

Pathways

Price £ 3.75 (Free to members)

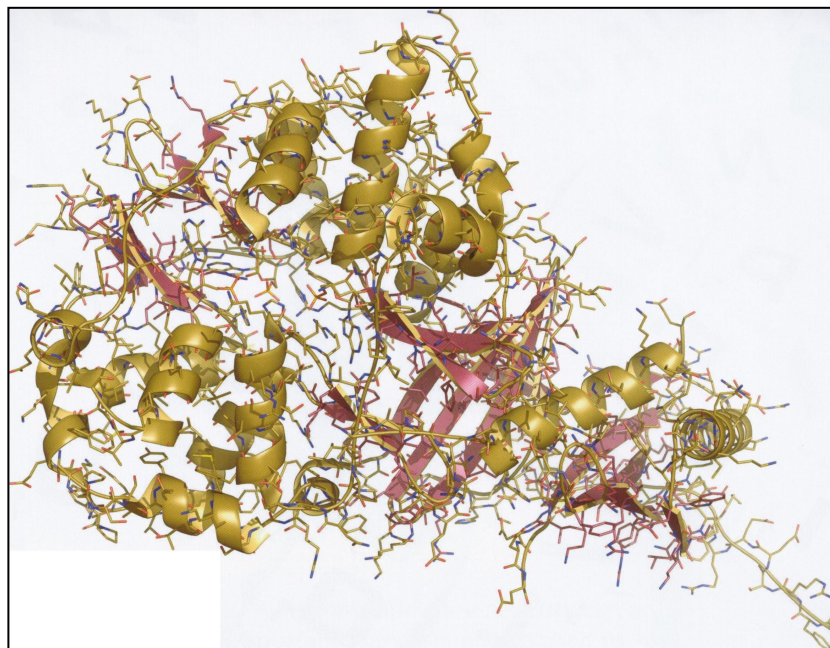
The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Welcome to Pathways 45.

Could this be the answer?

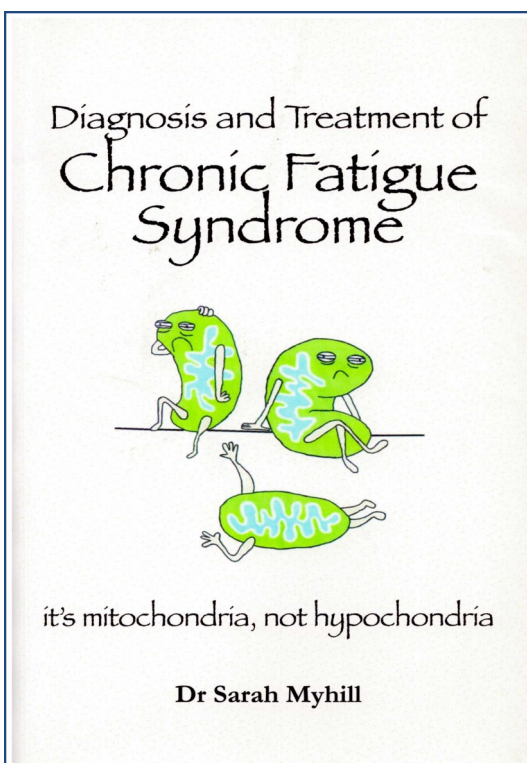
The picture on the right is a model of an enzyme that has a key role in the regulation of the supply of energy inside cells. It is known as AMP-activated protein kinase.

We have included a feature starting on page 14 from the portfolio of ME Research UK. The research finding regarding the lack of activation of AMPK during exercise in ME/CFS patients points to a muscle abnormality. Also it implies a link with type 2 diabetes metabolic syndrome and obesity, which are all associated with disturbances of energy metabolism. AMPK activating drugs are already used to treat type 2 diabetes, so maybe they may help with ME/CFS. Watch this space.



About 15% of Leger ME members have diabetes. On page 17 we have updated a feature “Double Troubles: ME/CFS and Diabetes” in which we updated a feature that originally appeared in ‘Balance’ 1992. For those with ME and diabetes it gives an insight in to the contradictory nature of the two conditions.

Starting on page 9 we have included at feature from a Sarah Myhill Interview: ‘The Role of Mitochondrial Function in ME/CFS’ from the recent Abundant Energy Summit. We have also included abstracts from her research papers. These are totally compatible with the recent finding on AMPK



We would also congratulate Sarah on getting The British Medical Association Book Awards 2015 for her book Diagnosis and Treatment of Chronic Fatigue Syndrome.

Have you ever wondered what happens when you hand in a waterworks sample at the doctors? In our feature ‘Multistix—The Laboratory in Strip’ we cover tell you how it’s done and some interesting non-medical uses for the strips.

Also starting on page 4 we have included three features on Yoga and ME plus all the usual Pathways features.

Please read on...



You write:

Carol Writes: Relating to a conversation a while ago about the DWP and insurance companies watching social networks for apparent benefit fraud. Here is an example from the US, not UK, and shows that authorities over there can request personal info from Facebook.

It turns out that Facebook has been forced to turn over photos from the accounts of nearly 400 users suspected of committing benefit fraud. A record number of search warrants were issued by prosecutors who want to see whether people who are claiming disability benefits have posted photos of themselves taking part in vigorous activities. In the past, Facebook photos showing people riding jet skis, playing golf and performing martial arts have led to successful prosecutions. Obviously Facebook objected to the search warrants issued by New York state prosecutors, and was backed by Google and Microsoft. However, the state's appeals court ordered Facebook to comply, saying it had no right to challenge the search warrants. The district attorney's office said the long-running investigation into fraud has already secured nearly around £16m from fraudsters. In many cases, Facebook accounts directly contradicted the lies the defendants told to the Social Security Administration. Here is the sky news internet reference

<http://news.sky.com/story/1523257/benefit-fraud-probe-targets-400-facebook-users>

I do not use social networking sites like Facebook simply because of privacy issues. Some people I know use an alias and remain anonymous, but recent changes forced new users to identify themselves. The problem is that once something is published on Facebook, it is in the public domain, it's all too easy to land yourself in trouble without realising as some people have found out.

Layinka writes: I enjoyed the trip on Ethel enormously and the opportunity to meet some of your members and their friends. We all had a lot of fun and the tableful of goodies was far better than we would have got at the pub. You took such care over the organisation but the unfortunately the weather did not play ball! Many thanks for having me on board.

Further to the research papers about Coenzyme Q10 which you sent me and your recent features about Statins and ME/CFS. I have had a look at the papers on Coenzyme Q10 which you sent me. It is interesting that blood levels can be measured so readily and the Maes Clinic has done useful work. I have seen other papers on the effects of statins and many nutritionists recommend CoQ10 supplementation for people on these drugs. However, it is a different matter identifying low Q10 blood levels and showing benefit from supplementation, whatever the theoretical basis. The turn-over, availability and blocks to utilisation rather than straight 'deficiency' or 'depletion' all make this a crucial area of speculation rather than evidence.

Have there been any more publications from the same centre as I see that this one is from 2009 and, if they had the funding, they have had time to produce some follow-up. I note that they were looking at it in relation to early cardio-vascular mortality in ME/CFS and I wonder where the evidence is for that. Apparently CoQ10 levels are also reduced by beta-blockers and it is interesting that the Newcastle ME Research group recommended those drugs for vasomotor instability and autonomic dysfunction! Medicine is difficult and seems to me even more so than ever.

I was glad to see you pushing Vitamin D - after this summer you don't need blood levels to predict that many people will be really low. Vitamin D is getting some publicity at last and a decent dose can get rid of a lot of muscular aches and pains which were blamed on other things.

Postscript: An original report was in the Telegraph last year. There are lots of papers on beta-blockers, and The Professor Julia Newton's Newcastle work is only the latest of many and is the result of many years of research team has studied people with autonomic dysfunction in ME and identifies many people with Chronic Fatigue Syndrome as suffering from Postural Tachycardia Syndrome. You could say that beta blockers are amongst a number of mentioned medicines helping some of these patients. You should look at the web-site for POTS, - www.potsuk.org. They have now formed a group of their own which is a huge step forward. They always believed that progress would only be made when patients with similar symptoms were carefully studied new methods, rather than re-writing all-inclusive definitions as happened recently the USA.

Smoking and CFS/ME: Preliminary Audit and Review

With thanks to Sheffield Health and Social Care Foundation Trust, the CFS/ME Service for South Yorkshire and North Derbyshire and Anne Nichol

The service is a specialist therapy service for people affected by CFS/ME, based at the Michael Carlisle Centre in Sheffield. CFS/ME is a neurological condition characterised by severe, disabling fatigue and where minimal increases in physical and mental effort result in a worsening of symptoms, often with a delayed impact.

Our starting point:

- Prior to November 2014, the service did not routinely ask clients if they smoked.
- Inspired by the Trust's move towards becoming 'smoke free', we then started to ask clients, as part of their initial assessment, whether they are current or past smokers.

First steps:

- Between 26 November 2014 and 25 March 2015 data was collected as part of each client's initial assessment. Data was available for 76 clients (62 females and 14 males).

Findings:

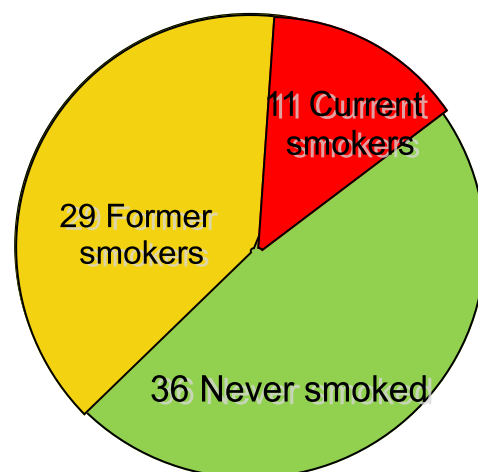
- Out of the 76 clients, 11 (14.5%) reported that they currently smoke. This is less than the average for Yorkshire and Humber (22.7%; Health and Social Care Information Centre, 2014).
- Of the 65 clients who reported that they do not smoke, 29 (38.2%) reported that they were smokers in the past. This is comparable to the general population (www.ash.org.uk)
- Of the 11 smokers, 3 reported that they would like to stop.
- In each case, smoking cessation advice was given and 1 client was referred to the Sheffield Stop Smoking Service.

Changes following the audit:

- Clinicians did not always ask about smoking at the initial assessment. As a result of this audit we have now revised our initial assessment form and we routinely ask all clients about their smoking status.

How will this be helpful to our clients?

- We know that people with CFS/ME often experience hypersensitivity / intolerance of chemicals and toxins, including those found in tobacco smoke (Baraniuk et al., 2000; Jay et al., 2000). Could smoking cessation have particular benefits in relation to managing CFS/ME?
- Smoking cessation can reduce the need for medication for people with mental health difficulties. Around 50% of our clients experience depression and anxiety in addition to having CFS/ME. So could smoking cessation have additional benefits for those clients?
- We plan to routinely ask clients who smoke whether they would like advice about smoking cessation. When appropriate, we can then refer them to their local stop smoking services.
- We could also collate the limited research available on CFS/ME and smoking in a form suitable for our clients, and ultimately aim to contribute to that research.



For more information about this audit or the CFS/ME Service, please contact: Anne Nichol, Service Manager, or Jayne Woodcock, Principal Clinical Psychologist, on 0114 2263232.

References:

Action on Smoking and Health (2015). Smoking Statistics.
 Baraniuk, J. N. et al. (2000). Tobacco sensitivity in chronic fatigue syndrome (CFS). *Journal of Chronic Fatigue Syndrome*, 7 (2), pp 33- 52

Jay, S. J.; Aaron, L. A.; and Buchwald, D. (2000). Tobacco use and chronic fatigue syndrome, fibromyalgia, and temporomandibular disorder. *Archives of Internal Medicine*, 160(15), pp 2398- 2401
 Health and Social care Information Centre (2014). Statistics on Smoking.

My thoughts on Yoga and ME by Glen Monks

CFS – The Missing Link. A multitude of reoccurring symptoms are never far away for those living with Chronic Fatigue Syndrome. The dilemma of looking healthy on the outside while fighting an inner battle is often frowned upon by those who don't understand the condition. Worst still, others claim the mentioned symptoms are psychosomatic or make believe. But, suppose the pain felt in your body is the working of your mind, and there was a way of tapping into this. This would raise the question, what is pain? Well, pain is subjective. Some people can tolerate more pain than others. For the CFS patient, the body pain seems to be easily agitated, due to a delayed response to activity. One thing is certain; the inconsistency of CFS is its biggest challenge, which is why it is so unfathomable. Of course the mental strain, of trying to fathom out things we don't understand, always adds to our predicament.

Does Your Mind Have The Answer? Your discriminating mind wants to work it out. It wants to fight for its identity. However, this part of your mind need not be won over, just better understood. Unlike animals, we humans struggle and do battle with our conscience. We often take life too personally, why me? It is this mind-set that perpetuates our suffering. When we begin to see life as a series of happenings that could not have been avoided we find acceptance. Acceptance creates a gap in the discriminating mind which opens the doorway to peace. When the mind is peaceful the stress response begins to decrease. Think about it, how stressful is it when you react to the turbulence of daily life? Did you ever stop to observe these vacillations of your mind? By better understanding the mind, we can smoke out emotional suffering. We get a taste of what it is to be free.

Does Your Body Have the Answer? Your body is your messenger. It is your body that tells you when things are out of balance. It may be your stomach saying your diet is not quite right, or a virus may cause your temperature to rise. One thing is for sure; your body is your keeper. Upon study of the bodily systems, one thing is known, balance is fundamental if health is to be restored or better managed. Whether we are talking about the nervous system, the digestive system, circulatory or cardiac systems, natural rhythm is paramount to our state of peace. It is this state of peace we obtain in the mind.

The Missing Link. For the CFS patient, it is clear the mind and body need as much support as possible. But standing alone, neither mind nor body provides a solution. On many occasions, we want to blame one or the other. We look outside of ourselves to find answers to our confusion. Some rely on prescribed medicine while others seek alternative therapies or try and read their way back to good health. But what if the missing link was in a simple whisper? Well, Yoga suggests it is.

The breath is capable of multi-tasking – it can be utilised voluntary as well as working involuntarily. We can choose to slow down, lengthen and even stop the breath at will. Of course, at some point, our little bellow like lungs will naturally override and continue pumping. Through the breath, your mind is indeed able to communicate with your body and this harmonises the whole. Conscious Yogic breathing, known as Pranayama, stabilises the glandular system. Here the nervous system begins to harmonise, hence reducing the amount of Cortisol released into the body. This is good news for the adrenal glands which in most CFS cases become severely fatigued. Such breath practice means we can finally extend our boundaries. Here the only limitation is imagining the breath has such capability.

Why Don't You Sleep On It? Another life enhancing factor vastly improved through Yoga is sleep. Yoga Nidra or Yoga sleep teaches us to relax. It teaches us to let go of that which binds us, keeps us awake. Although your breath has the power to heal, a good night's sleep can be your best friend. Imagine life without sleep, even your best friend could easily become your enemy! During sleep the body, mind and breath harmonise, that is for those fortunate enough to sleep well. One of the pivotal points for CFS is sleep quality – this determines whether the sufferer is within or outside recovery mode.



To Conclude: It is a travesty that modern education teaches us about the atom in science and the world in Geography, yet as students of life we are not taught about the vehicle in which we travel. Yoga is the teacher of such wonderment. *Glen*

The Benefits of Yoga for Those With ME/CFS by Cazzaw

The purpose of Hatha Yoga is to balance the mind, body and breath, the word yoga meaning balance, harmony and unity. Yoga originated in the East and has been used for many years throughout the world to help protect against illness, to help improve chronic illnesses and to maintain and improve the quality of life. It is a system that can be adapted to suit a particular need or ability. The health benefits and physiological effects of yoga have been well researched with over 1300 papers published in periodicals by 1989.

Which Magazine (December 2001) conducted a survey of its members to find out which complementary therapies they used and whether they were helpful. Yoga came out on top. Those practising yoga were more satisfied with their therapy and greater numbers had improvement in health when compared to other therapies such as acupuncture, osteopathy, homeopathy, massage, herbal medicine and reflexology. Sheffield Yoga for ME/CFS conducted a survey of its members in Autumn 2004. Of 16 people surveyed, all said that they had gained social benefits from attending the classes. 14 People reported that the yoga helped them to manage their illness better and 13 felt that their health had improved as a result. For more information please see the reports available on the information page by clicking <http://www.sheffieldyogaforme.org.uk/information.php#evaluation>.

As ME/CFS is a neurological illness which causes many symptoms including extreme debilitating fatigue, exhaustion and malaise (the onset of which is sometimes delayed) following over exertion. Some of the known problems of ME/CFS include malfunctioning of the central nervous system (CNS), particularly the hypothalamic/pituitary axis and the autonomic nervous system. This may give rise to hormone imbalances and many symptoms such as sleep disturbances, digestive disorders, circulation problems, fatigue, poor temperature control, neurally mediated hypotension, orthostatic intolerance, coordination problems, lack of blood flow to the brain, particularly the brain stem, a build-up of lactic acid in the muscles, irregular breathing, over breathing or hyperventilation, poor detoxification, oxidative stress and impaired lymphatic function and malfunctioning immune function/

Many people with ME/CFS find ordinary yoga classes unsuitable as they may be too strenuous and so they may need to adapt yoga to suit their individual needs and activity levels. For example, in therapeutic yoga classes run by Sheffield Yoga for ME/CFS, standing yoga postures are adapted so they are done lying down, as orthostatic intolerance (the inability to stand for long) is a common problem. Some of the other more traditional postures are modified too. There is also a much greater emphasis on relaxation and breathing than in a normal yoga class and participants are advised to stay well within their own limits and not overdo it. Those who are more severely affected may find they want to start by only doing relaxation, breathing and meditation; nothing else involving movement. Just doing yoga relaxation, visualisation, breathing and meditation with no actual physical movement at all can have many benefits and should not be underestimated. Studies on yoga students with MS showed improvements after simply visualising postures.

Fionar Agombar, who is the author of 'Beat Fatigue with Yoga' and has ME/CFS herself, describes in her book how she had her central nervous system (CNS) tested on a 'heart rate variable' monitor and it was shown to be dysfunctional. She repeated the test after a period of deep relaxation and meditation and it showed a much more normal reading, indicating that yoga helped to calm her CNS.

One deep relaxation technique, yoga nidra, is a favourite amongst members of my local yoga for ME group, whether mildly, moderate or severely affected. An article on yoga nidra for those with ME/CFS can be found by visiting <http://www.sheffieldyogaforme.org.uk/yogaNidra.php>.

Some articles about the effects of yoga nidra, meditation and relaxation can be found in Issue 11 of "Bindu", the magazine of the Scandinavian Yoga and Meditation School on the website www.yogameditation.com/articles/issues_of_bindu/bindu_11. This issue also refers to studies carried out on the beneficial effects of relaxation techniques on various illnesses including HIV infection, diabetes, epilepsy, cancer, chronic pain, irregular blood pressure and asthma.

For more information on the benefits of yoga for people with ME/CFS please refer to the book 'Beat Fatigue with Yoga' by Fiona Agombar (Thorsons) or Angela Stevens' website www.angela-stevens.co.uk



Sheffield Yoga for ME/CFS

Sheffield Yoga for ME/CFS is an independent voluntary organisation and was established in 2001 for the purpose of organising specialist remedial yoga lessons for people with ME or CFS in Sheffield. It became a registered charity in 2006. All the committee members have ME and experience of yoga themselves except for the treasurer who is an accountant. These people who help have diverse backgrounds, including health and disability and, work together to run the organisation. The trustees are elected each year by the membership. There are close links with the Sheffield ME Support Group. It had been clear for several years that there was a demand for yoga classes; for example, members of the Heeley ME Support Group had regularly requested yoga on their programme. Many people with ME have found yoga a tremendous help in managing the illness and coping with symptoms, although most people with ME are too ill to attend normal yoga classes. In remedial yoga, postures are adapted so they are appropriate for a particular group. In the case of ME, for example, many postures which would normally be done standing (such as "The Tree"), are carried out while lying down.

It had proved difficult to find a teacher willing and able to take a specialist class for people with ME or CFS in Sheffield until Autumn 2000 when contact was made with Linda Sole, now Linda Su Arnold, an experienced remedial yoga teacher who trained at the Yoga for Health Foundation. A trial session with Linda, run by the Heeley ME Group, was such a success that it was agreed to organise classes on a more permanent basis. Classes began regularly every two or three weeks from April 2001 once a committee had been formed and funds had been raised to cover the costs of the venue and the teacher. In March 2002 an evaluation performed which indicated that the classes were very successful indeed, with members reporting benefits to health and the ability to relax more deeply. November 2002 saw a move to a different venue in the South of Sheffield, more appropriate for the winter months and with disabled facilities.

A grant by the Community Fund (National Lottery) was awarded from January 2003 enabling the classes to go weekly and provision of free transport. The teacher was only available fortnightly so a pool of yoga teachers was created to ensure continuity of classes. All the additional teachers have some training in and experience of therapeutic yoga. The group continued to grow. Annual monitoring surveys since 2003 show that the classes have been very successful. You can read the monitoring surveys by visiting our website <http://www.sheffieldyogaforme.org.uk/iyengar.php>. In the autumn of 2005 pilot Lyengar yoga adapted for those with ME/CFS were held in the North of Sheffield and were very well received. Lyengar sessions are now being held regularly. Not only do these extra classes fulfil the need for some classes being held in the north of the city, as some people are too ill to travel to the weekly classes in the south, but they offer a different style of yoga.

The classes are publicised in a number of ways. Enquirers are added to the mailing list and sent written information about the yoga classes. By September 2010 there were over 250 people on the mailing list, with 10-24 people attending each session. Bulletins are sent out regularly every two to three months to all those on the mailing list. As well as giving dates for the yoga sessions they include some new yoga information. Telephone feedback indicates that some people who are too ill to attend the classes at present appreciate this positive contact with the group and feel that coming to the yoga classes is a goal for when they are well enough. North of Sheffield and were very well received. lyengar sessions are now being held regularly. Not only do these extra classes fulfill the need for some classes being held in the north of the city, as some people are too ill to travel to the weekly classes in the south, but they offer a different style of yoga.

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For further information see: www.sheffieldyogaforme.org.uk



Recipe Corner by Carolyn**Broccoli Lemon Chicken with Cashews**

Cooking Time: 15-25 minutes
Serves 2

Cooking Method:-

Heat the oil in a large frying pan or wok. Add the chicken and fry for 3-4 minutes until golden. Remove from the pan and add the garlic and broccoli. Stir fry for a minute or so then cover and cook for 2 minutes more, until almost tender.

Mix the stock, cornflour and honey or sugar well, then pour into the pan and stir until thickened. Tip the chicken back into the pan and let it heat through, then add the lemon zest and juice, and cashew nuts. Stir, then serve straight away with basmati rice or noodles.

Nutrition per serving:- kcalories 372, protein 48g, carbs 15g, fat 11g, saturates 2g fibre 3g, sugar 6g, salt 0.69g.

Ingredients:-

1 tbsp sunflower oil
340g pack of cooked mini chicken breast fillets (sometimes called goujons)
2 garlic cloves sliced
200g pack tender stem broccoli, stems halved if very long
200ml chicken stock
1 heaped tsp cornflour
1 tablespoon clear honey or, 2 teaspoon caster sugar
The zest of half a lemon and the juice of a whole one
A large handful of roasted cashews

Basmati rice or cooked noodles



Abstract: Chronic Fatigue Syndrome and Mitochondrial Dysfunction

by Dr Sarah Myhill

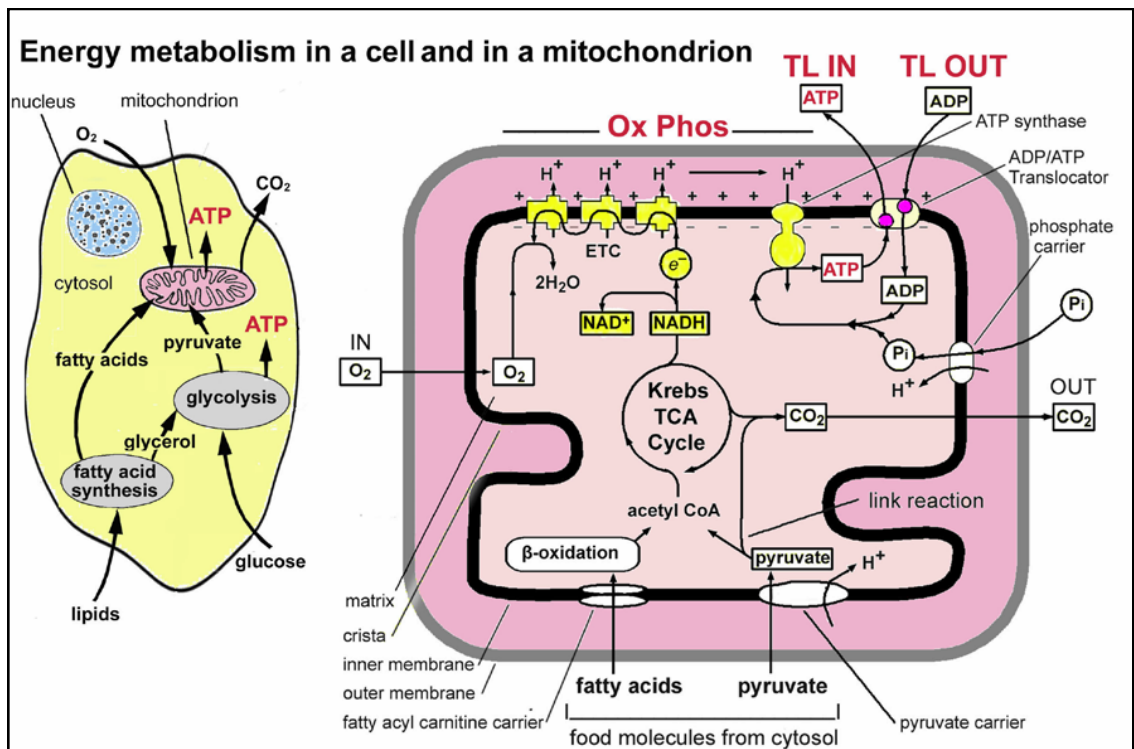
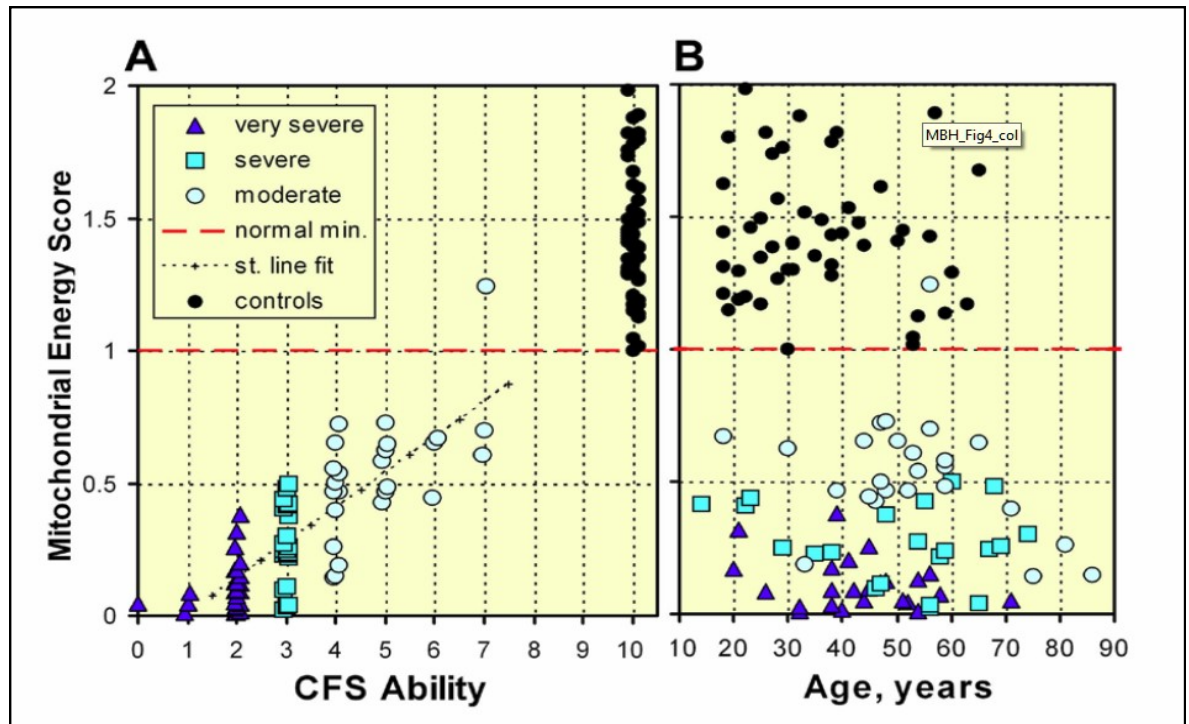
This study aims to improve the health of patients suffering from chronic fatigue syndrome (CFS) by interventions based on the biochemistry of the illness, specifically the function of mitochondria in producing ATP (adenosine triphosphate), the energy currency for all body functions, and recycling ADP (adenosine diphosphate) to

replenish the ATP supply as needed. Patients attending a private medical practice specializing in CFS were diagnosed using the Centres for Disease Control criteria.

In consultation with each patient, an integer on the Bell Ability Scale was assigned, and a blood sample was taken for the "ATP profile" test, designed for CFS and other fatigue conditions. Each test produced 5 numerical factors which describe the availability of ATP in neutrophils, the fraction complexed with magnesium, the efficiency of oxidative phosphorylation, and the transfer efficiencies of ADP into the mitochondria and ATP into the cytosol where the energy is used. With the consent of each of 71 patients and 53 normal, healthy controls the 5 factors have been collated and compared with the Bell Ability Scale. The individual numerical factors show that patients have different combinations of biochemical lesions. When the factors are combined, a remarkable correlation is observed between the degree of

mitochondrial dysfunction and the severity of illness ($P < 0.001$). Only 1 of the 71 patients overlaps the normal region. The "ATP profile" test is a powerful diagnostic tool and can differentiate patients who have fatigue and other symptoms as a result of energy wastage by stress and psychological factors from those who have insufficient energy due to cellular respiration dysfunction.

The individual factors indicate which remedial actions, in the form of dietary supplements, drugs and detoxification, are most likely to be of benefit, and what further tests should be carried out.



Sarah Myhill Interview: The role of mitochondrial function in ME/CFS

*At the recent Abundant Energy Summit: Sarah Myhill gave an interview speaking about the role of mitochondrial function in ME/CFS. Here is an abridged version with thanks to Google News. Sarah worked with the NHS for 20 years before entering into private practice. She was the Honorary Secretary for the British Society for Allergy and Nutritional Medicine for 17 years, and has worked with over 5,000 patients with fatigue. Her model is based on the concept that the main mechanism of fatigue is mitochondrial dysfunction. She is the author, with colleagues, of three scientific studies in the International Journal of Clinical and Experimental Medicine showing that the level of mitochondrial dysfunction correlates with the degree of fatigue. She is also the author of the book, *its Mitochondria Not Hypochondria*.*

Question: You have a car analogy in your book. Please explain that.

Sarah: Let's start from the beginning. The first and most important thing to grasp about Chronic Fatigue Syndrome is that it is not a diagnosis; it is a clinical picture that may have many causes. It is my job as a physician to find the causes. The second important thing to grasp is that we have symptoms for a very good reason. Symptoms protect us from ourselves. If we didn't experience fatigue we'd work all day and all night. And we'd be dead in eleven days, because nobody has survived eleven days without sleep. The symptom of fatigue can arise for many reasons that have to do with delivery systems and energy expenditure - how we spend and create our energy. We always have to keep ourselves where our energy demands don't exceed our energy delivery. We need to pay attention to both sides of the equation: energy demands vs energy delivery.

The body is just another machine, like a car. Like any machine it needs the right fuel in the tank. That fuel has everything to do with diet and gut function. Mitochondria are essential for creating energy from fuel. They are the little engines that exist in every cell in the body, and in every cell in every living organism. Without mitochondria we wouldn't have life as we know it. What mitochondria do is they take fuel from the bloodstream derived from carbohydrates, fats, and proteins (in the form of acetate groups) and burn them in the presence of oxygen to produce ATP. Think of ATP as a molecule with which you can do any function in the body.

The thyroid gland is also terribly important. It determines how fast those mitochondria go, like an accelerator pedal in a car. We have to be careful about how we spend our energy. Spend it too fast and we wouldn't have survived a harsh winter. What allows us to gear up energy spending is the adrenal gland, which I think of as the gear box in a car. Adrenaline is the short-term immediate hormone for energy delivery; cortisol is the intermediary and DHEA is for long-term energy delivery. Those hormones allow us to adjust energy demand to energy delivery very closely. Of course, all cars have to be serviced regularly. We service our bodies during sleep. Every single living thing, even bacteria, need a time in which metabolic processes shut down to allow healing and repair to take place are the central, important aspects.

Question: You talk about how the immune system takes up a huge amount of energy.

Sarah: That's on the other side of the equation, where we look at how energy is spent in the body. An astonishing amount of energy about two-thirds of all energy we generate just goes into staying alive: basic metabolic rate, heart function, lung function, gut function, liver function, and brain function. All those things demand energy. The rest we should spend physically, or mentally, in terms of mental exercise. I think of the immune system as a brain that isn't contained within the skull, but is spread throughout the body. It's intelligent, it's decision-making. It's highly active, and it's highly demanding of energy. It likes to run on fat, and so on. When the immune system is activated it uses up a massive amount of energy.

We know that because if a normal person gets flu, they get instant ME. They're bed-bound for a week or two until their immune system switches off and they get well again. When their immune system is activated because of infection, that's normal, desirable, and essential to dealing with an infectious threat. However, if the immune system is activated because of allergy, that's what I call useless inflammation. The body is spending immunological energy on something that is not a threat. That kicks an immunological hole in our energy bucket.

Question: Would you please expand on the production of ATP and ADP

Sarah: When ATP is being efficiently recycled, ATP forms ADP. Then it goes back into the mitochondria where it again forms ATP. That is an extraordinary efficient cycle. In fact, when we are functioning at our maximum potential, a molecule of ATP can be recycled back through our mitochondria every ten seconds. If there was no such recycling, then we would burn more than our body's weight of ATP every day. We run into problems when energy demand exceeds energy delivery. The body has some emergency mechanisms. Let's say I have to run for my life, all these energy systems would be employed. One of them is to switch into anaerobic metabolism that produces lactic acid. We all know about that. It's the lactic acid burn that slows athletes down and stops them, and stops ME patients as well.

Another mechanism is when two molecules of ADP combine to form one molecule of ATP and one of AMP. The ATP can be quickly recycled, but the AMP is recycled very slowly. So suddenly, you're pulling the plug on your supply of ATP. It's all draining out of your system. That is what I suspect causes the delayed fatigue in ME. Interestingly, another paper has come out recently, where they tried to reproduce that idea in a computer using low rates of metabolism and putting in all the variables. And they came up with the same conclusion.

Interviewer: What are some of the causes of mitochondrial under function?

Sarah: Broadly speaking, there are two important causes. The mitochondria can be deficient in raw materials – magnesium, CoQ10, acetyl-L-carnitine, vitamin B3, and D-ribose. Those are the 5 things we see that mean the mitochondria are deficient. We measure these things when we do mitochondrial tests. Or, mitochondria can be going slow because they are blocked by something. Blocking factors can include environmental toxins, energy delivery blockers, heavy metals, and fermenting gut products. You can block mitochondria by stacking things on top of the mitochondrial membrane. It's no good making ATP if you can't get the ATP out of the mitochondria and into the cell where it's needed. Mitochondrial membranes are made up of proteins that act like a little shuttle that takes ATP out of the mitochondria and then brings ADP back into the mitochondria where it is turned into ATP. There are lots of things that can block that shuttle. We can do tests to determine what those blocking factors are. I got interested in ME when I started seeing farmers with sheep dip flu. They had been poisoned by organophosphates. Organophosphates inhibit oxidative phosphorylation. That is how they block the mitochondria's ability to make ATP. Broadly speaking those blockers fall into two groups: they can be toxins from the outside world, such as pesticides and heavy metals, or they can be products from within the body. I suspect a major source of those is products from the fermenting gut.

Interviewer: What inflammatory processes lead back to the gut?

Sarah: Mitochondria are important, but I spend as much time with my patients talking about diet, as talking about gut function. So many problems start with the gut.

Interviewer: Also, mitochondrial malfunction explains the illness brilliantly, but it's not the cause, it's the effect?

Sarah: The whole thing is circular. We all come into this area with different theories, but we all end up offering similar patterns of treatment – diet, detoxing regime, nutritional supplements, correcting hormones, and so on. But mitochondria are central players.

Interviewer: Diet, pacing, micronutrients and sleep are your four foundational things. Do you want to expand a little on that, especially pacing?

Sarah: It's back to square one. Fatigue is a mechanism that protects us from ourselves. If someone is experiencing fatigue because they are overdoing, they are constantly stressing their mitochondria and their energy supply and they are constantly going into anaerobic metabolism and producing lactic acid. Normally, mitochondria function on oxygen. When you burn a molecule of sugar in the presence of oxygen, you'll produce about 26 molecules of ATP. But when you stress your mitochondria and switch to anaerobic metabolism, burning a molecule of sugar only produces two molecules of ATP.

If you do this on a regular basis you get a build-up of lactic acid. To convert that lactic acid back to pyruvic acetate takes six molecules of ATP. What that means is if you overdo things it takes an awfully long time to get back to square one. The point of pacing is to avoid getting into anaerobic metabolism. So, pacing is crucially important. People will get better if they pace. If they don't pace, eventually there is tissue damage and inflammation sets in, which kicks another hole in the energy bucket.

Interviewer: You have a basic protocol for micronutrients, what is that?

Sarah: Although I began by seeing patients with ME, I have come to the conclusion that no matter what a patient comes to me for, there is a basic package of treatment that we should all be doing.

Firstly, in terms of diet, this consists of a "stone age diet": meat, fish and eggs, nuts and seeds, lots of veggies, and low-fructose fruits, such as berries.

Number two is sleep. Most people are sleep deprived. If you need an alarm clock to wake up in the morning you are sleep deprived.

The third thing I talk about is micronutrients. Because modern farming depletes the soil of minerals, we should all be taking a basic package of micronutrients – vitamins, minerals, and amino acids.

Interviewer: Talking further about the Stone Age Diet, are you recommending a grain-free diet?

Sarah: Grains are too toxic for humans to consume. So, remove all gluten completely. The fermenting gut is a very big problem. The upper gut should be a near-sterile carnivorous digesting gut to deal with meat and fat. The lower gut, which is teeming with bacteria, digests vegetable fibre. So, the lower gut is a fermenting gut. If we overwhelm our liver with sugar, for example, we switch into the fermenting gut and have all the problems of metabolic syndrome. What I am saying is that a modest amount of carbohydrate is fine if you've got perfect digestion. But my ME patients don't have perfect digestion. So, carbohydrates are a major risk factor for chronic fatigue syndrome. I consider being vegetarian a major risk factor for chronic fatigue syndrome for two reasons. Vegetarian foods tend to be high GI, that is, grains and fruits. They are also high in the major antigens: dairy, gluten, and yeast.

Interviewer: Could you talk a little about B12 and magnesium?

Sarah: Magnesium is centrally important for mitochondrial function. In fact, 40% of all the energy that comes out of mitochondria simply maintains the ion pumps that kick calcium out of cells and drag magnesium in. If the mitochondria are going slow, they can't kick the calcium out, which is toxic within cells, and they can't drag the magnesium in. So they don't have the magnesium they need to make the mitochondria even work. There is a vicious cycle here. If you can't get the magnesium in, the mitochondria won't work, and if the mitochondria can't work, you don't get the magnesium in. The reason magnesium injections are so helpful is that you are spiking the level of magnesium in the blood for a short period of time. All of a sudden it's much easier to drag the magnesium into the cells. The mitochondria then start working again properly. Magnesium injections kick start the mitochondrial engine.

With B12 I think there may be a similar mechanism going. The thing about B12 is that it is very poorly absorbed. Even people with the best gut function will only absorb 1% of the B12 that they are taking. Only about another 1% actually gets into the brain, where it is very important for cognitive function. The point about B12 is that if you inject it, you spike the levels in the blood, and you get the B12 into the brain. I'm only hypothesizing, because so many of my ME patients find their brain function and their mood is so greatly improved with B12 injections. B12 is performance enhancing in athletes, and even in horses. Trainers give horses B12 injections, and they go faster. That means their mitochondria are working better. And, B12 injections are an incredibly safe thing to do.

Interviewer: Are you having much luck with transdermal forms?

Sarah: Transdermal forms of B12 are better than oral forms. They get about 6% absorption. But again, it's not as good as the injection because you don't spike blood levels.

Interviewer: You mentioned the mitochondrial cocktail?

Sarah: When we do tests, we tailor treatments to individuals because we measure CoQ10, carnitine, B12, magnesium, and ATP. But if you can't access those tests, you can do no harm by taking those supplements. I have yet to find an ME patient with normal levels of CoQ10. These days I tend to use ubiquinol, which gets much better blood levels. 200 mg of ubiquinol will correct all my patients.

Interviewer: Diet and environment need to be under control for any of this to work.

Sarah: That's very important. We are living in an age in which we are being overwhelmed with toxins. A supplement I routinely prescribe for my ME patients is glutathione, which is essential for getting rid of heavy metals and is a potent antioxidant. With 250 mg a day of glutathione you can do no harm. Another interesting facet of mitochondria is that they determine aging. We age at the rate that our mitochondria age.

Interviewer: There have to be different approaches for different people. Some may need thyroid support, some adrenal support.

Sarah: I always say that getting people well from chronic fatigue syndrome or ME is like a jigsaw puzzle. You've got to have all the pieces in place at the same time. You can't try one thing, and when it doesn't work, you try another. You've got to start with the foundation stones of pacing, diet, supplements, sleep. Then you build on that with the mitochondrial stuff, thyroid stuff, adrenal stuff, gut fermentation stuff. You can do a lot of this yourself with simple nutritional therapy. It's very doable.

Interviewer: What about tests?

Sarah: The tests we use are all documented research tests. We apply them clinically. The problem with new, innovative tests is that they are hideously expensive. But don't wait for the tests to come out to start to get better. Put the basic package in place as well as you possibly can. It's all about tipping points. I say to my patients, all we have to do is get you 51% better and your body will do the rest.

For more intimation see website: www.DrMyhill.co.uk

Sarah Myhill gets The British Medical Association Book Awards 2015

I was pleased to travel to London on 3rd September 2015 for the BMA Book Awards 2015. My book on diagnosing and treating CFS had been put forward in the "Best Popular Medicine" category by my publisher, Georgina Bentliff, of Hammersmith Books. To my surprise, it had been shortlisted from a pool of 630 titles and here we were my daughter, Ruth, and I, having lunch in London, before the "big event".



The proceedings started at 5pm in the Paget Room, where we were met by Craig and Penny Robinson, early birds! Craig had contributed Chapter 8 of my book and is also one of my patients. A few minutes later, we were joined by Hanie Baker, the editor of my book, and my former adviser and Secretary, now enjoying a well-earned retirement! Then, Georgina Bentliff and David Thompson, of Action PR, completed the party. Around 6pm we all went upstairs to the Great Hall and after a short introduction by Dr Mark Porter, Chairman of the BMA Council; the awards were announced by Miss Jacky Berry, BMA Librarian. We didn't win! But we were all very happy to receive a "Highly Commended" certificate. After this we had a hot supper, courtesy of the BMA, and then gradually made our separate ways home.

Of course, this award is not just for me; it is also for all my staff, for my patients, and non-patients, alike, and, for the members of the Dr Myhill Facebook groups, who have all supported me through the years, read my book and website and given me such courage to keep going! David Thompson took some pictures and we have placed these below, along with a scan of the certificate!

Finally, many thanks to you all!



Research Corner: Cellular workout

With thanks to ME Research UK

A fascinating new ME Research UK-funded study from Newcastle has found abnormalities in the muscle cells of ME/CFS patients. In the early scientific literature, the hallmark of Myalgic encephalomyelitis was muscle fatigue and weakness, often after relatively mild exercise. Muscle cramps, twitching and tenderness were also often present. Today, patients diagnosed with ME/CFS frequently highlight peripheral fatigue - such as impaired muscle power in the arms and legs - as a particular practical problem.

The biological mechanisms underlying muscle fatigue and weakness are currently being investigated in a number of different diseases. For almost a decade, ME Research UK has provided the pilot funding for distinct projects at the University of Newcastle designed to explore these mechanisms in ME/CFS. One of these projects using magnetic resonance scanning of peripheral muscle (a scanning technique that looks at how muscles work) revealed significant abnormalities in the way acid is handled - suggesting that acid build-up during exercise may be due to a problem with muscle cells themselves.

Muscle cell cultures

To explore these and other interesting leads, ME Research UK awarded further funding in 2009 to Prof. David Jones and Prof. Julia Newton to undertake. Laboratory studies involving assays and cultures of isolated muscle cells (myocytes) from ME/CFS patients and healthy individuals. The first scientific paper from this series of investigations was published recently in the journal PLoS ONE, and it makes fascinating reading.

For these experiments, cultures of isolated skeletal muscle cells were obtained (by needle biopsy of the muscle on the outside of the thigh) from ten people with ME/CFS and from seven age-matched healthy people. Electrical pulse stimulation was then applied to the cells for up to 24 hours to simulate an exercise challenge by inducing contractions in the cultured muscle fibres. In this way, the direct effect of exercise on the cells themselves could be observed. As the researchers point out, the attraction of using muscle cell cultures is that conditions can be standardised, so that any differences reflect changes in the cultured cells rather than personal or social differences between patients.

Exercise challenge:

The main findings of the experiments were that, after 16 hours of this simulated exercise, muscle cell cultures from the healthy individuals had increased levels of AMP-activated protein kinase (AMPK) phosphorylation, as well as a higher rate of glucose uptake. In contrast, cultures from ME/CFS patients showed no such increases after exercise. In addition, the secretion of interleukin 6 (which is involved in inflammation and fighting infections) in response to exercise was significantly lower in cells of ME/CFS patients than in those of healthy individuals. Finally, even without exercise, the muscle cells of ME/CFS patients had a higher than normal expression of myogenin (which co-ordinates skeletal muscle development and repair).

AMPK activation:

The impairments in AMPK activation and glucose uptake in the muscle cells of ME/CFS patients are particularly intriguing. The fact that the cultures were unable to increase the rate of glucose uptake in response to exercise most probably reflects the impaired activation of AMPK. This complex enzyme plays a key role in monitoring the use of energy in cells, sensing whether cells' 'batteries' are charged or discharged at any particular moment (see the box opposite for a more detailed explanation). As the authors say, the lack of activation of AMPK during exercise in muscle cells from ME/CFS points to a muscle abnormality at the level of AMPK (which is normally activated during muscle contraction) or in other regulatory enzymes further up the biochemical pathway. They plan to investigate these as well, using the system they have developed to analyse the workings of isolated muscle cells in the lab.

Overall, the evidence from this important study points to an exercise-related, primary abnormality in the muscle of ME/CFS patients. Because this occurs in cultured isolated muscle cells, it may well have a genetic or epigenetic basis. Exciting results, without a doubt.



"The lack of activation of AMPK during exercise in ME/CFS patients points to a muscle abnormality."

What is AMP-activated protein kinase?

AMP-activated protein kinase (or AMPK) is an enzyme that has a key role in the regulation of the supply of energy inside cells. It is particularly active in tissues with high energy requirements, such as the liver, brain and skeletal muscle.

Sometimes called the cellular fuel gauge, AMPK is activated by a drop in the energy status of the cell, such as when energy is being used up faster than it is being produced. During a bout of exercise, for example, AMPK activity increases as muscle cells experience the stress caused by the increased demands for energy. Such of AMPK during exercise involves a cascade of processes, including the stimulation of glucose and fatty acid uptake and oxidation.

Overall, the effect of AMPK activation is to switch off pathways that use energy and switch on pathways that generate energy helping to restore the energy balance within the cell.

Although much remains to be discovered, AMPK is thought to be an important player in conditions such as type 2 diabetes metabolic syndrome and obesity, which are all associated with disturbances of energy metabolism. AMPK activating Drugs are already used to treat type 2 diabetes.

"The lack of activation of AMPK during exercise in ME/CFS patients points to a muscle abnormality."

Multistix—The Laboratory in a strip

Almost all motorists know that what comes out of a car exhaust piper is an indication of what is happening in the car engine. For example, white steam indicates a cold engine, blue smoke indication that oil is being burnt (usually bad news because the engine is worn.) or black sooty smoke indicate that too much fuel in proportion to air is being burnt. Additionally to this exhaust gas analysis provides similar information to unseen gas emissions. In the human body, the kidney regulates the internal environment and disposes of unwanted products via the urinary system. The same concept follows that what is excreted must indicate something about the way the body and kidneys are working in addition to the general condition of the urinary tract.

Urine can be tested by the test tube method in a laboratory, this is expensive and time consuming. The real breakthrough came about fifty years ago when dip and read test strips appeared, giving an almost instant analysis of urine chemistry. Since then there have been various devilments and improvements of the technology, particularly with machines what read the strips automatically. Locally the most popular brand is multistix. You find these in most clinics and doctors surgeries. Normally you don't see these in use, but you can guarantee that if you hand in a urine sample to the doctor this is what will happen to it out of sight.

Dr Myhill promotes the home use of these test strips for her patients. The strip variant that she supplies strips can be used to test urine for glucose, ketones, specific gravity, blood, pH, protein, nitrites and leucocytes. All these are clues to disease of the kidneys, urinary tract and other problems such as diabetes. Urine testing should always be undertaken in any case where the diagnosis is in doubt. The dipsticks should be kept at all times in the sealed container. Heat, cold, moisture and light will spoil the sticks. Do not touch the coloured squares, not because they are poisonous, but because moisture on your fingers may spoil the test. A full pot of 25 sticks can be kept for up to 12 months, but check the "use by" date.

Take a look at one of the sticks. The colours on the stick should correspond with the colours on the left-hand side of the chart (except for specific gravity, which matches the colour on the right-hand side of the chart). For example, glucose should be a greenish-blue, ketones a pale pink, specific gravity a yellow, blood a pale yellow, pH an orange, protein a pale-yellow, nitrites a buff colour and leucocytes a pale cream colour. If the sticks are not these colours to start with, then they may have gone off and you shouldn't use them.

If you are doing you own urine testing, you need to check the reading for each substance at the correct time so be prepared to measure the time accurately, i.e. have the colour chart and a watch ready. Make a record of your reading on a piece of paper for future reference. To use a stick, collect a sample of urine into clean jar. Dip one multistix into the sample, hold for a couple of seconds, remove the stick and knock off the drips. Compare the colours with those on the colour chart.

When interpreting result, you have to understand that these tests are not perfect – there may well be false positives and false negatives. For example nitrites may test negative even in the presence of infection because the urine has not been in the bladder long enough for bacteria to convert urea to nitrite. There are other issues for People with ME/CFS. For example mega dosing with ascorbic acid (the acid form of vitamin C) may stop the glucose square reacting to sugar. For example some drugs may block or enhance reactions.

I always keep a tub of these around the house, but not for urine testing. I recently had a problem with our pond. The water kept going green and was and the fish looked very unhealthy. Using one of the test strips on the pond water revealed that the water was excessively acid and full of nitrite. Fish and other animals excrete urine, which is converted by bacteria to ammonia then nitrite then nitrate. Normally these don't accumulate if the eco system is balanced, but in closed system like a garden pond it can easily get out of balance. The fix was to reduce the algae growth by shading the pond from light, and increasing the number of plants. For this we used duckweed. Since then the fish have been very happy. A pond test kit for nitrate cost around £40, but a tub of these strips costs about £15.



Multistix Test outcome with examples of implications (*Thanks to Dr. Myhill*)

<u>No.</u>	<u>Symbol</u>	<u>Test</u>	<u>Read Time</u>	<u>Normal Colour</u>	<u>Abnormal Colours</u>	<u>Interpretation</u>	<u>Implication</u>	<u>None Medical Application</u>
1	GLU	Glucose	30	Sky Blue	Blue-green to brown	If there is any glucose (or sugar) present it will change colour, possibly to a dark	Any amount of glucose in the urine needs further investigation by your GP. You may be diabetic.	Test for reducing sugars in foods as e.g. as additives
2	KET	Ketones	40 s	Pink	Rose – Indigo	Ketones can be present in diabetes but the usual cause for them is hunger. If you've found ketones in your urine, go and have something to eat which includes some carbohydrate and test.	If ketones are still present then you need to see your GP urgently. One cause of ketones is a low carbohydrate diet used in some slimming regimes. Having ketones is not harmful but a clinical emergency if diabetic & glucose is present. (Eskimos are in a state of permanent ketosis).	Nail polish remover test, abnormal pasture conditions in milk
3	SG	Specific gravity	45	Dark Green	Green to Yellow	simply reflects how much or little you are drinking.	In chronic renal failure, the kidney cannot concentrate urine and it is always weak with a low specific gravity (dark green).	Can be a guide to dilution or alcohol content in wine
4	BLO	Blood	60	Yellow	Spotted yellow to green	a trace of blood appears as green flecks, but excessive blood is a dark-green colour.	Any amount of blood in the urine needs further investigation by your GP. This can be suggestive of infection, stones, autoimmunity or tumours. This test is extremely sensitive and, for example, the slightest contamination from a sample given by women at period time could cause this to go abnormal	Food contamination (unless a blood based product like black pudding)
5	PH	pH.	60	Orange	Orange-yellow-green (various shades)	how acid or alkali the urine is.	It can be used as a guide to hyperventilation as it goes greenish blue (alkali) in people who hyperventilate	Indexation of corrosiveness or and ability to damage teeth.
6	Pro	Protein	60	Very Light Green	Light green to Blue	if protein is present then the colour changes to a bottle-	Protein is a sign of disease of the renal tract—almost any kidney disease can present with protein in the urine.	In winemaking protein is bad news, but almost all foods
7	NIT	Nitrites	60	White	Shades of Pink	Nitrite are created when bacteria in the urine convert urea to nitrite – nitrites usually mean infection.	Nitrites and leucocytes — these two tests together may suggest infection of the urinary tract. If either is positive then you must see your GP so he can send a sample of urine off for microscopy and culture to see which bug is there and to which antibiotic it is sensitive. If there are no symptoms then it is reasonable just to monitor the situation for a while. Urine testing with multistix is an extremely useful test to do on children who have a high temperature because urine infections are often overlooked as a possible cause of fever.	Preservative in preserved meats. Excess algae or waste products in fish tanks or ponds'
8	LEU	Leucocytes (White Blood cells)	120	Pale beige	Darker beige to magenta	If these are present in large amounts as for example in infection, then there is a colour change to purple. .	See above	

Double Troubles: ME/CFS & Diabetes

A review of an old feature still very relevant today.

In a recent clear out I came across a feature about Diabetes and ME/CFS dating from 1992 in an old copy of 'Balance', magazine of the British Diabetic Association, now known as 'Diabetes UK'. The author of the original feature was Beth Noakes who looked into the problems experienced by people with both conditions. This feature uses many parts of the original text, which has been updated and clarified for non-diabetics.

As a matter of introduction, there are two main types of diabetes. Firstly Type 1 or Type A or insulin dependent diabetes. The pancreas no longer produces insulin, and to maintain life, insulin has to be injected. It mainly occurs in children or young adults. The mechanism is believed to be autoimmune destruction of the pancreatic islet cells, quite often triggered by an infection. The second type of diabetes is type 2 or Type B or non-insulin dependent diabetes. The disease mechanism being either reduced islet pancreatic function or insulin resistance due to metabolic syndrome. In early onset, it can be treated by diet alone, with increasing oral medication added as time goes by. Eventually, it needs insulin like type 1. Most cases are age related or maturity onset. Type 2 was originally called mild diabetes, but in many ways is more dangerous and serious than type 1. I have covered ME & Diabetes in previous issues of Pathways, and I would refer you to past issues for more in depth coverage.

Carol's Story: 'Overworked', 'overstressed', 'depressed', 'sinuses', 'lack of diabetic control': these were some of the phrases thrown at Carol for nine months when she felt very ill after a mystery viral illness. A neurologist told her that she had no physical problems, but was suffering from acute depression. "I knew I was not depressed," she says. "I was very upset because I felt so ill and no-one was listening to what I said. After twice getting lost in the small town I was born in, I spent two months of agony thinking I was going bonkers. I blamed my diabetes, and for the first time in over 20 years I resented and hated being diabetic."

Finally, Carol was diagnosed as having Myalgic Encephalomyelitis, or ME/CFS. ME/CFS is a debilitating illness that may begin suddenly, after a virus infection, or gradually, with no identifiable starting point. Research suggests that although the virus infection seems to be over, its effects persist in muscle and brain tissue. It can last for a year, for decades or for life. Its hallmark is exhaustion of muscle and mind, but other symptoms include loss of concentration, stomach problems, painful joints, visual disorders, giddiness, headaches and sleep disorders. The symptoms vary from hour to hour, from day to day, from person to person. Some sufferers can continue to live relatively normal lives, but others are confined to the house or even to bed. "A sudden attack of ME sweat (perspiration) followed by a sudden draining of physical energy is exactly the same feeling as a bad hypo. She says. "If I am out and cannot tell. There is (*1) no specific laboratory test that can diagnose ME, and the individual symptoms can have so many other explanations that it is easy for doctors to dismiss sufferers as hypochondriacs or neurotics. For people who have had diabetes for many years before they develop ME, the combination of symptoms can confuse their well-established strategies for coping with their diabetes.

When the two disorders develop more or less simultaneously, sufferers are liable to be even more confused. Control, she finds many halfway-between the two conditions, which is which, it can be quite frightening, and twice I have nearly collapsed with a hypo which I thought was an ME attack." Carol finds that the eyesight blurring - common to ME - is similar to the effects of blurring with hyperglycaemia; and an ME headache is similar to a hyper headache, too. Injecting into muscles that ache and hurt is also a problem. Sometimes she is too tired to worry about checking her diabetic control, and finds the programme on her blood count machine so confusing that she makes mistakes using it. "But by far the biggest problem and danger for me at present," says Carol, "is lack of memory and concentration, which causes me to forget to do my injections or forget the dosage. Twice recently I have drawn up and given myself my morning dose at teatime, not remembering what I have done until later when a bad hypo attack occurs."

A 'hypo' is a hypoglycaemic episode where blood sugar is reduced to abnormally low levels. Hypo's can cause tremor, agitation sweating and strange sensations which provide early warning of onset. Later on sedation, brain fog, unconsciousness and even death can occur within minutes. The cause is usually excessive physical activity, too much sugar lower insulin or other drugs, and too little food. The fix is sugar (carbohydrate) food an emergency injection of glucagon or emergency injection of glucose via a drip in an emergency. The problem is that ME hypo have very similar symptoms to diabetes hypos.

Gary's Story: Gary thinks that his ME developed at the same time as his diabetes, when he was ten. Every few weeks he would / have a week off school with fatigue dizziness plus high or unpredictable blood sugars. He still gets similar attacks, though now they feel more like flu. His sugars never stabilised, and he could not find an explanation for his other symptoms until he read an article about ME in The Observer in 1986. He was diagnosed by a specialist as having ME/CFS, and is convinced that the ME is the reason for the brittleness of his diabetes - and so at last are his doctors.

Gary finds that hypos (*lower blood sugar*) and hypers (*high blood sugar*) knock him out completely. He does many blood tests to try to avoid swings, and is on an insulin infusion pump which gives him some control. Like Carol, he finds the faint and dizzy symptoms of a hypo easy to confuse with similar symptoms of ME. He is sure that diabetes and ME/CFS interact both physically and emotionally. He has never been able to work full time, and has had to cope with the frustrations common to everyone with a chronic illness: "It's bad enough the way people react to diabetics - but if they know you've got ME too, they treat you like a cripple."

Late Microbiologist Dr Betty Dowsett, who has studied people with ME for many years, remembers a patient whose diabetes was well controlled until she got ME, when she had to be admitted to hospital and put on an insulin drip. