of Bolton Carers Support Group

How can I apply? Application forms are available from Doncaster Partnership for Carers.

Doncaster Partnership for Carers (DPfC) support adults living in Doncaster who care for a family member, partner or friend who cannot manage without their help because they are ill, frail, have a physical disability or a mental health problem. Their services are free and confidential. They help carers with Information, accessing services, complaints, training, attending support groups, a listening ear, language support, meeting other carers, & volunteering. They can also give you a 'voice' in health and social care service planning arenas.

Contact details:
DpFC, 74 Church Lane, Bessacarr, Doncaster, DN4 6QD Tel 01302531333
Email dpfc@doncastercarers.org.uk Web www.doncastercarers.org.uk

There is an outreach service at the Redmond Centre, on the 2nd and 4th Friday of the month, 9.03 p.m. to 10.30 a.m.

Do you know anyone who finds it difficult to talk? Sheffield Teaching Hospitals and the University of Sheffield are carrying out a research study looking at computer speech therapy. They want to find out if computer therapy can help people who have difficulty finding words since a neurological injury, no matte how long ago it was. They are looking for people who have word-finding difficulties and have finished having regular speech therapy. If you would like more information, would like to take part in the study or to find out more about using computers to help word-finding contact Rebecca or Gail on 0114 2225427 or email cactusproject@hotmail.co.uk

Local Helpful Organisations: The Doncaster Citizens Advice Bureau

There are 416 Citizens Advice Bureaux across England and Wales, all of which are members of Citizens Advice. The Doncaster Citizens Advice Bureau (DCAB) is for the residents of Doncaster Metropolitan Borough, with particular but not exclusive reference to families and individuals from deprived backgrounds. DCAB operate a generalist advice service from the Guildhall Advice Centre located in the town centre where each client is offered an initial gateway interview to assess their advice needs and priorities. They also offer specialist advice services in welfare benefits and debt. In partnership with a number of voluntary and community sector agencies, they have a number of different projects operating at outreach locations across the Borough providing advice services to a range of vulnerable clients.

The CAB aims to provide free, independent, confidential and impartial advice to everyone on their rights and responsibilities. It values diversity, promotes equality and challenges discrimination. The service aims to provide the advice people need for the problems they face. However the feedback I have received from Leger ME members indicates some shortcomings.

Doncaster Citizens Advice Bureau

About us

Doncaster Citizens Advice Bureau serves the residents of Doncaster Metropolitan Borough, with particular reference to families and individuals from deprived backgrounds.

We operate a generalist advice service from the Guildhall Advice Centre located in the town centre where each client is offered an initial gateway interview to assess their advice needs and priorities.

We also offers specialist advice services in welfare benefits and debt.

In partnership with a number of voluntary and community sector agencies, we have a number of different projects operating at outreach locations across the Borough providing advice services to a range of vulnerable clients.

- Annual report (470kb)

Doncaster Citizens Advice Bureau,
The Guildhall Advice Centre
Old Guildhall Yard
Doncaster DN 1 1 QW
Tel: 01302 735221
Fax: 01302 735230
Email: enquiries@doncab.org.uk
Web: www.doncab.org.uk

Get advice

The Citizens Advice service offers practical, up-to-date information and advice on a wide range of topics, including; debt, benefits, housing, legal, discrimination, employment, immigration, consumer and other problems.

Our advice is available to everyone regardless of race, gender, sexuality, age, nationality, disability or religion.

- Get advice online
- Get advice from Doncaster CAB

Other information sources:

- www.doncaster.gov.uk
- www.doncastercvs.org.uk
- www.dialdoncaster.co.uk

Volunteer

The majority of advisers are trained volunteers, helping the Citizens Advice service to resolve over 6 million new problems every year.

We couldn't survive without our 21,000 fantastic volunteers, but we need around 5,000 more. We're looking for all sorts of people with different backgrounds and skills to volunteer with us for a uniquely rewarding experience.

- More about volunteering for us
- Volunteer now

Support us

Because every Citizens Advice Bureau is an independent charity we rely on the support of people like you.

With a Citizens Advice Bureau in the community people always have somewhere to turn in times of crisis, but the unmet demand for our service is growing. Can you help us to help more people?

- Donate now

Citizens Advice service

There are 416 Citizens Advice Bureaux across England and Wales, all of which are members of Citizens Advice.

Together, we are the Citizens Advice service, and we help people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers.

- About the Citizens Advice service
- Our campaign work
- Citizens Advice news

Doncaster CAB Webpage. We have information leaflets from Doncaster CAB

Reports that I have received about the difficulties Doncaster CAB service from members are a cause of concern. In order to try and *'do summat about it'* Matthew Bennie from DCAB was invited to our February meeting. We conducted an inquest and identified three problems.

1) Our members report that in some local outreach centres, the CAB will only see three people per session. After that the fourth and above person is turned away. In order to ensure that they are seen this involves queuing outside the libraries at 8 am before they opened. There are issues with the queuing system and sometimes a scuffle.
2) For appointments for money matters there is a nine week waiting list, once they are seen.
3) Members have been declined help with ESA/ DLA form fill-outs.

Can you help ?

Citizens Advice
the charity for your community

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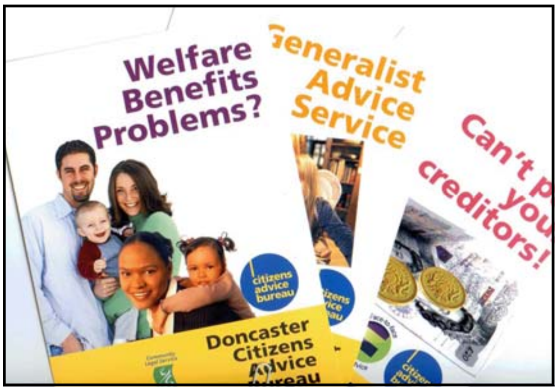
With a Citizens Advice Bureau in the community people always have somewhere to turn in times of crisis, but the unmet demand for our service is growing.

Can you help us to help more people?

With the first problem I had to explain to Matthew the people with ME/CFS are disabled and suffer from early morning stiffness which prevents many members from even dressing in a morning. The fact there were only morning appointments and none later in the day is a major access barrier, possibly unintentional in ignorance. Matthew apologised, and we have arranged a work around though the LME helpline.

For the second issue, there is no simple answer. With the recession, the surge in unemployment and funding cuts, there is unprecedented demand from all sectors for help with financial matters.

For the third issue, Matthew said that that the CAB had two workers for DMBC area that deal with welfare rights issues. In principle they can help with ESA/IB/DLA/AA refusals, fill outs and appeals. However there is a problem. The funding for these workers is for Legal Services on a legal aid type scheme, and it is means tested. So only the poorer members can get access. A simple phone call to CAB will find out if a case can be taken on. When the CAB do take these cases on, an entitlement check is not included, and there is no guaranteed outcome. There is no funding for home visits, but specific appointments can be made at the various centres the CAB uses around the area. They cannot do chaperoning on appointments and medicals.
I explained that there are workarounds for these issues, and Leger ME can help.



