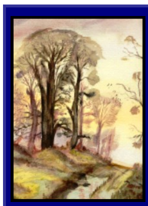


Pathways

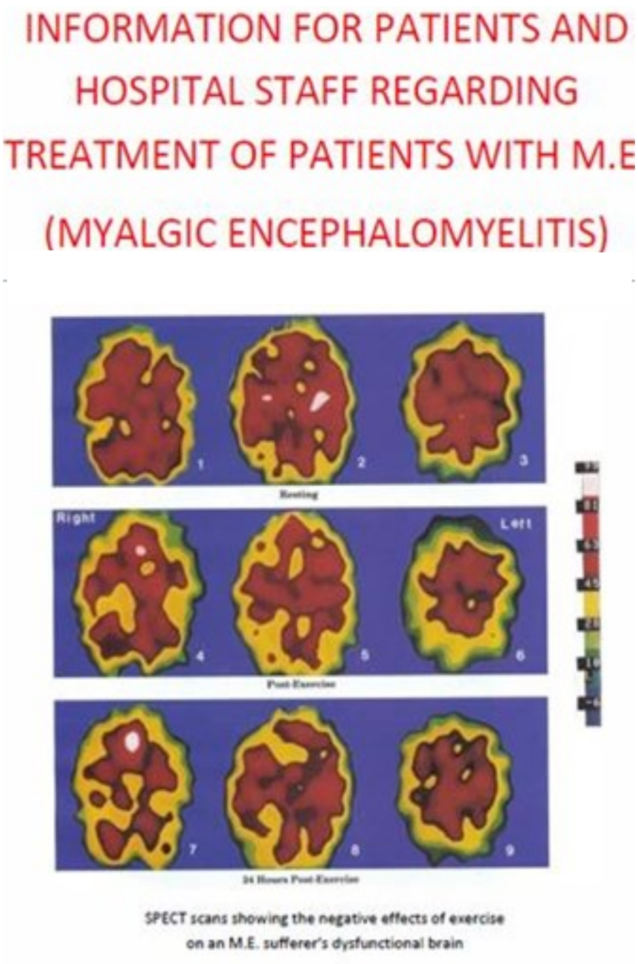
Price £ 3.75 (Free to members)

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.

Welcome to Pathways 41.

Inside this issue

Terre Haute Pt 2: Max Ehrmann & Desiderata *See page 22*



INFORMATION FOR PATIENTS AND HOSPITAL STAFF REGARDING TREATMENT OF PATIENTS WITH M.E (MYALGIC ENCEPHALOMYELITIS)

SPECT scans showing the negative effects of exercise on an M.E. sufferer's dysfunctional brain

A visit to the Cast Theatre Doncaster *See page 20*

Literature review:
The Grace Charity for M.E. Hospital Information Book
See page 10

Also in this issue...

More on issues around ME/CFS, Co Q10 and patients taking Statins

A little more on the pro & cons of statins See page 12

Personal Independence Payment (PIP) Update Avoiding the pitfalls

Are the problems the same with this new DWP benefit as with what it is intended to replace? See page 17

Useful Doncaster Telephone numbers

See page 8

You Write:

Pearl Writes: Thank you for Pathways.

I was very impressed by your article on Q10 Coenzyme which I purchase on a regular basis from Pharma Nord. I am seventy-seven and for many years have used this. I was given statins by a doctor for high cholesterol – WHAT? I found I couldn’t walk; I ached and felt really ill. I was given another type of statin, NO JOY!

I ‘phoned you and you suggested going back and asking about fish oil and nicotinamide. Then of course you guessed it, Drs answer, negative! So, I ‘phoned Pharma Nord, as they were always helpful; they suggested Q10 Bio Active Ubiquinol, backed up by Selinoprecise. I also take Bio Magnesium 200mg. Pharma Nord is the best.

I also use Q10 toothpaste (Pharma) and Q10 skin care; when I run out I can really tell the difference. These products are not cheap but they are not adulterated and the coatings are not harmful, some are vegetarian friendly. The delivery is swift and some categories have reductions. Bio Culture is marvellous. Doctors think its all hype but three minutes in the surgery, with some, is a waste of time “ME is all in the mind, never heard of it”! “Its old age” – what, at 40? Years on now the medical profession, not ALL, are still in the medieval period.

ME Saga

By Pearl

Oh, to be absolutely free;
of the scourge known as ME,
It skews your entire life,
I believe fibromyalgia is his wife,

What the cause be is unknown
The doctors (not all) only moan,
Join the gym, take up yoga,
Read a book about Caesar’s Toga

Try jogging “this to an old crone”
But what really helps me is this,
I know I won’t be ME free
But Q10 et al works for me

You say quite a lot in a few words. Statins are problem for many people with ME/CFS. Interestingly there are a few that say they can tolerate statins—but I often wonder about this. Sarah Myhill is not willing to accept that anyone with ME/CFS can tolerate a statin. Just how much are they affected and are the statins they take responsible for them not getting any better and maintaining the disability? The Pharma Nord supplements you take are along the same lines that Myhill suggests, although she tends to recommend the Biocare equivalent. These two companies tend to promote their products in a similar way. I agree with you that some doctors are still in the dark ages.

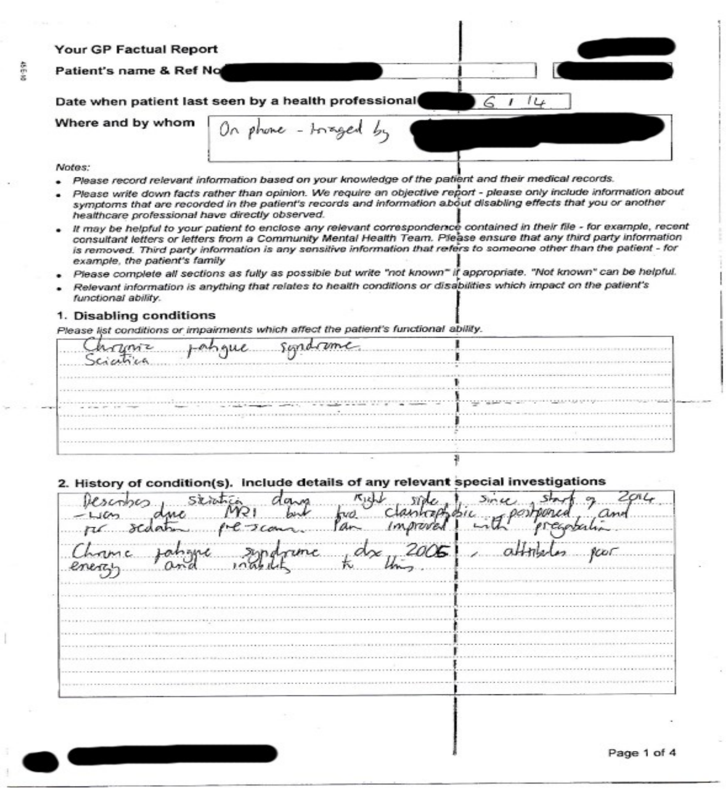
Sarah Myhill Writes: I am currently experiencing a very heavy work load and an exceptionally high number of referrals from other doctors, self-referrals, other requests for advice and interpretation of test results. I simply cannot deal with demand. This means I have no other option but to suspend all advice, appointments and test orders to those to whom I refer as "new patients". If you are a "new patient", i.e. you have never received advice from me before (by way of a face-to-face or a telephone consultation, or a letter of advice based on a questionnaire, or an interpretation of your test results), then any such first requests for advice and first test orders cannot currently be accepted.

I shall review the situation in January 2015 and perhaps then will be able to accept new patients. Please, keep an eye on MY website Dr Myhill.co.uk. I will continue to see and treat all current patients i.e. those who have had previous contact with me and already received advice from me.

If you have any difficulties with access to Sarah's services please let me know. There is a workaround on most matters depending on the problem. Contact me at the Redmond Centre for advice.

Ian Writes: I’ve just had PIP refused. I’ve enclosed copies of my forms. Any ideas why?

As with all benefit refusals we held an enquiry. Your forms are fine as far as I can see. The most likely reason you have been refused is your GP doctor’s report. This looks like a telephone-only practice with no doctor taking overall responsibility. There is nothing about symptoms or clinical findings worth talking about. When the Decision Maker saw such a document, he would put it in the reject pile and not waste time. We have reproduced this for Pathways readers next page. You should complain....



Your GP Factual Report [redacted]

Patient's name & Ref No [redacted] [redacted]

Date when patient last seen by a health professional [redacted] 6 / 14

Where and by whom On phone – triaged by [redacted]

Notes:

- *Please record relevant information based on your knowledge of the patient and their medical records.*
- *Please write down facts rather than opinion. We require an objective report - please only include information about symptoms that are recorded in the patient's records and information about disabling effects that you or another healthcare professional have directly observed.*
- *It may be helpful to your patient to enclose any relevant correspondence contained in their file - for example, recent consultant letters or letters from a Community Mental Health Team. Please ensure that any third party information is removed. Third party information is any sensitive information that refers to someone other than the patient - for example, the patient's family*
- *Please complete all sections as fully as possible but write "not known" if appropriate. "Not known" can be helpful.*
- *Relevant information is anything that relates to health conditions or disabilities which impact on the patient's functional ability.*

1. Disabling conditions

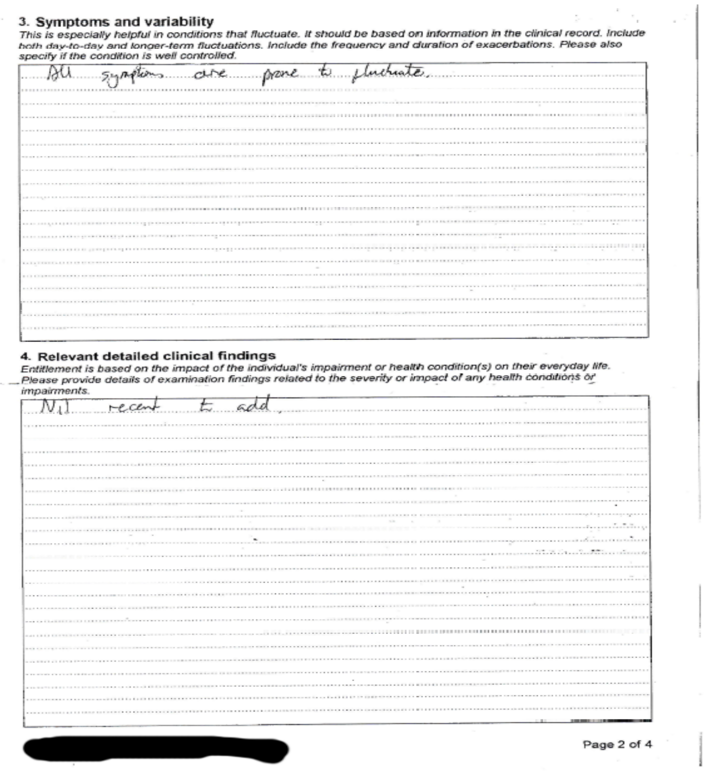
Please list conditions or impairments which affect the patient's functional ability.

Chronic fatigue syndrome.
Sciatica

2. History of condition(s). Include details of any relevant special investigations

Describes sciatica down Right side since start of 2014 – was due MRI but too claustrophobic – postponed and for sedation pre-scan. Pain improved with pregabalin.
Chronic fatigue syndrome dx 2005, attributes poor energy and inability to this.

[redacted] Page 1 of 4



3. Symptoms and variability

This is especially helpful in conditions that fluctuate. It should be based on information in the clinical record. Include both day-to-day and longer-term fluctuations. Include the frequency and duration of exacerbations. Please also specify if the condition is well controlled.

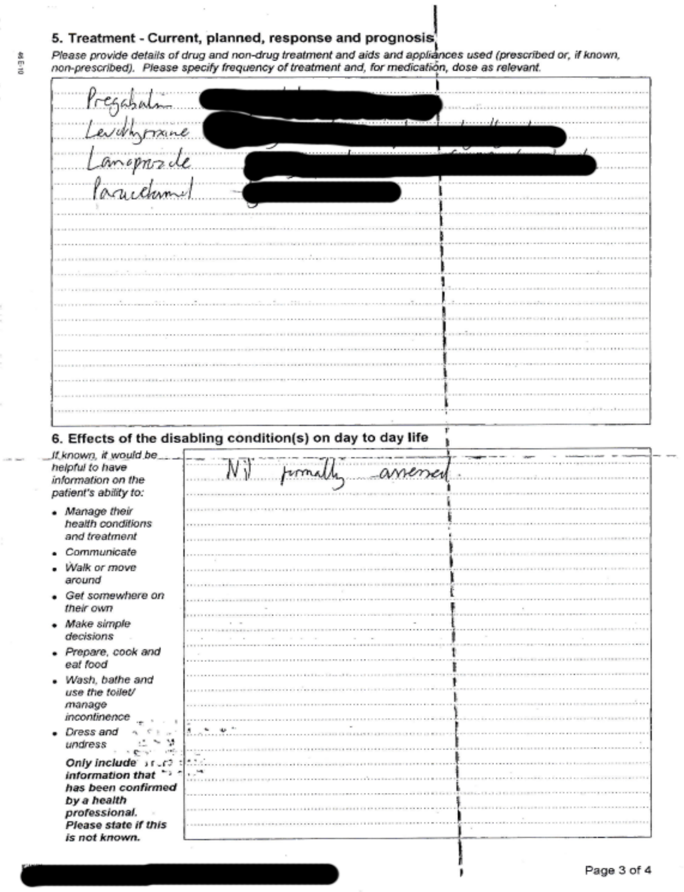
All symptoms are prone to fluctuate.

4. Relevant detailed clinical findings

Entitlement is based on the impact of the individual's impairment or health condition(s) on their everyday life. Please provide details of examination findings related to the severity or impact of any health conditions or impairments.

Nil recent to add.

[redacted] Page 2 of 4



5. Treatment - Current, planned, response and prognosis

Please provide details of drug and non-drug treatment and aids and appliances used (prescribed or, if known, non-prescribed). Please specify frequency of treatment and, for medication, dose as relevant.

Pregabalin [redacted]
Levothyroxine [redacted]
Lansoprazole [redacted]
Paracetamol [redacted]

6. Effects of the disabling condition(s) on day to day life

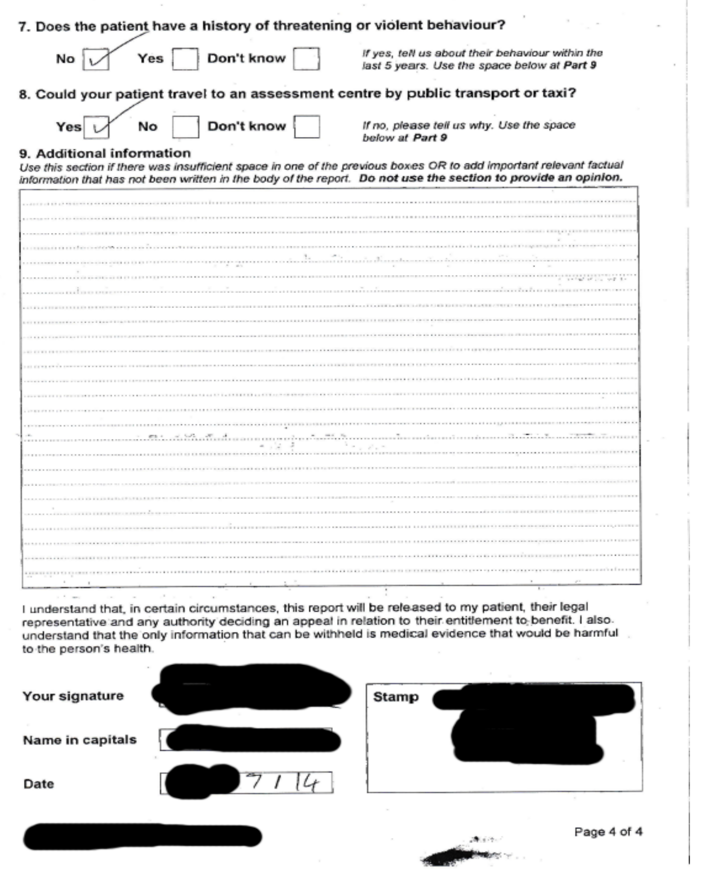
If known, it would be helpful to have information on the patient's ability to:

- *Manage their health conditions and treatment*
- *Communicate*
- *Walk or move around*
- *Get somewhere on their own*
- *Make simple decisions*
- *Prepare, cook and eat food*
- *Wash, bathe and use the toilet/ manage incontinence*
- *Dress and undress*

Only include information that has been confirmed by a health professional. Please state if this is not known.

Nil formally assessed.

[redacted] Page 3 of 4



7. Does the patient have a history of threatening or violent behaviour?

No ☑ Yes ☐ Don't know ☐ *If yes, tell us about their behaviour within the last 5 years. Use the space below at **Part 9***

8. Could your patient travel to an assessment centre by public transport or taxi?

Yes ☑ No ☐ Don't know ☐ *If no, please tell us why. Use the space below at **Part 9***

9. Additional information

Use this section if there was insufficient space in one of the previous boxes OR to add important relevant factual information that has not been written in the body of the report. ***Do not use the section to provide an opinion.***

I understand that, in certain circumstances, this report will be released to my patient, their legal representative and any authority deciding an appeal in relation to their entitlement to benefit. I also understand that the only information that can be withheld is medical evidence that would be harmful to the person's health.

Your signature [redacted]

Name in capitals [redacted]

Date [redacted] 7 / 14

Stamp [redacted]

[redacted] Page 4 of 4

This is an enquiry form sent to a General Practitioner by the DWP in response to a PIP claim. Similar forms are sent in ESA and DLA claims. Although the doctor has filled in basic clinical details, he or she has not put any details about how the person is affected. The comments made are unhelpful to say the least. In this case it is unlikely that the doctor knew the patient personally. In my view this report is not worth the paper it is printed on, and really the doctor is not doing his job to the point where it is detrimental to the well-being of the patient. The DWP take the view that it is the patient's responsibility to prove their case so the claim will be rejected. However as it was a first PIP claim, this patient was called to a medical examination. We've seen this before with other benefits where the medical examination is a lottery rather that a true reflection of reality. This is borne out by the number of appeals that are won at tribunal. Leger ME advice to members is that they should keep in regular touch with their doctor, otherwise this is what happens. The remedy is dependent on the individual case. If you don't submit any further evidence after this happens the only recourse is a tribunal—which locally have been taking around 12 months to be heard. A welfare rights adviser would have been aware of this issue and taken action before the original form was submitted.

Welfare Rights: Hope4Benfits (H4B), A new Doncaster-based service.

Over recent years the support for members with welfare rights issues has been slowly eroded due to government funding cuts. We have lost the DMBC welfare rights service, and the CVS Welfare Right Service formally headed by Liz Pennington has also been cut. Feedback from our members indicates they have found great difficulties accessing the services provided by DiAL and the Citizens Advice Bureau, mainly because there appears to be some sort of means test which has worked against the interests of Leger ME members due to the nature of the condition. The support services provided formally provided by SYCIL have now been cut. However two of the former SYCIL employees have seen a business opportunity to provide support services on a private basis and have set up a business. This service has to be paid for by the user, or someone on their behalf. It has the advantage of being immune form government cuts—but like all businesses it has to make a profit. Recently, I asked Helen and Jane to come to a meeting at the Redmond Centre to find out more about their service and how they could help Leger ME members.

Mike: "What made you decide to create your own business?
Helen: "I worked for 11 years for SYCIL as a Disability Worker. Over the past few years we've seen what's happened with loss of jobs due funding withdrawal with other organisations and we saw a business opportunity. So we did our research and one our redundancy notices came through we were ready to go."

Mike: "So what is your mission?"
Helen: "At Hope4Benefits we know that trying to find out about the benefits which you might be able to claim. Filling the forms in, attending medical assessments, and then maybe having to go through a tribunal if things don't work out first time, is a worrying and stressful process. Often this is made worse by not being able to access help when you need it either because services have been cut, or because they are overstretched. This is where we can help."

Mike: "Where is your office?"
Helen: In order to provide a local service, we will hold sessions at local community centres around Doncaster, to make it easier to access our help. After all, if money is tight, or you don't feel well, the stress of a long journey to get help is the last thing you need."

Mike: "If someone is short of money how do you take account of this?"
Helen: "We know that often the people who use our service will be short of money, and if when we see you things are really desperate, we can in some cases issue a food bank voucher to help tide you over."

Mike: "So what are the services you offer?"
Helen: "Our core work is welfare benefits, but we are also happy to help with other forms such as a Blue Badge or bus pass. Perhaps someone doesn't need help with benefits, but is worried about attending that hospital appointment on your own. If so, they could get in touch, as we can accompany you to your appointment, and if you need us to do so we can make some notes afterwards for you to refer back to later. We also know that many support groups struggle to keep up with changes to the benefits their members may be able to claim. If this sounds familiar to you, then again, please let us know, as we can help with giving a presentation to your members."

Mike: "So, how much does this service cost?"
Helen: "Benefits Support for Disability Benefits, Attendance Allowance, Disability Living Allowance, Personal Independence Payment, Employment and Support Allowance, our fee is equivalent to 2 weeks award, after a successful claim. Our service includes form filling, support at medical assessments, and when required, support at a tribunal. However, If you are claiming under 'The Special Rules', then all disability benefit forms are charged at a flat rate of £10.00."

(Ed: Fortunately this is not often the case with ME/CFS.)

Mike: "What about smaller forms like the blue badge forms"
Helen: For all other benefits forms, or Blue Badge, Bus Pass or Rail Card applications we charge £10.00. Support at a hospital appointment is £20.00."

Mike: "Do you offer any service to community groups like Leger ME?"
Helen: "Yes, For a presentation about benefits, then we charge £25.00 for up to half a day and £50.00 for a full day to local community groups."

Mike: "Is there anything else you would like to say?"
Helen: "We are a new business, and keen to do what we can to help. If you know of a community centre where we could use a room to reach that community, or are holding an awareness-raising event, then we would love to hear about it."

Mike: "How does someone contact you ?"
Helen: "here are our contact details:-

Telephone: 07929 976922 or-: 07759 859292
E-Mail: Hope4Benefits@hotmail.com
Twitter: #Hope4Benefits
Or write to us at Hope4Benefits PO Box 1097 Hatfield Doncaster"

Mike: "You been up and going a couple of weeks—how has the start-up been going?"
Kath: "The 'phones has never stopped ringing with enquiries since we started up."

Mike: " Would like to do a welfare rights session for Leger ME in the next few months?"
Helen: "Yes—just give us a ring and we'll sort out a date."

Mike: "I know you both have mobility problems, as most of our members can walk to some extent I can foresee you attending with one of our members and DWP getting going for the wrong person."
Jane: "Yes, that would very humorous. We'll let you know if it happens."

Could I just clarify to Pathways readers that Leger ME policy is that fully paid up Leger ME members have access to Leger ME Advice line, email support for Benefit & Work Guides, Form fill out Service and other Support. This service is free to members provided it is at an organised Leger ME event at the Redmond Centre. It is our intention that Helen or Jane will be invited to some of these sessions as needs arise. For further information please use the usual service number. Please note that il you wish to contact Hope4benefits directly that is a private matter and does not involve Leger ME.—Mike.

Medicines in Use:
Benzodiazepine-use linked to high risk of Alzheimer's Disease

A recent research paper indicates that long use of medicines for anxiety and sleep problems may be linked to Alzheimer's, the research suggests. A study of older Canadian adults found that past benzodiazepine-use for three months or more was linked to an increased risk (up to 51%) of dementia. The current NHS guidelines say the drugs should be used for eight to 12 weeks at most. The research was carried out by a The French-Canadian team. They say that the link is not definitive. The study involved about 2000 cases of Alzheimer's disease in adults aged over 66 living in Quebec. All had been prescribed benzodiazepines. They were compared with about 7,000 healthy people of the same age living in the same community. While an increased risk was found in those on benzodiazepines, the nature of the link was unclear. However, with around 1.5 million people in the UK being prescribed benzodiazepines at any one time, this evidence that their long-term use increases the risk of dementia is significant, and raises questions about their use, and is a major public health concern. This has implications for the new Z-hypnotics e.g. zopiclone.

What's the Big Deal about High-Potassium Foods?

Thanks to Leger ME member Sandy who lives in the USA for this Pathways feature.

High-potassium foods are an essential part of any balanced diet. This mineral helps to regulate your body's fluid levels, aids in muscular function and waste removal, and plays a vital part in your nervous system. Potassium also helps reduce blood pressure in people with hypertension and lowers your risk for stroke. A deficiency in potassium can cause fatigue, insomnia, depression, muscular weakness, and many cardiovascular issues.

Some food sources of Potassium

How much do you need? For adults, the Guideline Daily Amount for potassium is 4700 milligrams a day.

Here are 10 high-potassium foods to help you reach that number.

Potatoes: Whether they're red, white, or sweet, potatoes can be a great source of potassium and many other nutrients, if prepared correctly. They're also an excellent source of vitamin C, iron, fibre, and vitamin B6. Refrain from frying them and make sure to eat the skin because that's where you'll find most of the nutrients. Baking potatoes is arguably one of the healthiest ways to prepare them, but make sure to avoid adding fats such as sour cream and melted cheese. Opt for a dollop or two of homemade hummus or guacamole instead.

Sun-dried Tomatoes: Eating one cup of sun-dried tomatoes will give you 44 percent of your daily recommended potassium. Low in fat and calories, these tomatoes are high in fibre and vitamin C, promoting both digestive and immune-system health. They can have a lot of sugar and sodium, though, so make sure to take this into account when preparing meals. Sun-dried tomatoes make a delicious addition to any salad, sandwich, or pasta sauce. You can even use them as a pizza topping.

Kidney Beans: If you enjoy kidney beans, finding more ways to add them to your meals may be just what you need to get more potassium into your diet, with over 600 milligrams per cup. They're also high in fibre, at 14 grams per cup. One cup of kidney beans contains about 225 calories. You can add them to your salads or mash them up with salt and pepper to use as a burrito filing. *(Ed :Ensure they are thoroughly cooked as uncooked kidney beans are toxic; cooking destroys the toxin)*

Dried Fruits: Apricots, Peaches, and Figs: For a great potassium-rich snack that can also satisfy a sugar craving, try dried apricots. Apricots are actually most beneficial to your health when served dry, or dehydrated. Just one cup can get you about one-third of the recommended daily potassium level. If dried apricots aren't your thing, try dried peaches or figs. Both are also high-potassium foods and available all year round.

Bananas: Bananas are more beneficial than sports drinks when consumed during intense activity. They are also a good source of fibre and vitamins B6 and C.

Avocado: Avocado is a nutrient-dense food, full of multivitamins and good fats and is naturally free of sodium and cholesterol. It can be used with any meal of the day. A suggested breakfast smoothie : - blend 1/2 avocado with 1/2 banana, 1//4 cup low fat vanilla yogurt, 1/4 cup ice, 1 cup coconut water, 1 teaspoon of of agave nectar, and 1/4 teaspoon of ground cinnamon.

Fish: Most fish will give you at least 10 percent of the recommended daily amount of potassium. Certain fish, like baked flounder, halibut, Pacific cod, and salmon, are better sources than others. Most fish are also rich in omega-3 fatty acids and vitamin D. Avoid breading or frying.

Soybeans: Soybeans are packed with potassium and are a rich source of carbohydrates, protein, fibre, magnesium, and omega fatty acids. They should always be cooked thoroughly before eating. Soybeans help keep your heart healthy by lowering cholesterol levels and may help reduce the risk of prostate cancer. Try roasting them after boiling or, to add some more flavour, cook them in a skillet with olive oil, red pepper, garlic, and lime juice. Edamame, immature soybeans usually still in the pod, can make a great snack.

Kiwi: Kiwi is a potassium-rich fruit that will promote heart-health and lower blood pressure. It aids digestive health due to its high fibre-content and an enzyme called actinidain. It is also rich in vitamin C, which promotes beautiful skin and helps boost your immune system. Kiwis are also a safe option for diabetics because they have a low glycaemic index.

The Warm Home Discount Scheme

If you have received a letter from HM Government working in partnership with your energy supplier don't forget to call the helpline **on 0800 917 1003 before 30th January, 2015** if you think you are entitled to qualify for the £140 help with the cost of your electricity bill.

(If you need information about the discount scheme look online at:-
www.gov.uk/the-warm-home-discount-scheme

Who can get the discount?

- . You may be eligible if on 12th July 2014
- . You got your electricity from a participating energy supplier
- . Your name or your partner's name appeared on your electricity bill
- . You were getting the Guarantee Credit element of Pension Credit (even if you got Savings Credit as well)

The electricity suppliers participating in the scheme are as follows:-

Atlantic, British Gas, Co-operative Energy, Ebico, EDF Energy, E.ON, Equigas, Equipower, First Utility, Manweb, M&S Energy, npower, Sainsbury's Energy, Scottish Gas, Scottish Hydro, Scottish Power, Southern Electric, SSE, Swalec and Utility Warehouse.

If you do qualify, the discount will be shown on your bill as a Warm Home Discount of £133-33. With VAT this will mean an overall £140 towards your electricity costs. If you pay your electricity costs by pre-payment meter, your electricity supplier will let you know how you will get your discount. Discounts will be applied before 31st March, 2015.

This discount will not affect any Winter Fuel Payment or Cold Weather Payments you may get.

Remember, you must call before 30th January 2015 or you will not get the discount.

"As we grow older, we realize that it is LESS important to have more friends and MORE important to have real ones"

Genuine Notes to Milkmen

Dear milkman, I've just had a baby, please leave another one.

Please leave an extra pint of paralysed milk.
Milkman please could I have a loaf but no bread today.

Sorry not to have paid your bill before, but my wife had a baby and I've been carrying it around in my pocket for weeks.

Milk is needed for the baby. Father is unable to supply it.

Please leave no milk today. When I say today, I mean tomorrow, for I wrote this note yesterday.

Please send me a form for cheap milk, for I have a baby two months old and did not know about it until a neighbour told me.

Useful Doncaster Telephone Numbers

Accessible Taxis - DIAL Doncaster	**t: 01302 327800**
Action for Hearing Loss	**Information line (telephone): 08088080123 Information line (textphone): 08088089000 SMS: 0780 0000 360**
Doncaster Carers' Service	**t: 01302 812827**
Doncaster Council Adult Contact Team	**t: 01302 737391 (8.30am to 5.00pm)**
Doncaster Council Emergency Social Services Team	**t: 01302 796000**
Attendance Allowance and Disability Living Allowance	**t: 08457 123456**
Blue Badge Scheme Information	**t: 01302 862549**
Bus Travel Passes	**t: 01302 735336**
Doncaster Citizens Advice Centre	**t: 01302 735221**
Doncaster Council	**t: 01302 736000 minicom: 01302 736252 SMS: 71006**
Doncaster CVS	**t: 01302 343300**
Doncaster Royal Infirmary	**t: 01302 366666 f: 01302 320098**
IAPT- Improving Access to Psychological Therapist	**t: 01302 565 556 or at Talking Shop 63 Hallgate**
Emergency Services	**t: 999 SMS: 71006**
Hospital Shuttle	**t: 0800 953 6633**
Leger Bus/Dial-a-Ride	**t: 01302 342400**
Montagu Hospital Mexborough	**t: 01709 585171 f: 01709 571689**
Motability	**t: 0845 456 4566**
National Grid Gas Emergencies	**t: 0800 111 999**
Rail Travel Passes	**t: 0845 605 0525**
RNIB Helpline	**t: 0303 123 9999**

The Young ME Sufferers Trust: ME Awareness Day 2013, How Things Stand Research:

With special thanks to Jane Colby and the The Young ME Sufferers (TYMES) Trust

What causes ME?

We feel it is vital that enteroviral studies by Dr John Chia of the Enterovirus Foundation in America be repeated in the UK. Over ten years, his work has demonstrated, just as microbiologist Dr Elizabeth Dowsett always maintained, that ME is a persistent enteroviral infection. So it could be treated by enteroviral drugs (yet to be developed) and vaccination could also be possible. This is the priority area of research in our view. However, when we raised the matter of enteroviral studies in a meeting with the Medical Research Council, they showed no interest. We therefore have little confidence in the MRC in this respect, which is a matter of serious regret.

ME (myalgic encephalomyelitis) v CFS (chronic fatigue syndrome)

ME specialist Byron Hyde MD stated in his book *Missed Diagnoses*: “Patients are now being diagnosed with CFS as if it were a disease. It is not. It is a patchwork of symptoms that could mean anything.” He emphasises the importance of identifying what is underlying the symptoms; does the patient have a sudden-onset virally based disease (a typical ME presentation) or another as yet unidentified disease? Fatigue itself can be a symptom of major organ disease, or depression, whereas Post Exertional Malaise (becoming ill after effort) is typical of ME. The latest doctors’ guide to detail ME as a separate condition is the ME International Consensus Primer from an international panel led by Professor Bruce Carruthers. This recommends Tymes Trust for education advice. TYMES’ Dublin partner group has arranged for Dr Ros Vallings, one of the authors, to give four talks in Ireland in May. For details, contact the Trust.

Child Protection Implications

The March APPG Group meeting minuted Tymes Trust’s finding that both the severity and chronicity of ME/CFS can trigger child protection investigations. If the illness is severe or of long duration, even an original diagnosis of ME/CFS can become suspect because of the perception that ME/CFS is neither that severe nor that long-lasting. The number of erroneous child protection investigations the Trust has helped with over recent years had gone up to 96 as of the meeting date. Contact us immediately if you think social workers are investigating your situation.

The Tymes Trust is the longest established national UK service for children and young people with ME and their families. It is a respected national charity whose entire professional team give their time free of charge. They work constantly with doctors, teachers and other specialists, and played a major role in producing the children’s section of the Dept of Health Report on CFS/ME (2002).

Contact details:

Tymes Trust, PO Box 4347, Stock, Ingatestone
CM4 9TE

Telephone: 0845 003 9002: Advice Line hours : 11am-1pm and 5pm-7pm Weekdays. Outside these hours you may leave a message and we will call you back.

Website: http://www.tymestrust.org

Fatigue Clinics are not ME Clinics

In 2002 the Department of Health published a report on CFS/ME, with which we assisted (Jane Colby was on the children s panel). We did not, however, like the report’s recommendation for services, which we thought would be chronic fatigue-based. This is what happened. Despite some clinic therapists helping families in their dealings with schools, most seem to follow a standard line in psychological therapy and graded exercise regimes. Many seem unable to grasp the seriousness of ME, which is potentially severe and chronic, and easily made worse. The new Lothian fatigue clinic was set up against the wishes of patients at the Scottish Cross Party Parliamentary Group who voted overwhelmingly in favour of an ME centre of excellence like neurologist Dr Abhijit Chaudhuri’s former Glasgow-based service.

His specialist ME clinic also referred doubtful cases for tests, and other appropriate care. But patient groups pressing for ME services have typically ended up with the fatigue model being rolled out everywhere. It is important never to suspend your own judgement when visiting such a clinic.

Literature review: The Grace Charity for M.E. Hospital Information Book.

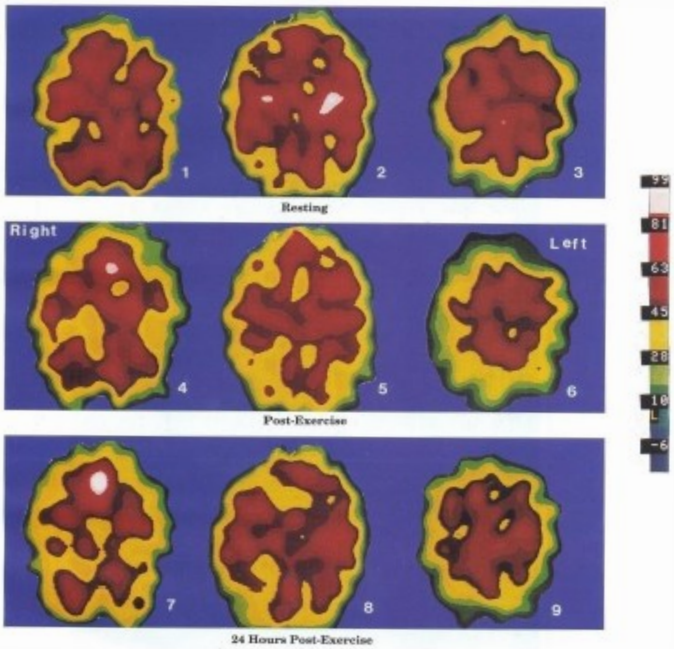
From time to time I receive an enquiry from Leger ME members regarding admission to hospital for various reasons. Locally the most useful document I've come across has been the Sheffield Hospital Nursing Guidelines. While being better than nothing, it is far from ideal. The Grace Charity literature is the best I've seen. It is positive and straight to the point, and gives us a lot of technical information doctors may need.

The document starts with asking what the difference is between ME & CFS. It then follows on to M.E. and hospital environments. Chemicals and drugs (including anaesthetics) are covered followed by a section on Surgery. For the recovery phase, it includes Exercise and ME along with Diet and Allergies. The text is medical standard, so someone without medical knowledge would have great difficulty in understanding it. It makes sense and heavily quotes references which are used to back up statements. Many well known ME/CFS specialist doctors are quoted.

The booklet in its brief summary states:

1) An M.E. patient must only have surgery if absolutely necessary.
2) M.E. patients are usually chemically-sensitive and may have a worsening of their symptoms from drugs and surgery.
3) A private room may be necessary for the patient to make the best recovery, as noise can cause severe distress to sufferers, along with sleep deprivation, due to sensory overload of the brain.
4) M.E. patients will not normally be able to do the usual post-operative exercises due to muscle weakness.
5) Sufferers will need more support than usual when recovering at home.

INFORMATION FOR PATIENTS AND HOSPITAL STAFF REGARDING TREATMENT OF PATIENTS WITH M.E. (MYALGIC ENCEPHALOMYELITIS)



SPECT scans showing the negative effects of exercise on an M.E. sufferer's dysfunctional brain

This says it all (above)

The front page images are of Xenon SPECT scans of a 37 year-old female M.E./CFS patient and their concept was provided by Dr. Jay Goldstein of Anaheim, California. The technical expertise is that of Dr. Ismael Mena, UCLA Harbor, California.
Images 1, 2 and 3 represent the abnormal resting state of an M.E./CFS brain, with perfusion defect (poor blood flow).
Images 4, 5 and 6 represent a further decrease in perfusion immediately after exercise.
Images 7, 8 and 9 illustrate the severely decreased brain perfusion of the same patient 24 hours after physical exercise. Similar brain perfusion could be produced in an M.E./CFS patient as a result of sleep deprivation, a secondary infectious state, as well as cognitive, sensory or emotional factors. A normal healthy patient will probably exhibit increased brain perfusion after similar modest exercise.

So who authored this document?? All I know is that the Grace Charity for M.E. (Myalgic Encephalomyelitis) is operation in Kent, England, and gained charity status in 2006. Although the charity is based on Christian prayer, they state they want to help M.E. sufferers of any faith or of no faith at all. They have a website which is www.thegracecharityforme.org which contains further information. Interestingly they state they not DO NOT promote or encourage GET (Graded Exercise Therapy) or CBT (Cognitive Behavioural Therapy) for M.E. sufferers. Neither do they promote patented & named CBT like therapies or processes. They state "However, we DO PROMOTE a biomedical perspective of M.E." On the website there are acknowledgments to the Police Property Fund and to the Kent ME Network, for the grant used to fund the hospital booklet.

Roasted Autumn Vegetables with Lancashire Cheese

By Carolyn

Cooking Time: 40-45 mins
Servings: Serves 4 as a side dish
Serves 2 as a main dish

Nutrition:

Kcals:306 Protein:8g Carbs:14g
Fat:22g Saturates:7g Fibre:3g
Sugar:0g Salt:0.39g

Ingredients:

1 large butternut squash (about 600-700g/1lb 5oz – 1lb 9oz in weight)
1 medium red onion
6 tbsp olive oil
1 large sprig fresh sage
1 large courgette
1 tbsp balsamic or sherry vinegar
100g Lancashire cheese

Method:

Preheat the oven to fan 180C/conventional200C/gas6. Using a sharp knife, cut the squash in half and scoop out the seeds. Cut the halves into smaller pieces so you can peel them more easily. Chop the flesh into big bite-sized pieces – they don't have to be neat.

Halve the onion and trim the root end leaving a little on to hold the segments together. Peel and then cut each half into four wedges. Scatter the squash and onion in a large roasting tin so they have plenty of room to roast, drizzle over 5tbsp of the oil and toss together. Strip the sage leaves from the stem and roughly chop – you should have about 2tbsps. Scatter over the vegetables and season. Roast for 20 minutes, stirring once halfway through.

Meanwhile, slice the courgette thickly and toss with the remaining oil. Remove the roasting tin from the oven and push the partly cooked squash and onion to the side. Put the courgette slices flat on the base and season. Roast for a further 10 minutes, until all the vegetables are tender.

Remove the tin from the oven, sprinkle the vinegar over the vegetables and toss. Crumble over the Lancashire cheese. Toss again lightly so the cheese melts a little and serve.

* * *

A Problem with a Dog

Two dog owners were talking in the park.
One said "I'm sick of my dog.
The trouble is he'll chase anyone on a bike."
"What are you going to do?" asked the other
"have him put down?"
"No, I think I'll just take his bike away."

More on issues around ME/CFS, Co Q10 and patients taking Statins.

In the last Pathways I detailed the following research paper, and discussed the background:

Reference: Maes M1, Mihaylova I, Kubera M, Uytterhoeven M, Vrydags N, Bosmans E.Neuro Endocrinol Lett. 2009;30(4):470-6.)
Coenzyme Q10 deficiency in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is related to fatigue, autonomic and neurocognitive symptoms and is another risk factor explaining the early mortality in ME/CFS due to cardiovascular disorder.

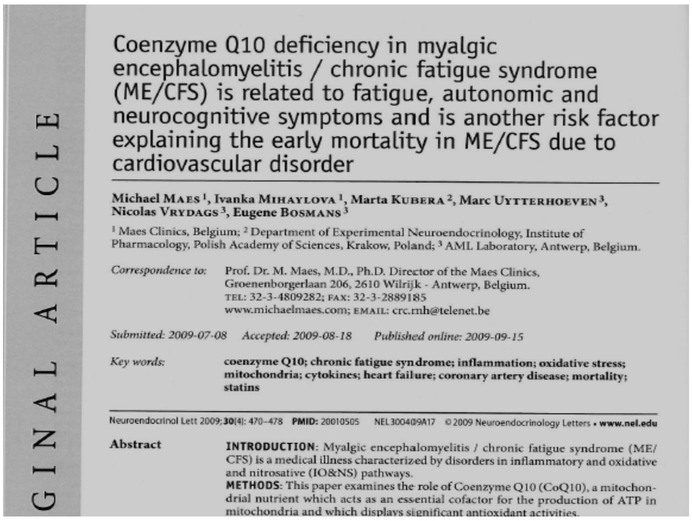
What was quite clear to me from previous experience was that statins for people with ME/CFS may be a credible threat to the wellbeing of some people with ME/CFS because they depress further already depressed Coenzyme Q10 levels. This obviously needs further in-depth investigation to ascertain the credibility of threat, the level and how it can be mitigated and managed.

Firstly, because of the serious potential implications, I obtained the full copy of the research paper from *Neuroendocrinology Letters* and read through it. It cost £20, and will be available to members via the group library. The paper is from a Belgian ME centre and based on what I read, the paper is credible. There a significant number of research papers by the same author around ME/CFS-related matters which suggests he is well versed in the subject. One paper translates to: “Chronic Fatigue Syndrome: The *bête noire* of the Belgian Healthcare system.” That says it all.

In order to further clarify the paper’s findings I obtained the second paper from an independent source, *The American Journal of Cardiology*. This is specific research into atorvastatin, the statin variant that is most likely to be prescribed locally. This supports the contention that a statin reduces Q10 levels, and puts numbers—so it is possible to forecast Q10 depletion. It also shows the full effect can take several weeks to show itself...

I obtained a third research paper from the American Medical Association. This supports the contention. For me it provides the confirmations of my suspicion that low Q10 reduces the heart’s pumping ability and that can be restored by increasing Q10 levels. With low Q10 levels and heart muscle damage there must be an increased risk of an adverse event. This paper indicates that taking Q10 could mitigate the threat.

If you have been prescribed statin-type medicines for a proven cardiovascular disorder for example:
a past history of stroke, heart attack, or hyperlipidaemia you MUST discuss that matter with your doctor before making any changes to your medication.



GINAL ARTICLE

Coenzyme Q10 deficiency in myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is related to fatigue, autonomic and neurocognitive symptoms and is another risk factor explaining the early mortality in ME/CFS due to cardiovascular disorder

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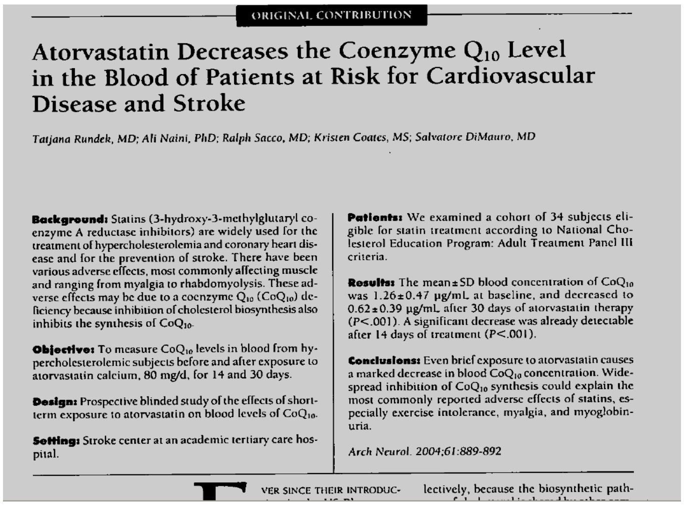
Submitted: 2009-07-08 Accepted: 2009-08-18 Published online: 2009-09-15

Key words: **coenzyme Q10; chronic fatigue syndrome; inflammation; oxidative stress; mitochondria; cytokines; heart failure; coronary artery disease; mortality; statins**

Neuroendocrinol Lett 2009; **30**(4): 470–478 **PMID:** 20010505 NEL300409A17 ©2009 Neuroendocrinology Letters • **www.nel.edu**

Abstract

INTRODUCTION: Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is a medical illness characterized by disorders in inflammatory and oxidative and nitrosative (IO&NS) pathways.
METHODS: This paper examines the role of Coenzyme Q10 (CoQ10), a mitochondrial nutrient which acts as an essential cofactor for the production of ATP in mitochondria and which displays significant antioxidant activities.



ORIGINAL CONTRIBUTION

Atorvastatin Decreases the Coenzyme Q_{10} Level in the Blood of Patients at Risk for Cardiovascular Disease and Stroke

Tatjana Rundek, MD; Ali Naini, PhD; Ralph Sacco, MD; Kristen Coates, MS; Salvatore DiMauro, MD

Background: Statins (3-hydroxy-3-methylglutaryl coenzyme A reductase inhibitors) are widely used for the treatment of hypercholesterolemia and coronary heart disease and for the prevention of stroke. There have been various adverse effects, most commonly affecting muscle and ranging from myalgia to rhabdomyolysis. These adverse effects may be due to a coenzyme Q_{10} (CoQ_{10}) deficiency because inhibition of cholesterol biosynthesis also inhibits the synthesis of CoQ_{10}.

Objective: To measure CoQ_{10} levels in blood from hypercholesterolemic subjects before and after exposure to atorvastatin calcium, 80 mg/d, for 14 and 30 days.

Design: Prospective blinded study of the effects of short-term exposure to atorvastatin on blood levels of CoQ_{10}.

Setting: Stroke center at an academic tertiary care hospital.

Patients: We examined a cohort of 34 subjects eligible for statin treatment according to National Cholesterol Education Program: Adult Treatment Panel III criteria.

Results: The mean±SD blood concentration of CoQ_{10} was 1.26±0.47 μg/mL at baseline, and decreased to 0.62±0.39 μg/mL after 30 days of atorvastatin therapy ($P<.001$). A significant decrease was already detectable after 14 days of treatment ($P<.001$).

Conclusions: Even brief exposure to atorvastatin causes a marked decrease in blood CoQ_{10} concentration. Widespread inhibition of CoQ_{10} synthesis could explain the most commonly reported adverse effects of statins, especially exercise intolerance, myalgia, and myoglobinuria.

Arch Neurol. 2004;61:889-892

VER SINCE THEIR INTRODUC- lectively, because the biosynthetic path-

Effect of *Atorvastatin* on Left Ventricular Diastolic Function and Ability of Coenzyme Q_{10} to Reverse That Dysfunction

Marc A. Silver, MD, Peter H. Langsjoen, MD, Szabolcs Szabo, MD, Harish Patil, MD, and Allan Zelinger, MD

This study evaluated left ventricular diastolic function with Doppler echocardiography before and after statin therapy. Statin therapy worsened diastolic parameters in most patients; coenzyme Q_{10} supplementation in patients with worsening diastolic function with statin therapy improved parameters of diastolic function. ©2004 by Excerpta Medica, Inc.
(Am J Cardiol 2004;94:1306–1310)

On the basis of the known nonselective inhibition of cholesterol synthesis by statins, previously reported data, and the widespread use of statin therapy, we hypothesized that atorvastatin might have its greatest initial impact on sensitive measures of left ventricular (LV) diastolic heart performance. We therefore prospectively studied 14 asymptomatic patients who were to begin atorvastatin therapy, with baseline and follow-up measurements of clinical status, LV diastolic parameters on Doppler echocardiography, and plasma coenzyme Q_{10} (CoQ_{10}) levels. Ten of the 14 patients (71%) had worsening of ≥1 marker of LV diastolic function. Eight of the 9 patients who received CoQ_{10} supplementation with atorvastatin had reversal of ≥1 diastolic abnormality.

• • •

The protocol and consent process were approved by the institutional review board for the Protection of and all patients gave informed consent. All patients met the National Cholesterol Education Program’s recommendations for initiating pharmacologic therapy. The decision to initiate therapy was made by the primary physician. Patients who began statin therapy as outpatients were eligible for the trial. Patients were excluded if they had poor acoustic windows, were <50 years old, had a history of heart failure or previous myocardial infarctions with ejection fractions of <40%, had unstable angina pectoris, or were currently receiving statin or CoQ_{10} therapy. Baseline measurements of plasma CoQ_{10}, total cholesterol, low-density lipoprotein cholesterol, high-density lipoprotein cholesterol, and triglycerides were made. Standard M-mode, 2-dimensional, and Doppler echocardiograms were performed. The 2-dimensional images were acquired in parasternal long-axis, short-axis, and apical 2-, 4-, and 5-chamber views. Doppler spectral recordings were obtained in the apical 4-chamber view, with the sample volume positioned at the tip of the mitral leaflets. The transmitral pulse Doppler velocity recordings (peak E, peak A, E/A ratio), deceleration time (DT), and isovolumetric relaxation time (IVRT) were averaged from 3 cardiac cycles. The IVRT was obtained in the 5-chamber view with a continuous-wave cursor or a pulse Doppler sample positioned to obtain signals from aortic valve closure and the mitral

The Basis of Current Attitudes by the Medical Profession

Information adapted from Patient UK

The currently available statins (atorvastatin, fluvastatin, pravastatin, rosuvastatin, and simvastatin) competitively inhibit HMG-CoA reductase (see Pathways 40 for more detailed explanation). Statins are more effective than other lipid-regulating drugs. This is the way they work:-

Statins are competitive inhibitors of the rate-limiting step of liver cholesterol synthesis. This protects against the development of atheroma and there is a firm evidence base for their use in both primary and secondary prevention of cardio vascular disease.

Statins are also thought (*note thought, not proven*) to have non-cholesterol-related effects such as restoring/improving endothelial function and anti-inflammatory properties. This is inference from case clinical experience following heart attacks and angiography, and in acute coronary syndrome.

Statins may (*i.e. not proven)* also have a role to play in the regression of atheroma.

Statins may (*i.e. not proven*) also reduce the risk of developing atrial fibrillation.

Current National Institute for Health and Care Excellence (NIHCE) guidelines suggests that statins should be prescribed for:-

Firstly all adults with a history of cardiovascular disease, including, angina, acute myocardial infarction, acute coronary syndrome, stroke, transient ischaemic attack (TIA), and peripheral arterial disease (secondary prevention) and also certain lipid disorders - e.g., familial hypercholesterolaemia.

Secondly as protection or insurance for all those aged up to 84 years who have a 10-year risk of cardiovascular disease of 10% or more as measured by the QRISK2 risk assessment tool; certain diabetics and those with other cardiovascular risk factors and chronic kidney disease. NIHCE also says that in the past there has been much debate as to the long-term benefits versus risk of statins. They say that benefits far outweigh the risks.

That may be true for non-ME/CFS sufferers, but from my experience and what I’ve seen from research papers I have concerns because a different approach is needed for people with ME/CFS: I’ve seen a lot of medical literature about statins. Apart from the few overseas research papers which I have obtained and checked there is nothing I’ve seen or mentioned relating to statins’ safety with ME/CFS and Q10 levels. I am well versed with Dr. Myhill’s similar opinions but I also needed to check independently. So where do we go from here?

So, are NIHCE being not so nice and hiding something?

We frequently hear in the news about NIHCE blocking new cancer treatments on the grounds of expense. In our own back yard with the NIHCE Guidelines of ME/CFS, apart from diagnosis, GET & CBT, they reject all the other therapies known to be effective for ME/CFS which are used in other parts of the world. Instead of going as far as saying there is no evidence, not evidence etc., they basically say ‘do not use’. Within medical circles NIHCE is known as the *National Institute of Health and Clinical Economics.* About the same time as the summer *Pathways* was being compiled new NIHCE Guidelines were published. ‘’Lipid modification: cardiovascular risk-assessment and the modification of blood lipids for the primary and secondary prevention of cardiovascular disease”, Issued July 2014 last modified in September 2014. (NIHCE clinical guideline 181 guidance. www.nice.org.uk/cg181). Statins should be tried first and if a problem occurs the doctor should tinker with the dose or try a different type of statin then consider a none statin alternative if all else fails. As well as this, for adherence to statin therapy advice to doctors is:
1.3.44 “Do not offer coenzyme Q10 or vitamin D to increase adherence to statin treatment.” *and also*
1.3.36 “Do not measure creatine kinase levels in asymptomatic people who are being treated with a statin.” (Creatine kinase metabolism is sometimes abnormal in ME/CFS patients.)

Although it is not acknowledged, it is quite clear to me that NIHCE are aware of the Q10 reduction issue and choose not to address it. With the research so far, I can only conclude that they are not acting in the interests of ME/CFS patients.by choosing not to address it. Furthermore, there was an interesting feature in the *British Medical Journal Practice Guidelines* (BMJ 2014; 349;g4356).

"Statin blockage of co-enzyme Q10 makes side effects inevitable "

Rabar and the Guideline Development Group advise that there is no evidence of benefit from adding supplements of coenzyme Q10 to reduce muscle-related adverse events. They ignore the fact that statins block the endogenous production of co-enzyme Q10. Tiredness, or muscle pain, become inevitable side-effects for many people due to this fundamental interference with mitochondrial energy production.

Co-enzyme Q10 is the most important acceptor and donor of electrons in the Krebs citric acid cycle (oxidative phosphorylation). Biochemist Dr John McLaren-Howard's ATP profile test measures the rate of oxidative phosphorylation which controls the rate of conversion of ADP (adenosine diphosphate) to ATP (adenosine triphosphate) . His clinical co-author, Dr Sarah Myhill, writes that statins invariably worsen fatigue syndromes and probably also accelerate ageing.

It is a disgrace that so much money has been spent on epidemiological research and worldwide promotion of extensive statin-use while frequent adverse effects are ignored and under-investigated. (References are quoted and names related to Sarah Myhill's practice appear.)

Also I note that the Pharma Nord information which started off this line of enquiry has been revised in the light the new NIHCE guidelines and the information has been sanitised.

So is there something underhand going on? Yes, I think so: and whatever it is it is more to do with clinical economics than patient care and it is not in our interests as ME/CFS patients….

So what can members do about Q10 blood tests?

My research indicates that locally no facilities exist for GPs or local hospitals to check Q10 through normal NHS channels. A blood sample is needed. It is not possible to take the sample yourself. The best option would be for you to get your GP's practice to take the sample and handle the paperwork. However I suspect that some GPs would be favourable, and others will simply refuse, possibly because of practice insurance considerations or simply because they don't have the confidence or interest. This frequently happens with other unrelated ME/CFS-related issues.

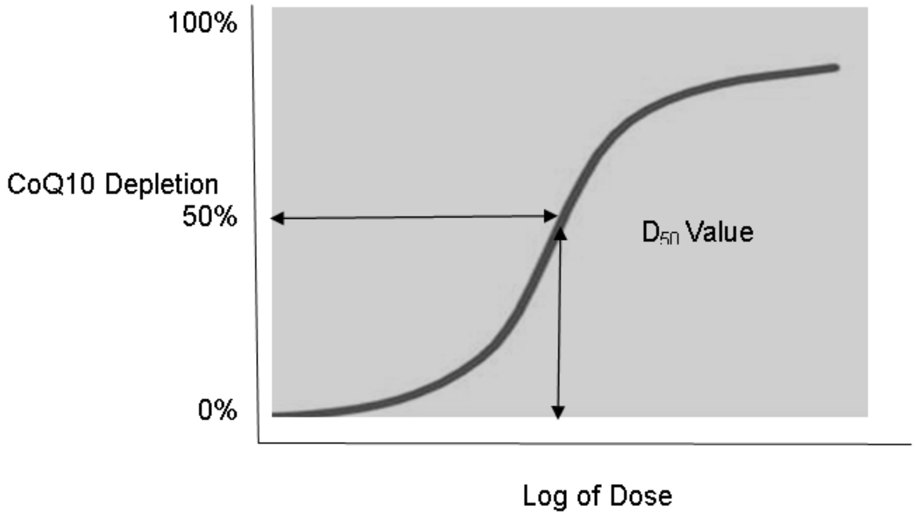
The Sheffield NHS ME/CFS clinic has no facilities to test for Q10. If you are a patient of Dr. Myhill or a similar private doctor, you can get the Q10 blood test done simply by enquiring, as it would be part of the standard workup. At the time of writing Dr Myhill is willing to organise a single private blood Q10 test for £93. This will include an explanatory letter from her to your GP. If you have recently had the mitochondrial function test, then the Q10 test will have been included as part of the overall package. At the time of writing, the cost of this package is £320. However at present Dr Myhill is unable to take on any new patients. (*Ed. I have made alternative arrangements for Members.*)

So having a strong indication that the statin threat is credible, what next?

I approached my own GP practice to see if I could get my own Q10 levels checked .as it means obtaining a blood sample. So off to the GP's surgery I went with the literature and stated my case. The GP's practice agreed to do the test, but as there is no local NHS facility where it was available, it had to be sent away to London. The 'trade price' is £35 pounds for the test which I had to pay upfront. When the letter came back, the result was at the bottom of the normal range. According to Myhill's book, this is to be expected in ME/CFS. Certainly for me, any consideration of statins are out unless something is done about my Q10 levels. At the time of writing my best course of action is unclear.

How could we predict how taking a statin affects Q10 levels ?

There is no doubt that it would deplete them. The question is by how much. Apart from a Q10 blood test after taking a challenge dose, the matter is open to estimation.



Fortunately there is a way to forecast this. Many biological systems follow what is known as a sigmoid 'S' shaped curve if the log of the dose is plotted against the response. It is used in many applications including medicines modelling, population, and nutrition prediction. The reason the log of the dose is used it that biological systems respond in an unusual way.

If you were to buy a tin of beans from the supermarket costing 25p, two tins would cost 50p and four £1. So you could calculate the cost of any number of tins of beans by multiplying the price by the quantity. The relationship is called a linear or proportional relationship. However if you were buying a quantity you might go to a wholesaler, and at that point the bulk purchasing would apply—the more you bought the cheaper the tin of beans. The deal may then by complicated by offers like buy 1 get 1 free etc. The way biological systems behave is different and is like special offers. The steps on a linear graph would be 1,2,3,4,5 where as the step on the biological graph would be by 1,2,4,8,16. etc. i.e. double your money. If to get the next level of response the steps have to double. This is why many medicines are manufactured in strengths that double up.

Using the log of the dose enables the system to fit a sigmoid curve. Quite logically if no dose is given there is a baseline response. There is a maximum effect that can be obtained, where increasing the dose has no effect this is the maximum response or saturation point. The difference between 10% and 90% is usually two log base units. In our case doubling the dose twice ie quadrupling the dose at 10% roughly gives 90%. The dose at mid point of the line at 50% of the effect is known as the D_{50} value. This value together with the maximum and minimum response can predict the likely response for stating any dose by some simple schooldays maths.

The third research paper does give enough information to estimate a D_{50} value for atorvastatin calcium. This turns out to be around 80mg. NIHCE produced the following information regarding currently available statins in terms of LDL reduction. Assuming that this is an indicator of CoQ10 reduction we can estimate the effect. If you relate these levels to increases in pain and fatigue even the lowest dose would lead to a significant increase in the level of pain & fatigue.

Statin	**5mg**	**10mg**	**20mg**	**40 mg**	**80mg**
Fluvastatin			20-30%	20-30%	20-30%
Pravastatin		20-30%	20-30%	20-30%	
Simvastatin		20-30%	31-40%	31-40%	40%+
Atorvastatin		31-40%	40%+	40%+	40%+(D_{50} dose ?)
Rosuvastatin	31-40%	40%+	40%+	40%+	

Obviously there are massive individual variations, but in general this matches the experience that members report to me and provides a rational explanation of what happens as reported by members.

What are the acceptable safe limits of statins for people with ME/CFS.

Many ME/CFS patients are prone to adverse reactions of any medicines and that could be anything from allergies, angioedema or sensitivities that apply to any medicines to specific dangerous rhabdomyolysis (severe and potentially fatal muscle damage). Furthermore, where statins are concerned, there is a huge individual variation in pain and fatigue sensitivity.

The issue of Q10 depletion is a bit more complex. In the light of what she writes in her book, I wrote to Dr. Myhill explaining that some members can tolerate statins without apparent side effects. The answer that came back was *"Well they can only be the minority of CFS's who have reasonable levels of Co Q10-possibly because they are already taking it as a supplement."*

Biolab Q10 tests levels come back with a number. At the time of writing the normal limits are 0.55 to 1.6. Assuming that a dose of a statin halves the existing level, without supplementation to avoid lowering your Q10 levels below the limit you would have to have a level of at least 1.2 when starting, to tolerate the statin.

The bottom line.

- There is no doubt that statin-type medicines, for many sufferers, add to the pain & fatigue already intrinsic to the condition. For some, the increase in pain will be small and tolerable . For a significant number the pain will be substantial and this is will be a put off. There are many blogs about this problem within social networking and elsewhere on the internet.

- If you have proven cardiovascular disease and are taking a statin, it is good insurance to protect against further disease progression. If this affects you, after careful consideration you will probably find that you have no choice in the matter of taking a statin. I was speaking with a member of the British Heart Foundation who said: "*Before statins there was very little we could do to protect people from heart attacks and cardiovascular disease. Now statins have changed all that—at least we can now give good protection to someone who is vulnerable*".

- Where people are symptom free of cardiovascular disease, taking a statin is claimed to be good insurance to protect against further disease progression especially if you suffer from a specific condition e.g. diabetes. However there are more acceptable medicines, food supplements and dietary interventions that could lower the LDL to an acceptable point for people with ME/CFS. However this is not the first line NHS approach. There is ***no proof*** that they work to give cardiovascular protection.

- We are aware of no UK double blind evidence on the side effects of statins & ME/CFS.

- Many doctors still don't understand ME/CFS, and many likewise will have nothing to do with related statins issues. This is aggravated by the current revision of the NIHCE guidelines.

- If you have statin side effects, supplementing with Q10 could mitigate the side effects, but it is unlikely that GPs will be able to prescribe it on the NHS. Co Q10 would cost you around £10 per month. Many ME/CFS patients are on basic state benefits and simply cannot afford that.

- Although not available on the local NHS, Q10 testing is available at a cost of around £100 in the private sector, and is a routine test with a number of ME/CFS specialists.

- If you have been advised to take a statin, you could buy Q10 from pharmacies & health shops. However it is not good medical ethics to do this without your doctor knowing and appropriate monitoring checks. Also many members reported side effects taking Q10, mainly abdominal disturbances. If possible I think it prudent to have blood levels checked to see if it is really necessary before take this course of action. These could be done by your GP, if he/she is interested, at the same time as other monitoring checks or a private doctor can do it for you.

Personal Independence Payment (PIP) Update: Avoiding the Pitfalls.

In our area it will be a few months before mass migration from DLA to PIP starts. In past issues of *Pathways* I've pointed out the main features of PIP. At the time of writing I have dealt with four claims for members. Two were new claims which resulted in high rate mobility and care. One migration resulted in high rate mobility and care, while the other resulted in only low rate care. The latter is disputed and is at the review stage for the mobility component. The outcome will give us valuable experience before the main changeover starts to take place, possibly starting in October 2015. However under certain circumstances this may happen sooner if there is a change in an existing claimant's circumstances so it is important to start preparing as early as possible.

Compared to the average outcome in which 75% of ME/CFS DLA claims are rejected, Leger ME members have been quite fortunate with a success rate around 90%. There is one big issue with PIP. PIP forms do not take into account fatigue, pain and suffering following any exertion or event. This also applied when DLA first started in the 90's. However subsequent House of Lords decisions resulted in fatigue being taking into account. One particularly helpful case law issue resulted in what is known as the Jacobs ruling which we quoted on many DLA forms as a matter of course, and which was instrumental in the mobility component being available for ME/CFS. This has now gone.

As a result it is expected that 200,000 people will lose the mobility component as the walking test has been decreased from 50 to 20 metres. Additionally, there is no 'cooking test, in which the Heggs rules helped. All that has gone. It is expected that 500,000 of the lower DLA claimants will lose the benefit altogether when changed to PIP as the cooking section has been removed. Additionally, it is expected that 99% of people will have a medical when migrating to PIP. All members so far have had to have an in-depth medical examination by ATOS. I am anticipating that with the issues with ATOS concerned with ESA and DLA and many assessments subsequently overturned by tribunals, it is certain that getting PIP won't be easy. As well as this, there is a long wait for PIP assessments. One member waited 12 months.

The PIP claim forms are different from DLA forms. The initial claim has to be done over the phone. Subsequently a PIP claim forms is sent through the post. Leger ME has its own version of the form which members can access for drafting purposes. Also Leger ME has access to the Benefit & Work Guides. While you can say anything on the form, it has to be substantiated to count. The easiest way to do this is to submit a form with lots of information and plenty of medical evidence. As with all DWP forms, don't write the form yourself. Use a welfare rights advisor, otherwise your claim runs a high risk of being rejected. Leger ME will provide assistance in whatever way we can. On average, the forms I have completed have taken around four hours. All physical and mental health issues apply including those around concentration, brain fog and anxiety. The usual rules apply about not referring to good days. For ME/CFS all days are bad days some being better than others.

Previously I've said that if you are dealing with the DWP for a benefit claim you must have a current ongoing dialogue with your doctor. If it is a problem we can get around this but it will take time. You need to be attending some specialist clinic or other or have a track record. Make sure you have a specialist. A claim without a specialist clinic involvement will be weak, and will be looked upon less favourably. Specialist clinics could be any of the ME/CFS clinics Sheffield, Leeds or York or a local mental health, pain management, incontinence or other clinic run by a physiotherapist or a counsellor.

As I am a registered health professional I will give you a report as part of the Leger ME membership service. If you are not a Leger ME member then my professional charges will apply and they start at £50. You will need copies of any letters, appointment cards or reports. You will also need to obtain a report from your GP but please contact me first because most surgeries' computer systems can generate this without the need for an elaborate report or for the complete medical record. You need to have a track record of a least six months of the conditions you are claiming for. Stand-alone reports older than two years are useless unless they can be substantiated by your current treatment or medicines etc. In general NHS-based reports or hospital-based reports carry a lot of credibility.

Private doctors carry some weight. If you are just using an alternative or complementary therapist without a doctor being involved, then there is little point in putting in a claim. Where no medical evidence is available I help you obtain further evidence, but can’t take it further until, that is obtained.

GP's letters are not usually enough as they can be short and vague *(see page 3)*. This is a problem especially if the GP doesn't know you well enough and it can result in a claim being rejected. I can supply various forms & paperwork to take to your GP to inform your GP of the difficulties you face on a daily basis. I frequently do this with members. Sometimes it is a waste of time whereas in other cases it is very valuable. Your medicines may provide evidence; I will be able to elaborate on this when I do a case review. For example issues of sedation, dizziness & falls-risk are very relevant,

Attending the PIP medical: Watching for the Pitfalls and Ruses.

The PIP Assessment is supposed to be a minimum of 1 hour and the examiner could be either a doctor, nurse, occupational therapist or a physiotherapist. The medical examination is really a test to see if you are telling the truth and how valid your claim is. I frequently get members who get unfavourable reports from the DWP. Very often the reports are inaccurate and are easily disputed. However by following a few simple rules you can stack the odds in your favour.

- Above all you need a carer with you. NEVER go on your own. This can be a friend, a family member or a neighbour that helps, listens out for and checks everything you say. They can be a second source of information on how your condition affects you. Leger ME can help find you support or a chaperone if there are difficulties.
- We recommend that you and your carer go by car and are dropped off at the door preferably by taxi. There is a taxi office next to the Doncaster examination centre. A common tactic used by ATOS for ESA medicals was to send you a detailed letter of how to get there by public transport, including bus numbers times and the route to walk. Simply going by public transport or saying so proves to ATOS that you can walk at least 500 metres and so blows your chances of your claim being accepted. At the Doncaster examination centre a Member’s husband parked in the car park around the corner, and she was asked about it. Naturally she told the DWP she had walked from the car-park. The result was a complete refusal. We eventually won this at tribunal, but it took 18 months.
- You may be asked in a casual and apparently friendly way some seemingly quite irrelevant question and from the answer the examiner may then make assumptions against your interest.
- Don't be led into agreeing to something if it isn't true. Whoever is with you should be aware of this and intervene. Very often I’ve heard reports like ‘”You don't have any problems walking?”, a negative question. If you are stressed, what answers do you give? The examiner wants a straight ‘yes’ or ‘no’, but really the answers would need to start “I have problems with walking….” followed by a detailed description of your problems.
- One trick is for the examiner to give you several things to remember and then ask you about them later. It’s a trick to test short term memory. If you can’t remember them say so don’t guess.
- If you are asked about going shopping and you say you do, it will be assumed you can walk around the biggest supermarket in Doncaster without any problem and will blow any chance of the mobility component unless you qualify it e.g. go round on a scooter or whatever. A support trolley or appliance usage assumes you can walk without limitation.
- Any questions about a pet unless very carefully answered will imply you have a dog and can take it regular walks or look after it even if it is a goldfish and someone else cleans it out.
- You may be asked about having any young children between 3 and 7. If you just answer yes, you need to make it clear that you have help from others, otherwise it will be assumed you can cope alone without difficulty. Things like attending school functions will count against you unless you quality this by saying how you cope, for example you always go with your spouse.

Sometimes misleading inferences are made from observed activity test and ruses

- Your examination starts even before you arrive in the examiner's office. The DWP properties are riddled with TV cameras. You will be watched walking into the building from the car or the street. This is taken as part of your assessment.
- I've seen a known examiner stand outside the examination centre making conversation with people going in. This is a test for eye contact, gesture (moving of arms) and maybe speech.
- Even if you arrive on time you will deliberately be kept waiting for about 15 minutes. You will be observed as to the way you stand or sit.
- If you carry a bag or even drink water from the machine this will be noted. This provides the examiner with an insight into lifting and carrying. One member had his claim declined because he carried in a large bag containing all his medicines & supplements.
- If you drop something and pick it up that will be taken into account. I've seen a £1 coin be dropped by examination centre staff, I suspect deliberately. This proves you can see & bend down.
- If you've said on the form you carry something like an emergency inhaler, injector or appliance (eg. incontinence pads) and you don't carry it, then that counts against you.
- Walking in to the desk and to the examination room proves you can walk 20-50 metes.
- One member reported the assessor held the door open, but let go at the last minute. We frequently get reports of a handshake. That can test for reflex, grip and tremor.
- Your appearance counts. We generally advise people not to wear makeup or nail varnish or have a general 'night out' appearance. Most people with ME/CFS look like they've had a good night on the tiles.
- I have heard of people going to the medical with a bottle of whisky distinctly sticking out of their pocket. I think ATOS will be aware of that ruse.

If your application does not succeed or give you what you want don't just ask for a review without taking further advice. I prefer to conduct an inquest and then look at the issues. Very often I can tell why an application has failed. I am very reluctant to ask for a review without putting in further evidence. I like to obtain the examining practitioner's report before asking for a review—but very often this takes several weeks and by the time you've received the paperwork, you've run out of time. As regards PIP appeals, we have not experienced any yet but I strongly suspect that there will be many similarities with DLA and ESA.

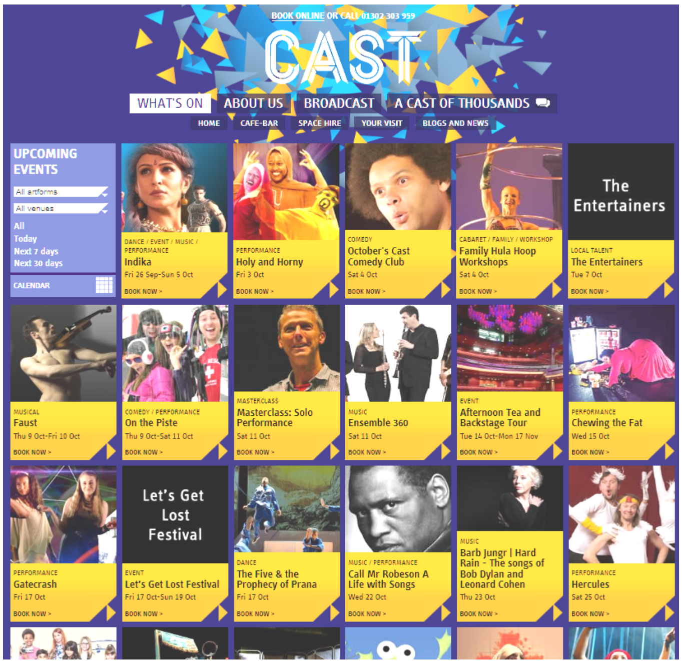
In conclusion, for the best chance with DWP forms I like to put in strong medical evidence simply because it makes it more difficult for ATOS to challenge. Also ATOS make mistakes and system errors. I've also caught ATOS out with having a physiotherapist reporting on mental health issues which they are not qualified to do. I've won one case where it was proven the examiner, a nurse, did not know anything about ME/CFS. Some time ago one member had his benefits stopped because 'there was nothing wrong'. A response to the DWP was 'this guy is diabetic, a first year medical student would be able to diagnose this'. After that there was no more trouble from the DWP.

Out & About in Doncaster: A night to remember at 'CAST' theatre

Carolyn and Mike

I'm guessing that most people will have heard of 'A Kestrel for A Knave' by Barry Hines, either having read the book or seen the film.

On a balmy night in early September we made our way for a first time visit to 'Cast' the new theatre in Doncaster to see a new version of this classic story "KES".



DANCE / EVENT / MUSIC / PERFORMANCE
Indika
Fri 26 Sep-Sun 5 Oct
BOOK NOW >

PERFORMANCE
Holy and Horny
Fri 3 Oct
BOOK NOW >

COMEDY
October's Cast Comedy Club
Sat 4 Oct
BOOK NOW >

CABARET / FAMILY / WORKSHOP
Family Hula Hoop Workshops
Sat 4 Oct
BOOK NOW >

The Entertainers
LOCAL TALENT
The Entertainers
Tue 7 Oct
BOOK NOW >

MUSICAL
Faust
Thu 9 Oct-Fri 10 Oct
BOOK NOW >

COMEDY / PERFORMANCE
On the Piste
Thu 9 Oct-Sat 11 Oct
BOOK NOW >

MASTERCLASS
Masterclass: Solo Performance
Sat 11 Oct
BOOK NOW >

MUSIC
Ensemble 360
Sat 11 Oct
BOOK NOW >

EVENT
Afternoon Tea and Backstage Tour
Tue 14 Oct-Mon 17 Nov
BOOK NOW >

PERFORMANCE
Chewing the Fat
Wed 15 Oct
BOOK NOW >

PERFORMANCE
Gatecrash
Fri 17 Oct
BOOK NOW >

Let's Get Lost Festival
EVENT
Let's Get Lost Festival
Fri 17 Oct-Sun 19 Oct
BOOK NOW >

DANCE
The Five & the Prophecy of Prana
Fri 17 Oct
BOOK NOW >

MUSIC / PERFORMANCE
Call Mr Robeson A Life with Songs
Wed 22 Oct
BOOK NOW >

MUSIC
Barb Jungr | Hard Rain - The songs of Bob Dylan and Leonard Cohen
Thu 23 Oct
BOOK NOW >

PERFORMANCE
Hercules
Sat 25 Oct
BOOK NOW >

The first surprise was to find excellent and free parking close to the theatre and though we chose to leave the car on the car park itself we noted plenty of Disabled Bays on the short walk round to the theatre with a wide entrance to the theatre itself and an easily accessible café to the left of the foyer. Entrances to the stalls are also wide and level and there is a lift to all floors - all appears to be very accessible for a wheelchair. Seats are comfortable with, except for the front row, more leg space than is usual in many theatres.

The story is told through a grown-up Billy Casper, who is recounting events to a modern-day kindred-spirit young reprobate. (This in itself we thought was a clever way to do it). This is a story about a boy who has been failed by the education system and given little opportunity to think of a life other than going 'down't local pit'. The mining industry may now be long gone, but the failure of our society to realise the full potential of our young people is just as relevant today as it was in 1968.

So Billy is useless, and there's nothing much to be happy about. His mum is more interested in finding another man; his brother bullies him; his teachers humiliate him and he's always the last to be picked at football. But one day he adopts a fledging kestrel Kes, trains it after training himself, and dreams about flying away from a life, away from his run-down estate and a job in the coal mine.

(*continued on page 23*)

Jacob James Beswick (Sheffield born and seen in *Casualty*) undoubtedly delivered a strong performance. His is a Billy we are behind 100%, and even when he steals a drink from the milkman, we're all admiring his cheekiness. The script calls on Jacob to display a full range of emotions, and he certainly achieved that. The scene where Billy describes to his class the feeling he gets from flying Kes is an absolute joy to behold; you could see the audience lean forward in concentration.
Billy's nemesis of a bother Jud, played by Ben Burman, has a menace and a threat which truly comes from a dysfunctional family. You don't turn your back on this Jud, or decide not to put his bet on the horses or at the bookies, but still there's an air of a wasted life here – what could Jud have been if a South Yorkshire lad's place in the 1960s wasn't just about going down the mine?

Sally Carman (known best in *Shameless* and *Holby City*) as Billy and Jud's mum displays a frustration with her life which many must have felt in that era, as well as almost a fear of her eldest son Jud, which adds a prickly dynamic to the family. Her acting was very impressive we thought.

A strong supporting cast all play their part in this production, with many playing several parts. Along with the professional cast, the play featured 34 community performers from 12 to 76 – a result of Cast's promise to nurture new local talent - and very good they all were.

For a story so focused on a bird, we rarely see the animal in the play. Perhaps it is too much to ask for a real kestrel to be flying around the auditorium (that would have been the icing on the cake!) but the interpretation of the bird is very well thought out with the use of puppetry and some very imaginative projection which becomes part of the set, particularly towards the end of the play. Despite the numerous adaptations of the original novel, there was plenty of humour, bringing laughter to the audience in this new version.

Being used to seeing professional theatre on a regular basis we were so pleasantly surprised by the quality of this show. If Cast continue to stage such exhilarating, beautiful and culturally significant productions as this we can only look forward to joining in their future which is surely set to soar!

The Cast is showing the classic pantomime 'Aladdin' over the Christmas and New Year season. It's been a long time since we've seen anything like that—so we've taken the plunge and booked a couple of tickets.

Access to the Cast Theatre

Ticket Office: 01302 303 959 Online: (castindoncaster.com). In person: Cast, Waterdale, Doncaster, DN1 3BU Opening times: Mon–Fri 10am–6pm, Sun 10am–4pm (later on performance nights) Cast is part of Doncaster Ticket Office. We share our booking system with The Dome and also sell tickets for other events around the area. Tickets can be collected on the night or posted in advance for an additional fee. When booking, you will be asked if you would like to support our work through making a small donation. Terms and conditions apply. Please visit www.castindoncaster.com for full details.

via Rail: Doncaster Train Station is about an 8 minute walk from Cast and has excellent national rail links. Check http://www.nationalrail.co.uk/ for timetables and bookings.
via Bus: Doncaster Interchange has excellent regional bus links, as well as National Express and Megabus coach links. Check http://www.travelsouthyorkshire.com/ for more information.
via Road: Cast is located within Doncaster Town Centre, and are a short walk away from the Doncaster Civic Quarter Car Park.
Parking: Doncaster Civic Quarter Car Park has 850 spaces in a covered multi storey car park which is safe and secure, and is less than 3 minutes walk to Cast. Opening hours: 5am to 11.30pm (Monday to Saturday) 10am to 11.30pm (Sunday)
Tariffs are competitive, including a£2 evening tariff for theatregoers. There are passenger lifts to all floors, including one disabled-compliant lift. Disabled parking spaces are available on all floors in close proximity to passenger lifts.

There is also some nearby street-level parking which is free after 6.0 pm.

North of Doncaster: Terre Haute Pt 2: Max Ehrmann & Desiderata

Personal Comment from Trevor Wainwright.

Desiderata by Max Ehrmann,

Go placidly amid the noise and haste,
and remember what peace there may be in silence.
As far as possible without surrender
be on good terms with all persons.
Speak your truth quietly and clearly;
and listen to others,
even the dull and the ignorant;
they too have their story.

Avoid loud and aggressive persons,
they are vexations to the spirit.
If you compare yourself with others,
you may become vain and bitter;
for always there will be greater and lesser persons than yourself.
Enjoy your achievements as well as your plans.

Keep interested in your own career, however humble;
it is a real possession in the changing fortunes of time.
Exercise caution in your business affairs;
for the world is full of trickery.
But let this not blind you to what virtue there is;
many persons strive for high ideals;
and everywhere life is full of heroism.

Be yourself.
Especially, do not feign affection.
Neither be cynical about love;
for in the face of all aridity and disenchantment
it is as perennial as the grass.

Take kindly the counsel of the years,
gracefully surrendering the things of youth.
Nurture strength of spirit to shield you in sudden misfortune.
But do not distress yourself with dark imaginings.
Many fears are born of fatigue and loneliness.
Beyond a wholesome discipline,
be gentle with yourself.

You are a child of the universe,
no less than the trees and the stars;
you have a right to be here.
And whether or not it is clear to you,
no doubt the universe is unfolding as it should.

Therefore be at peace with God,
whatever you conceive Him to be,
and whatever your labours and aspirations,
in the noisy confusion of life keep peace with your soul.

With all its sham, drudgery, and broken dreams,
it is still a beautiful world.
Be cheerful.
Strive to be happy.

In late 1971, I heard a spoken recording which began "Go placidly amid the noise and haste" it was Radio Announcer and Talk Show Host, Les Crane's reading of *Desiderata* (Latin for 'Things to be desired'). I didn't know at the time how over the years it would influence me and as I grew as a poet, I would want to know more about it, and the man who wrote it.

I had already been bought his book, The Desiderata of Happiness by my eldest daughter who know of my liking for his work, and it's relevance still with us today, it travelled with me to America in 2011 and had done on every tour since; some of the poems have actually inspired me to write my own in a similar vein. This year I decided I would visit Ehrmann's birthplace' Terre Haute, learn more about him and walk in his footsteps. Max was born in 1872 into a comfortable German-American family. Educated locally he went on to receive a law Degree at De Pauw University, after which he studied law and philosophy at Harvard before returning to Terre Haute where he practised law, becoming a Deputy State's Attorney in Vigo County, Indiana for two years. After that he joined his family's meat packing business. At the age of 40 he left the business to write. Contemporaries often spoke of him lying on the grass looking up at the sky, contemplating—an early flower child. In 1927, aged 54, he wrote Desiderata, which achieved fame only after his death.

His deep and abiding concern over social issues are reflected throughout his many works which reflect life as he saw it. If I were asked to choose, I would choose *American Women 1918* in which he saw complacency and was regarded by many as very true at the time and is still regarded by some as relevant today. He searched endlessly for spiritual contentment*, often turning to nature as in his poem, *The Noise of the City*[1]. His poem *Simple Fishermen*[2] is as if written by a stressful man. It strips away the veneer of rural idyllism when he realises the life of a fisherman is far from simple. *A Piece of Toast* illustrates eloquently how small things which seem so severe at the time. All are in his book *The Desiderata of Happiness*. He was awarded the honorary degree of Doctor of Letters from DePauw University in about 1937. He was also elected to the Delta Tau Delta Distinguished Service Chapter, the fraternity's highest alumni award.

He married Bertha Pratt King founder of the King Classical School in Terre Haute in June of 1945. Sadly, he died only three months later, although they were companions for many years before their marriage. Perhaps this was to make sure. Towards the end of his life he told an interviewer "*At De Pauw I contracted a disease which I have nave shaken off. The disease was idealism. Because of it I did the thing in life I wanted to do – Writing*".

He was honoured by the citizens of Terre Haute in 2010 with a life-size bronze statue by sculptor Bill Wolfe. He is depicted sitting on a downtown bench, pen in hand, with a notebook in his lap. "Desiderata" is engraved on a plaque that resides next to the statue and lines from the poem are embedded in the walkway. It is an interactive monument where visitors can sit on the bench, reflect on their surroundings and possibly see the world as he saw it, as he wrote in Desiderata "*with all its sham, drudgery and broken dreams it is still a beautiful world*". I certainly found inspiration there. Bertha died in 1962 maintaining copyright of Desiderata and writing her husband's biography, '*Max Ehrmann: A Poets Life'*, published in 1951. She is buried with Max in the family grave in Highland Lawn Cemetery in Terre Haute,


Me (Tevor) sat with the Ehrmann statue

*My 2013 tour poems, '*Some time for Me'*[1]and 2014 '*And Back to the Hotel'* are based loosely on these poems.