I thought that had settled the issue when a couple of days ago I received the following email:

"Hi Mike, Could you please send me the numbers for the people to help with DLA, I can only find CAB which we have used. They no longer help with tribunals, but will help with filling in. This happened to my wife Michelle, she had to recently reapply for DLA. She took all her information up to our local CAB, they asked her to fill in her address medication and then sign the back when Michelle asked about the rest of the form he said I will fill that in later. Michelle lost a lot of her money it has gone from high mobility, high care, to low for them both, Michelle has really bad EP that means she can end up in hospital when it gets out of hand, none of this was put on her forms.
All the best Phillip"

Oh Well! This is Mexborough, an independent CAB to Doncaster. Here we go!.
Another DLA refusal inquest to be sorted out next mentoring session. Things don't change. *Mike*

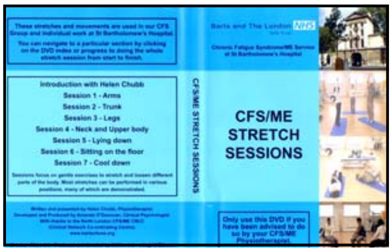
News from Fairlawns.

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.

Clinic Contact Information

CFS/ME service for South Yorkshire and North Derbyshire, Fairlawns, 621 Middlewood Road, Sheffield, S6 1TT, Tel 0114 2292937 or 07968 376750.

The Barts and CFS/ME Stretch Exercise Session DVD



Following the review of the DVD of stretch sessions that is used by the Sheffield clinic reported in Pathways 26. I have spoken with several other ME/CFS groups. Two have their own 'Yoga for ME' groups which are well supported for those able and are very similar to the stretch sessions in the DVD. There is an issue of access to the Sheffield ME/CFS for people in Doncaster, so why not sort something out in Doncaster? Why not ask the Sheffield ME/CFS for Advice? That's what I did at the LPIG meeting. Mark Adams, the physiotherapy team leader for long term neurological conditions at the Sheffield clinic came up with this advice:

'I have contacted David Bird, Group Exercise Referral Manager for Sheffield International Venues for advice on fitness instructor qualifications required for someone to be suitable for supervising a stretching group for people with CFS/ME. He recommended the following:
The instructor would have to be either Level 3 or 4 REPS (Register of Exercise Professionals) registered with qualifications in Advanced Instructing (YMCA) and a G P Referral Qualification (YMCA or WRIGHT FOUNDATION). If the patients have co-morbidities such as CHD they would also require a BACR (British Association for Cardiac Rehabilitation) qualification.
He added this about the Doncaster Dome. I've not been but I am aware that the Doncaster Dome runs a referral scheme in their fitness department, I suggest starting there!'

Leger ME
Group Meeting

FRIDAY APRIL 15th

1.00pm to 3.00pm
at
The Redmond Centre, Carcroft , Doncaster

Speaker: **Anne Nichol**

CFS/ME Service Manager CFS/ME Service
for South Yorkshire and North Derbyshire Clinic Fairlawns

Anne will be talking about the CFS/ME Service and how it can be accessed.
There will also be time to ask questions about ME/CFS and its management.

Refreshments will be available and there will be a raffle to raise funds for the group

Please email mike@leger.me,uk or contact 01302 787353.

The Young ME Sufferers Trust (Tymes) *Registered Charity 1080985*

Here is a reprint content of their leaflet ‘A Quick Tour of ME, Symptoms, Management & Trust Services.

Myalgic Encephalomyelitis ME (Myalgic Encephalomyelitis) is a serious neurological condition also known as Post Viral Fatigue Syndrome (PVFS). It was formerly known as Atypical Polio. The term Chronic Fatigue Syndrome (CFS) is also used but may include other fatigue states. Viral infections are known triggers of ME.

Incidence of ME. An estimated 25,000 of the 300,000 UK sufferers are children. ME is the biggest cause of long-term sickness absence in schools; a study of 333,000 pupils revealed that 51 % of those on long-term sick leave had ME. This is the biggest category of pupils with medical needs requiring home tuition or distance learning on a long-term basis. Clusters of ME occur in schools, families and communities.

Symptoms of ME

Brain and central nervous system

- Loss of memory, concentration, balance, coordination and fine motor skills
- Difficulty sequencing words and numbers, speaking, thinking and absorbing information
- Abnormalities of sensation (e.g. pins and needles, numbness), vision, hearing, sleep rhythm, appetite, temperature control, digestion, blood pressure, circulation, hormone production, response to stress
- Development of sensitivities (e.g. to light, sound, touch, certain foods, chemical substances such as perfume, paint, medication and anaesthesia)
- Bouts of racing pulse (tachycardia) and breathlessness
- Mood swings, panic, anxiety or depression may result from brain dysfunction and the distress of misunderstood illness

Generalised pain and weakness

- Pain in muscles, joints, head, back, limbs, chest and stomach
- Muscular weakness and twitching is common

Exhaustion, up to 72 hours after effort

- Even minimal exertion (cognitive or physical) can trigger exhaustion; the delayed effect is a classic sign of ME, differentiating it from other types of fatigue.
- Temporary hyperactivity may be experienced due to brain dysfunction, resulting in exhaustion.

Management

- There is no known cure. The body needs energy to heal, so personal energy management is a safe way to live with ME without provoking side-effects.
- Pacing life carefully, using physical aids and finding alternatives to energy-sapping activities are often effective in promoting recovery.
- Studies claiming the effectiveness of 'graded exercise' have generally been restricted to the less sick or the partially recovered and to those without classic ME symptoms.
- Some treatments may be harmful, such as overzealous physiotherapy. The condition naturally fluctuates, and may improve despite, rather than because of, treatments.
- GPs may be able to assist with symptomatic relief but medication can cause side effects and may not always be of benefit e.g. for inducing sleep or relieving pain.
- The illness tends to resolve over an extended period but relapses can occur.
- If treated inappropriately, the patient can become much worse. In extreme cases, children can suffer fits or collapse. Some go through periods of partial paralysis and may have to be tube-fed.
- Good old-fashioned convalescence is a good start, followed by careful management of the young person's life and education to avoid the downturns associated with trying to force recovery.

Education in Young People

- Inappropriate educational demands impede recovery and are a key cause of relapse in children. Energy Efficient Education (home tuition, distance or virtual learning) can maximise achievement whilst protecting health.
- Social contact can be preserved through visits from school and friends and through making new friends who understand the limitations imposed by the illness, for example, through the Trust.
- Children with ME are legally entitled to education suited to their medical and special educational needs.

Advice Line

- The Trust provides an Advice Line manned by our own trained and experienced Advice Line Team, all of them with personal experience of ME. Most are parents of children with the condition and some have also had ME themselves.
- Advice Line hours are Monday to Friday, from 11.00am to 1.00pm and 5.00pm to 7.00pm.
- Outside Advice Line hours or when the line is busy you may leave a message and one of our Team will call you back.

Magazine

- Members receive our magazine, Vision, which includes medical and educational articles, activities
- for and contributions from children, young people and their families. Each issue has an information pullout, *The Brief*, for parents and older readers.
- Professionals Referral Service
- We can refer doctors, teachers, social workers and other professionals to an appropriate ME expert from our panel. So your GP could talk with an ME specialist GP, your consultant could talk with an ME specialist consultant, your teacher could talk with an ME specialist teacher and so on.

The Young ME Sufferers Trust. The Trust is a national ME charity specialising in children and young people. We played a major role in the government Chief Medical Officer's Working Group on CFS/ME, focusing on compiling the children's chapter of the report published by the Department of Health in 2002.

Our Ethos We are the longest running national organisation supporting children with ME, inaugurated in 1989 by two young people with ME. We realise that much distress is experienced when a young person is diagnosed with a serious and disabling illness. Members tell us that our friendly, personal approach, coupled with the provision of reputable information supplied by a professional and experienced team, makes us a 'lifeline' and a 'port in the storm' of controversy surrounding ME. We hope that we shall be able to help you too.

The Trustcard Carry the Young ME Sufferer's Trust card at school or college to make sure you get the help you need. Endorsed by the Association of School and College Leaders and by Lord Adonis, Parliamentary Under-Secretary of State for Schools.

Become a Friend of the Trust *“Let us together support this excellent charity that is providing so much practical help to children with ME. As you consider whether to become a Friend, I urge you to remember that everyone at the Trust works free of charge. This is a cause they believe in. “*

Lady Elizabeth Anson, Cousin to the Queen, ME sufferer, Patron of the Trust

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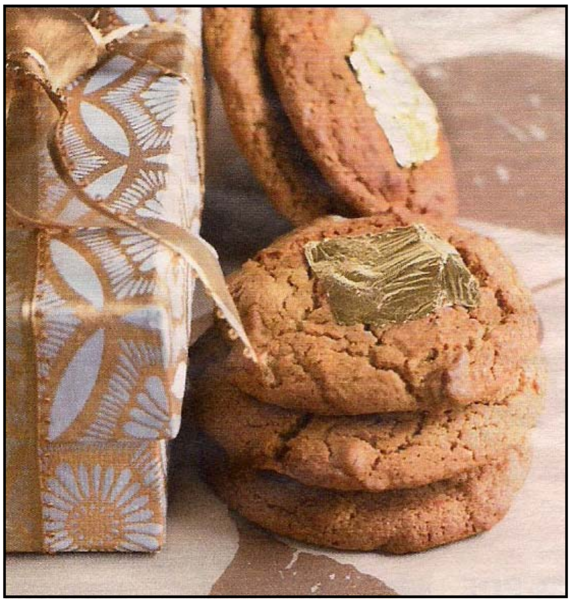
www.tymestrust.org Much more information (including this leaflet) is available free from the Trust's website, from a single sheet to give your friends to show them how to help, to detailed guides for your doctor or your school. You can find out about the Young Hearts book of poetry, watch the ITV Central News interview with Jane Colby which was aired when the book was launched by Terry Waite at Warwick Castle, and download *Vision and The Brief’.*

To Register: The Young ME Sufferers Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE
Donate £15 or more at www.tymestrust.org/donations.htm and register as a Friend using our website Contact Form or just write in with your cheque. Thank you and welcome.

Recipe Corner



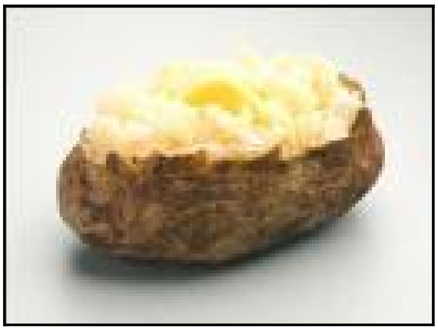
Ginger Snapdragon Biscuits

Makes about 20 large biscuits.

200g/8oz unsalted butter, softened
125g/4oz caster sugar
175g/6oz golden syrup
75g/3oz black treacle
1 large egg, beaten
425g/15oz self-raising flour
1 tsp bicarbonate of soda
4-5 tsp ground ginger
Large pinch of cayenne pepper
Pinch of salt
2 nuggets of stem ginger, finely chopped

***If making for special occasions add edible gold leaf to decorate.**

Preheat the oven to 180C/350F/gas mark4 and line 2 solid baking sheets with non-stick baking parchment.
Cream together the softened butter and caster sugar until light and fluffy.
Add the golden syrup, treacle and beaten egg and mix until smooth.
Sift together the dry ingredients and stir into the mixture.
Add the chopped stem ginger and mix again until all the ingredients are thoroughly combined.
Using 2 spoons, place walnut-sized balls of the mixture on the prepared baking sheets, spacing them well apart to allow enough room for them to spread during cooking.
Bake in batches on the middle shelf of the preheated oven for about 10-12 minutes, or until the cookies are golden brown – the edges should be crisp and the middle still slightly soft.
Cool completely before packaging.
Stored in an airtight box or biscuit tin, these will keep for 4-5 days.



The Perfect Baked Potato

If doing two potatoes – choose medium sized ones, as similar in size as possible. Put oven on to pre-heat it at 190 degrees and wait for the oven to reach temperature – the light has gone out.

Wash and dry the potatoes, prick through each one with a sharp knife once, and then place them on a rack in the middle of the oven, with the potatoes in the middle of the rack with a space between them.
Note what time they went in and then in half an hour, go to the oven and turn each potato over. This is important to ensure even cooking of the potatoes.
Leave for another half hour and then check they are thoroughly cooked. Bigger ones will need longer to cook.
Slice open potatoes and fluff up the potato inside, add some butter and then add the filling and any seasoning. Suggested fillings are:

- Tin of tuna put into a bowl with seasoning and a little vinegar added. Mix well and add seasoning to taste. Chop up some spring onions into small chunks and mix in.
- A small tin of sardines or pilchards mashed in bowl, seasoned with salt pepper and vinegar and then added to the potatoes. (Tarragon vinegar is especially good when seasoning fish.)
- Homemade chilli-con-carne cooked and used for filling
- Grated cheese mixed with cream cheese.

The PACE Study Results by Tony Britton, ME Association

From a Medical Research Council (UK) news report, published on 18 February 2011

Two effective treatments benefit up to 60 per cent of patients with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis (CFS/ME), according to a collaborative trial funded by the Medical Research Council (MRC) and UK government departments. The largest ever study of CFS/ME treatments, called the PACE trial, assessed the safety and effectiveness of four separate treatments and found that graded exercise therapy and cognitive behavioural therapy were the most effective. The findings suggest these two treatments should be offered to all patients who are able to attend hospital if they are suffering from fatigue caused by CFS/ME. The findings support current guidance from the National Institute for Health and Clinical Excellence (NICE). CFS/ME is a long-term, complex and debilitating condition which causes fatigue and other symptoms such as poor concentration and memory, disturbed sleep and muscle and joint pain. The cause is not known. CFS/ME affects around 250,000 people in the UK. The PACE trial included 640 patients with CFS from England and Scotland who were able to attend hospital clinics for treatment. All patients in the trial received specialist medical care which included general advice about managing the illness and prescribed medicines for symptoms such as insomnia and pain. Patients were divided into four trial groups and three of the groups were also given one of the following therapies over six months:

Cognitive behavioural therapy (CBT) – A clinical psychologist or specially trained nurse helps the patient to understand how their symptoms are affected by the way that they think about and cope with them, and encourages them to try out increasing their activity.

Graded exercise therapy (GET) – A physiotherapist helps the patient to try a gradually increasing tailored exercise programme which takes into account the individual patient's symptoms, fitness, and current level of activity.

Adaptive pacing therapy (APT) – An occupational therapist helps the patient to match their activity level to the amount of energy they have, aiming to help the patient adapt to the illness rather than assuming they can gradually do more.

CBT and GET are used for a wide range of conditions including rheumatoid arthritis, heart disease, diabetes and chronic pain. (*i.e. where there is no prospect of a cure or effective treatment—Ed*).

Professor Michael Sharpe, from the University of Edinburgh and co-author on the PACE trial, said:

"Patients can suffer for years with debilitating symptoms which affect their ability to lead a normal life. Although previous small trials had suggested that CBT and GET help some patients, concerns had been raised about the safety of these treatments. An alternative approach called pacing was widely advocated but had not been scientifically tested. The PACE trial was designed to find out the relative benefits and harms of all of these treatments when combined with specialist medical care."

All patients saw a specialist doctor approximately three times over the 12 month period. Those receiving an additional treatment had 14 further one hour treatment sessions over the first six months. The success of the treatments was measured by patient ratings of fatigue, physical function, overall health and the ability to lead a normal life, plus assessments of how far the patient could walk in six minutes, and of sleep, mood and specific symptoms such as fatigue after exertion.

Professor Peter White, from Barts and The London School of Medicine and Dentistry, Queen Mary, University of London and a co-author, said:

"We have found that both CBT and GET can safely help a significant number of patients. While there is still room for improvement, this is a real step forward in informing patients with CFS/ME which treatments can help to improve their health and ability to lead a more normal life."

Professor Trudie Chalder from King's College London and a co-author, said:
"It is very encouraging that we have found not one but two treatments that are similarly helpful to patients, which provides them with a choice. We now need to find out what the common essential ingredient is that makes these treatments work, and which particular types of patients will respond best to which therapy."

Not so NICE decision on ME treatment

Sir,

ANYONE whose family has been affected by ME (Myalgic Encephalomyelitis), or chronic fatigue syndrome, will not be surprised to read in the Lancet and other national media that current treatments have been found to be, at best, only moderately effective.

But they will be stunned to discover that graded exercise – the therapy which patients tell us has a greater risk of causing them harm – has been rated more effective than pacing... the therapy which patients say carries least risk and does most good!

Before the National Institute for Health and Clinic Excellence (NICE) jumps to change its guidelines on the diagnosis and management of ME, based on this study, it must bear in mind that the specialist expertise and safeguards which apply in a controlled research environment do not apply across the NHS as a whole.

The Medical Research Council must spend the £1.5m it has earmarked for research on ME on finding the cause of this horribly disabling illness, so science can find a cure.

Sir Peter Spencer,
Chief Executive,
Action for ME

A clipping from the South Yorkshire Times sent in by Pathways reader Ian

Dr Declan Mulkeen, director of Research Programmes at the MRC, said:
"There is an urgent need to find ways of improving the healthcare and quality of life for patients with CFS/ME, and the PACE trial is a great example of how MRC-funded research can evaluate treatments and help to bring them to patients as quickly as possible. The MRC's next step is to support further high quality research proposals in this area and we are committing £1.5m to encourage research that looks at the root causes of the illness."

Adverse reactions to treatment were monitored closely by experts independent of the trial. Serious adverse reactions to treatment were rare and no different in frequency between treatments. The trial was carried out by a team of experts and led by researchers from Queen Mary, University London; King's College London and the University of Edinburgh and was designed with input from the charity, Action for M.E. The research proposals were subject to extensive review and scrutiny by independent experts and trial committees.

Oh yeh ? I really wonder just how well the trial has been researched and is representative of ME/CFS sufferers as a whole. Personally I think the trial was biased in favour of mild cases. How many moderate and severe sufferers were included ? I bet none. CBT does have it's place on some cases, GET may help with rehabilitation. Both CBT and GET are effective when properly applied in specialist clinics. But the real issue is how is it applied, and does it make any difference in the long term. Maybe, but I need to be convinced. We've been here before.

NHS Health Reforms

The British Medical Association has weighed in on the new coalition Governments NHS reform proposals.

The Allergists voted to scratch it, but the Dermatologists advised not to make any rash moves.
The Gastroenterologists had a sort of a gut feeling about it, but the neurologists thought the Administration had a lot of nerve.
The Obstetricians felt they were all labouring under a misconception.
Ophthalmologists considered the idea short-sighted.
Pathologists yelled, "Over my dead body!" while the Paediatricians said, "Oh, Grow up!"
The Psychiatrists thought the whole idea was madness, while the Radiologists could see right through it.
The Surgeons were fed up with the cuts and decided to wash their hands of the whole thing.
The ENT specialists didn't swallow it, and just wouldn't hear of it.
The Pharmacologists thought it was a bitter pill to swallow, and the Plastic Surgeons said, "This puts a whole new face on the matter...."
*The Podiatrists thought it was a step forward, but the Urologists were p*****d off at the whole idea.*
The Anaesthetists thought the whole idea was gas, but the Cardiologists didn't have the heart to say no.

The GMC v. Dr Myhill—Update:

The Interim Orders Panel issued further directions on the 6th January 2011. The registration suspension is lifted, but Dr Myhill's right to practice is restricted. Directions as to what she must do if she works for the NHS or other doctors followed the usual preamble, arguments and reports. The main issues affecting her ME/CFS patients are as follows.

She may only prescribe or advise the prescription of medication or treatment including repeat prescriptions when she has adequate knowledge of the patient's health and medical history to do so safely. She can only prescribe or advise the prescription of medication for which a prescription is necessary in accordance with the guidelines as laid down in the British National Formulary (BNF) and also National Institute of Clinical Excellence (NICE) guidelines where appropriate, and for a clinical condition for which it is intended or indicated as laid down in the BNF and also NICE guidelines where appropriate, and not exceeding the maximum safe recommended daily dosage, and not outside the uses permitted by its licence.

She has also to maintain a log detailing every case where she personally prescribes, or advises the prescription of any medication by another doctor. This log should detail anonymised patient information, the date the patient was treated, the condition for which the patient was treated, and the name of the medication or treatment and the dose prescribed.

She must continue to ensure in relation to her website, or any website relating to her medical practice or business, that there are no pages, downloadable content, including documents, forum or discussion board content or other references or online media relating to the following subjects: The medical management of cases relating to cardiology, or cardiovascular disease including chest pain due to ischemic heart disease, acute coronary syndrome; heart failure; or pulmonary embolus; the treatment of asthma; the treatment, testing, identification, diagnosis or management of breast cancer; the use of hormonal contraceptive medication; the pharmacological management of primary or secondary prevention of vascular disease; any immunisation or vaccination.

The direction will be reviewed in 3 months time.

The sanctions and what they mean for Dr Myhill and her patients (from her support website)

Having carefully studied the terms and conditions of the determination today, Dr Myhill feels that she is now able to carry out about 95% of her normal work. However, there are difficulties in using B12 and magnesium by injection. There might be alternative preparations available but Sarah does not feel the short-term gain from using them outweighs the risk to her licence at this stage. The High Court hearing should take place later this month and Sarah could have her licence restored in full.

What is apparent is that the sanctions applied yesterday specifically target ME/CFS patients more than any other group Sarah treats. This may seem unfair, but as we move towards the High Court hearing we need to remain buoyant and optimistic - after all we did not expect the GMC to overturn its own ruling despite common sense and the law indicating that it should.

I can't believe it's not chocolate!

Ingredients
100g Green and Black's organic cocoa powder
20g D-Ribose
200g coconut oil

Preparation:
Warm the coconut oil in a jug or saucepan until it is just melted
Stir in the cocoa powder and D-ribose
Pour into an ice cube tray
Freeze and eat direct from the freezer, do not thaw.

Sarah's comments:
Perfect brain food?

More on Water Fluoridation *by Elizabeth Mc Donagh*

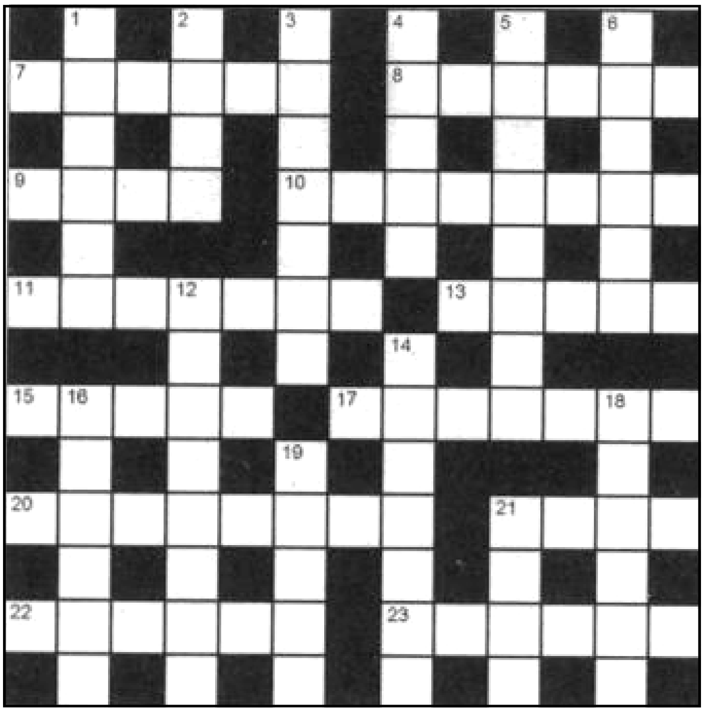
A High Court Judge has declared that Strategic Health Authorities can order fluoridation of water supplies even when the affected population is against the measure. During a Judicial Review brought by Southampton resident, Geraldine Milner, against the South Central Strategic Health Authority's decision to fluoridate parts of Southampton and Hampshire, when 72% of the population were opposed.

- Ground 1 amounted to the claim that Government policy required a majority of the population in favour and was based on numerous statements to that effect, inside and outside Parliament, by Government Ministers.
- Ground 2 was that the SHA had failed to assess adequately the cogency of the arguments put to them during the consultation by those opposed to the scheme. I attended the Hearing at the Royal Courts of Justice in London on 19 and 20 January and the Judgment on February 11th.

The case had no bearing on whether fluoride is or is not harmful; it was purely an examination of the legality of the SHA's decision. The Judge decided that the legislation was not ambiguous. The law gave the SHA ultimate discretion and there was no requirement in law for a majority in favour. The Judge also took the view that the SHA had followed proper procedures in coming to its decision. This law takes away an individual's right to determine what he puts into his own body and as such it must be repealed. Please write to your MP asking for the Government to withdraw Section 58 of the Water Act 2003 and its associated Statutory Instruments. This legislation removed the right of water companies to refuse to fluoridate and gave the power to Strategic Health Authorities to demand fluoridation even when the population affected has expressed its opposition during the statutory consultation on the issue.

I would like to remind members that the symptoms of chronic fluoride poisoning are very similar to the symptoms of ME. It is possible that some (but not all) cases of ME are caused by excessive fluoride intake. Geraldine Milner has asked her lawyers to mount an Appeal against the Judge's verdict. The unelected Strategic Health Authorities are to be abolished next year and their public health functions will revert to local authorities who may have more concern for the opinions of their constituents.

Pathways Crossword



ACROSS

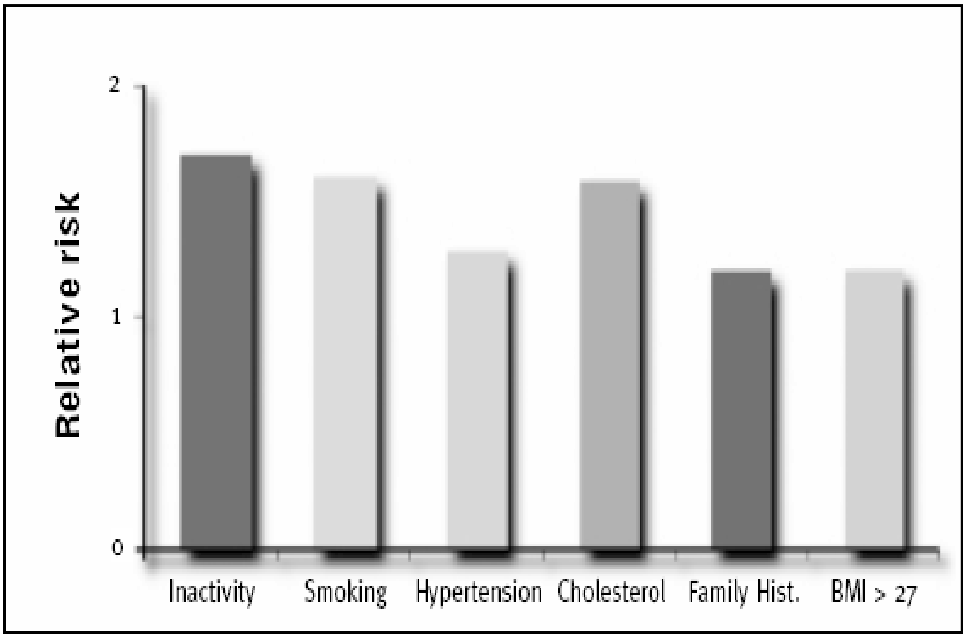
7. Leave (6)
8. Recommend (6)
9. Cask (4)
10. Flare up (8)
11. No ethical considerations (7)
13. Small trumpet (5)
15. Mass of small loose stones (5)
17. Neatly arranged (7)
20. Desert island resident (8)
21. Proceed approach (4)
22. Animals with bony outgrowths (6)
23. Grieve (6)

DOWN

1. Monolith (6)
2. Arrange (4)
3. Turkish empire (7)
4. Section of a poem (5)
5. Introduction (8)
6. Set upon (6)
12.Implication (8)
14. Swiss cheese (7)
16. Coloured pencil (6)
18. Wail (6)
19. Yellow root vegetable (5)
21. Sleeveless cloak (4)

Cardio Vascular Disease (CVD) Prevention in ME/CFS

There are no exemptions from cardiovascular disease for people with ME/CFS. Over the years I've not seen a primary causal link, but the ME/CFS circumstantial lifestyle limitations of the condition make us more prone to cardiovascular catastrophes (strokes, heart attacks and deep vein thrombosis). About 7% of people with ME/CFS are diabetic, and that is really the biggest CVD risks group I see. Most of us will have had a full medical screen as part of the diagnostic procedure, apart from the need to your doctor for management and welfare rights purposes, as you suffer a chronic condition, you should have a check-up at least once a year just to ensure no other conditions are emerging. More and more, this is being done by Practice Nurses Over recent years the NHS has started to look at CVD for economic reasons, and there are various NHS based schemes around to encourage people to maintain better health, and in some cases doctors get extra money if their targets are met.



For people with ME/CFS, the biggest risk is inactivity, higher than smoking. Weight (BMI), though significant, is not as high a factor. Many of the risk factors go hand in hand. For example more activity/exercise lowers weight, cholesterol, and hypertension. The smoking risk is additional to the various cancers and other well-known health damage that smoking causes.

Primary prevention of cardiovascular disease (CVD) involves prevention in people without existing disease, as opposed to secondary prevention for patients with known CVD. Ischemic heart disease alone (IHD) causes 30% of male and 22% of female deaths in England. The focus of prevention in recent guidelines has switched from IHD to cardiovascular disease to emphasise the need for stroke prevention.

Primary care practices (doctors & nurses in health centres. pharmacists etc) is ideally placed to do primary prevention, and this should be done both systematically in patients at increased risk (e.g. hypertensives, diabetics, familial hyperlipidaemia or a strong family history of CVD), and whenever a doctor or nurse becomes aware of any new risk factors. The Joint British Societies' guidelines recommend that all adults from age 40 years onwards should be considered for an opportunistic comprehensive CVD risk assessment in primary care.1 Ideally this should be repeated every 5 years.

	Modifiable	Non-modifiable
Age	☐	☒
Alcohol	☒	☐
Blood pressure	☒	☐
Diabetes	☒	☐
Diet	☒	☐
Exercise	☒	☐
Family history of CHD	☐	☒
Obesity	☒	☐
Personal history of CHD	☐	☒
Sex	☐	☒
Thrombogenic factors	☒	☐

Some Risk factors can be modified, and some can't. The fact that people of South Asian origin are particularly prone to CVD is thought due to the evolution of strategies to survive famine.

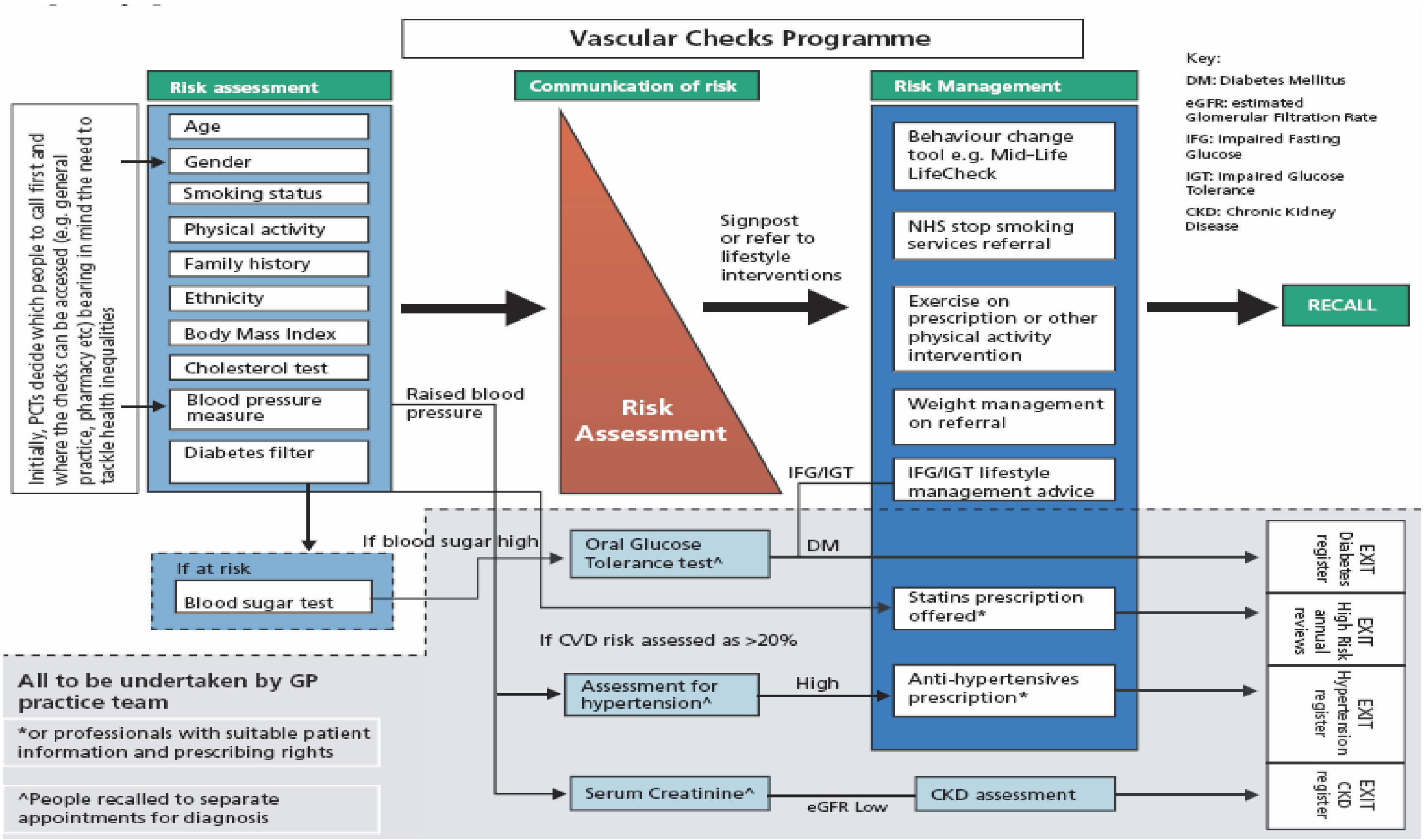
Whenever risk factors are identified they should not be considered in isolation, but the 10-year CVD risk should be calculated and used as the basis for recommendations to reduce the risk. The risk assessment is done usually in a doctor's surgery by means of a computer programme which takes information from a person's medical records. There is no one standard way of doing it, and there are various tools that individuals can download from the internet. Once all risk factors have been identified, if the programme produces a risk of over 20% over 10 years it is defined as high-risk. People with moderate-to-high risk are more likely to be compliant with lifestyle changes and preventative medication if given information about their individual cardiovascular risk. I've included a table and illustrated the NHS strategies on following pages.

Non-modifiable Risk Factors for CVD Prevention *(Things you cannot control)*

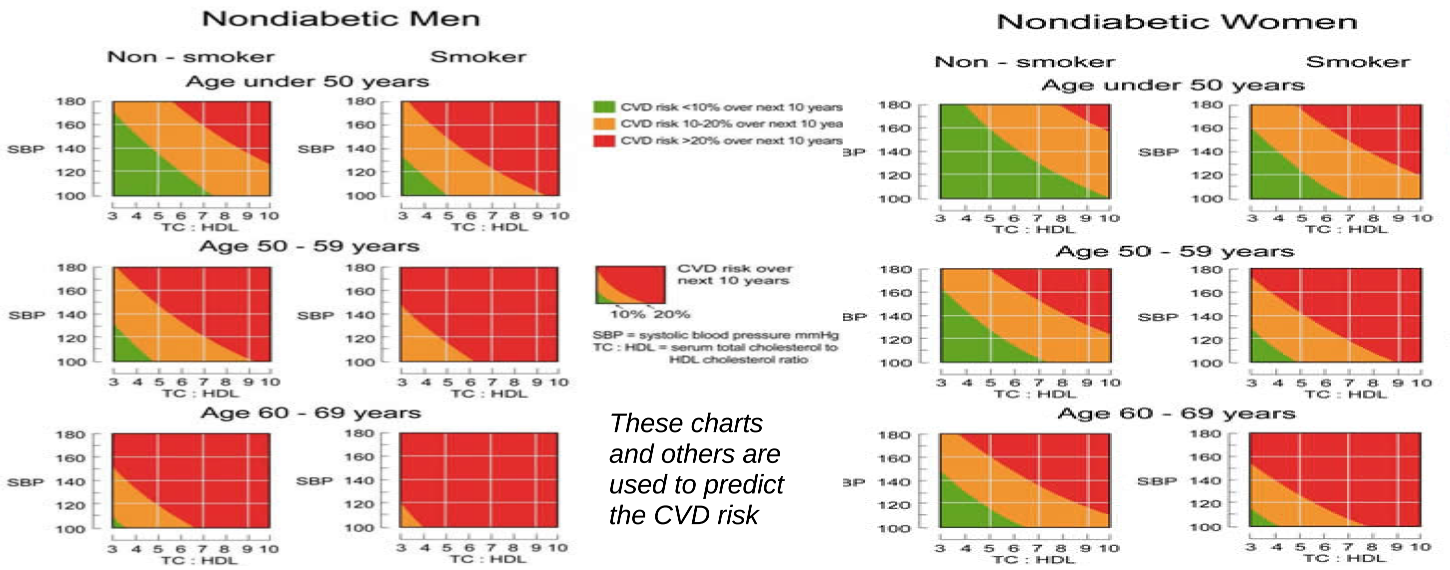
Race: If of South Asian origin, you are more prone–well known to South Asian communities.
Family History: Family History of heart attacks or stroke is a good predictor of future problems.
Age Over 40's, especially men over 55 and women over 65 years.
Sex Men are more prone than women.
Personal History: If previous CVD problems or other related conditions have occurred :
Central Obesity: A spare tyre apple-shaped abdomen as opposed to a pear shape indicates more metabolically active cholesterol, which needs treating.
Raised Blood glucose: Diabetes & Glucose intolerance; tight control of sugar levels is preventative.
Left ventricular hypertrophy: prone to arrhythmias, Careful ECG and other controls are preventative.
Clotting disorders: DVT or previous CVD needs control of causative factors.

Modifiable risk Factors for CVD prevention *(Things you can control to some extent)*

Factors	Alert	Don't	Do	ME/CFS
Smoking	Any smoking activity either active or passive e.g. in the presence of a smoking family member.	Don't suddenly stop—this may cause problems and is unlikely to succeed in the long term.	Do seek professional advice and support, with use of medication to help smoking cessation when appropriate.	Smoking is one of the most dangerous things you ca do to make ME/CFS worse
Lack of exercise	Lack of or reduced physical activity	Don't stay in bed all day. Don't do more than you are capable of, particularly on the graded exercise course. Don't push yourself in bad periods.	Take into account needs, preferences and circumstances. Know your limitations. The advice is to take 30 minutes of at least moderate-intensity exercise a day, at least 5 days a week.	Many people who cannot manage this to exercise at their maximum safe capacity as advised by the ME/CFS Clinic. Agree goals and provide written information about the benefits of activity and local opportunities to be active.
Alcohol	Alcohol consumption:	Don't binge-drink. Take alcohol for health purposes e.g. red wine.	Men should limit alcohol to 3-4 units a day, women to 2-3.	Many people with ME/CFS are intolerant to alcohol, and it can lead to a worsening.
Body Mass Index (Height & Weight)	BMI = 703 multiplied by Weight (in pounds), then divided by height in inches twice. 703xweight/(height)^2	Maintain an ideal weight for your height.	Seek medical advice if BMI is less than 18.5 (underweight) or more than 27 (overweight)	The is a tendency to put weight on, particularly when tricyclics or other neuro–type painkillers are used
Diet	Nutritional deficiencies and unbalanced biased diets	Don't excessively restrict the fat content of food.	Keep total fat to less than one third of calorie intake and saturated fats to less than one tenth of total calories Keep dietary cholesterol to less than 300 mg/day ◦Replace saturated fats with monounsaturated and polyunsaturated fats. Eat five portions of fruit or vegetables per day and two portions of fish per week, including a portion of oily fish.	Omega-3 fatty acid supplements (fish oil) work as a treatment for some people with ME/CFS e.g. vegEPA
Cholesterol (Dyslipideamia)	High cholesterol (figure varies with age) Takes into account HDL (good cholesterol) LDL (bad cholesterol) Triglycerides (fat fragments)	Omega-3 fatty acid supplements (fish oil), plant sterols and stanols (e.g.Benecol) Guidelines do not recommend for primary prevention.	Get your doctor to check if there is a problem and and treat appropriately. Statins usually first choice, but there are other treatment options.	Some ME/CFS are prone to side effects of cholesterol-reducing drugs like Statins. (Rhabdomyolisis). If on them get your doctor to check blood CPK
Blood pressure	Systolic BP & Diastolic BP	Ignore advice	Get checked at least once a year, treat if a problem.	Not part of ME/CFS spectrum.



Above is an example of the NHS scheme ‘Pathways to manage CVD risk’.
Below: Examples of BNF risk predictions charts for CVD risk which are used by the NHS.
These show the increased risk with sex, age, blood pressure, smoking and cholesterol.



These charts and others are used to predict the CVD risk

These are the sort of questions asked by health workers in assessing CVD risk

Aged under 50 yrs 50-59 Yrs 60yrs over

Gender Male Female

TC:HDL ratio

Systolic BP

Smoker* Non-Smoker

*If given up more than 5 yrs ago assume non-smoker

Please Tick Current Smoker ☐ Ex-smoker ☐ Never Smoked ☐

(Smoker – number per day) ________ (Ex-smoker and date when given up) ____

Safe Alcohol ☐

Smoking cessation leaflet ☐

Exercise Activity
Light ☐
Moderate ☐
Strenous ☐

Healthy eating ☐

Salt intake ☐

Blood Glucose level

Weight (Kg)

Height (cm)

Waist Circumference (cm)

Wkly Av Alcohol consumption

Registered with Stop Smoking Service ☐

BP Systolic 1) 2) 3)

BP Diastolic 1) 2) 3)

Cholesterol TC HDL TC:HDL ratio

CVD risk score	(Please Tick)	
CVD risk < 10% over next 10 yrs	🟩	☐
CVD risk 10-20% over next 10 yrs	🟨	☐
CVD risk 20-30% over next 10 yrs	🟥	☐
CVD risk > 30% over next 10 yrs	🟥	☐

The bottom line ——

Hints and tips about Cholesterol.

Lisa Wilson is a 'Pathways' reader from the USA , and an enthusiastic anti-cholesterol campaigner. She authors a website http://www.cholesterolloweringdiets.net, a dedicated cholesterol lowering site. Her personal crusade blog shares suggestions to help visitors to lower high cholesterol and help spread the knowledge on healthy eating. She writes:
:

Have you ever thought how you are taking care of your own heart? In case you are attempting to maintain healthy cholesterol, or your physician states you need to reduce your cholesterol, you are probably wanting to keep an eye on what you eat. Taking safe practices today could stop heart problems tomorrow. I am not saying you have to avoid all of your favorite foods. Learning the main difference in the kinds of fat we eat and where these fats come from in our food is important to manage the levels of cholesterol within our blood.
Below are 10 of the most popular truth and lies and facts I think that you need to know:-

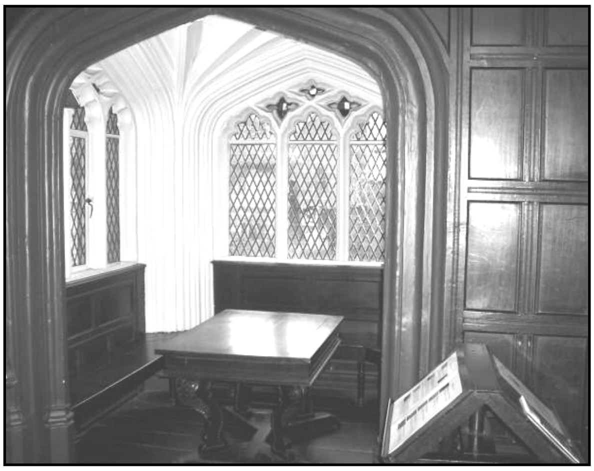
1**) The healthiest weight loss program is the one which limits all fats.**	You ought to get 25-35 % of your total calories from fats because your body can't make some fatty acids it requires for correct functioning.
2) All fat molecules are fundamentally the same. There are different types of fats. Mono unsaturated and polyunsaturated fats could actually reduce your LDL (bad) cholesterol while saturated and trans-fat tend to be more closely related to high LDL.	Samples of foods that include each variety include: - Mono saturated: extra virgin olive oil, peanut butter and avocados. - Polyunsaturated: salmon, seeds and nuts and vegetable oils for example corn, soybean and safflower. - Saturated: unhealthy red beefs, bacon, real butter, and tropical oils for example palm oil and coconut oil. - Trans-fat: fast food fried potatoes, and a lot of commercially manufactured foods for example donuts, crackers and cookies.
3) Items that are labeled "low fat" are often also low-calorie options.	Some food manufacturers replace fat with things that might have equally as many calories
4) Foods labeled "trans-fat free" usually are healthy alternatives.	Food producers may replace trans-fat with saturated fats, that may also raise the LDL (bad) cholesterol levels.
5) I will have a sufficient volume of plant sterols from the foods I consume to get benefit from the plant sterols.	While plant sterols are found in many vegetable natural oils and whole grains to vegetables and fruit, you'll have to eat about 100 pounds of fruit and veggies daily to have the total daily intake of 0.8 grams necessary for plant sterols to take down cholesterol.
6) Plant sterols help reduce cholesterol levels inside the blood by dissolving it within the intestinal tract.	Plant sterols work by lowering the absorption of cholesterol from your digestive system, which often cuts down the higher level of LDL (bad) cholesterol inside you. Cholesterol that's not absorbed is eliminated from the body.
7) Individuals with normal cholesterol levels will never take advantage of eating products produced with plant sterols.	Plant sterols lower cholesterol levels in those with both normal and elevated blood cholesterol level. Plant sterols can appreciably lower trans-fat levels whatever is the starting point.
8) Children and expectant mothers ought not eat huge doses of plant sterols.	While plant sterols are likely to be acknowledged as safe food components, they're generally considered a bad idea for pregnant or breast-feeding women, and for children under 5yrs old, because they consumers typically don't have nutritional requirements for a reduction of cholesterol.
9) If you're attempting to reduce your cholesterol, you should attempt to get rid of it from the diet almost entirely.	For most of us, it's perfectly safe to get around 300 mg of cholesterol every day which can be the suggested daily limit.
10) Seafood is low in cholesterol	While shrimp is higher in cholesterol than other animal products, it's still very lean and low in fats.

Manchester Trilogy - Part 2: Chetham's School

A brief history By Trevor Wainwright

Chetham's, the most complete late-medieval residential complex to survive in the north west of England occupies the site of the manor house of Manchester, which, together with the parish church (now the Cathedral) formed the core of the medieval town.

In 1421 Thomas de la Warre, Lord of Manchester and rector of the parish church, obtained a licence from Henry V to re-found the church as a collegiate foundation. The troubled history of the college, however, makes its survival all the more surprising. Dissolved under the Chantries Act, the buildings were purchased by the Earl of Derby and converted into a town residence. Later it became Catholic, only to be closed down again on the accession of Elizabeth I. In 1578 it was formally established with a new charter as Christ's College. During the Civil War the buildings had various uses; parts were allowed to become derelict, eventually it was taken over by the Parliamentary Committee of Sequestration. It was then that Humphrey Chetham, a prosperous Manchester merchant, made his first overtures to purchase the College to house a school and library. Chetham died in 1653 before negotiations to purchase the College were completed, and it was left to his executors to carry out his intentions. Under the terms of his will, the bulk of his fortune was to be used to endow a hospital for the maintenance and education of forty poor boys, and to adapt and equip part of the building as a library for the use of scholars. Chetham's Library continues to serve its founders purpose, although the Hospital has modified its activities through the centuries, eventually being re-established as a co-educational music school in 1969. Walking into the library building through the Baronial Hall, but for the electric lighting, one could be stepping back in time. What was once the dining area is now used for music recitals. The Library itself is reached up a flight of stairs to where it houses its distinguished collection of 150,000 rare, early books



The Reading Room adjacent to the Library boasts an impressive array of pictures; centrepiece is a Cromwellian gate-legged table,one of the largest of its type in existence. Made from oak, along with the 10 Cromwellian Chairs round it, there are 24 of these chairs in total. On the outer wall is a bay which houses one of two oak draw-top tables and it was here that Karl Marx, when he visited Chetham's Library during 1846 on the invitation of his friend Frederick Engels, carried out the research for Das Kapital, a critical analysis of capitalism. The pair of them used to sit overlooking a slum area, and forged a scholarly partnership that later created such influential works as The Communist Manifesto. Visitors to the library can actually sit in the place of which it could be said it made Marx aware of social inequalities.

Chetham's arms and motto, *Quod tuum tene* (Hold that which is yours) appear above the fireplace flanked by tall pedestals holding torches, which rest on piles of books. These symbolise enlightenment supported by learning. To the right is a pelican feeding her young, the drops of blood on her chest symbolising charity. To the left is a cockerel, the meaning of which is less clear and may represent vigilance or hard work. Above the whole is an eagle, a symbol of authority and power.

North of Doncaster

Personal Comment by Trevor Wainwright

As many *Pathways* readers are aware, I am a keen follower of the issues around the politics of ME/CFS research. Yesterday, I received the following reply from Paul Bustow via my MP Yvette Cooper, referring to a letter to Earl Howe sent 28 Jan 2011, Ref PO00000588919.

D*ear Yvette,*

Thank you for your letter of 28 Jan to Earl Howe on behalf of your constituent Trevor Wainwright about CFS/ME. I am replying as the Minister responsible for this policy area.

(This paragraph usual apologetic crap). (This paragraph was the usual “as you know dross” Trev)*.*

As Mr Wainwright may be aware, the main agency for supporting medical and clinical research is the Medical Research Council (MRC). The MRC has just confirmed a commitment of up to £1.5 million to support research into the causes of CFS/ME. The new funding will focus on six priority areas that have been identified by leading experts in the research community. One of these research areas is immune deregulation, such as viral infection. The five other research areas that have been identified are: autonomic dysfunction, cognitive symptoms, fatigue, pain and sleep disorders. [Note this appears to be looking at the symptoms of ME separately, rather than the ME/CFS syndrome. Is this the right approach to finding causes for the illness? Editors]

The call will also encourage capacity building in CFS/ME research and the entry of new researchers into the field. Details of the call are currently being finalised in consultation with the MRC’s CFS/ME expert group, and the full specification of the call will be published on the MRC website shortly at: http//www.mrc.ac.uk/Ourresearch/ResearchInitiatives/CFSME/index.htm

Mr Wainwright may also be interested to know that, in 2008, the MRC set up a new group to consider how, by looking not only at new technologies but also at associated areas it might encourage new high-quality research into CFS/ME and partnerships between researchers already working on CFS/ME and those in associated areas. The group is chaired by Professor Stephen Holgate and brings together leading experts in CFS/ME and from associated fields that may be involved in the underlying mechanisms of CFS?ME, as well as from the charity sector.

The aim of the group is to look at new ways of encouraging new research in the CFS/ME field by looking not only at new technologies but also at associated areas that could help inform on the diverse range of symptoms and possible underlying causes of CFS/ME. The MRC hopes that this will encourage new research towards understanding the causes and subtypes of CFS/ME and can lead to an advancement of knowledge in this field and the development of new therapeutic approaches. More information on the group can be found by visiting the MRC’s website www.mrc.ac.uk and entering ‘MRC CFS/ME Expert Group’ into the search bar.

The MRC also had a small research workshop for CFS/ME on 19 and 20 November 2009. A note of the meeting is available on the MRC website.

Solution to crossword on page 18

I hope this reply is helpful,

Paul Burstow

My first reply to Yvette, after thanking her, was to say that the reply didn't tell me anything I didn't already know or could not access; anybody any other comments? - *Trev*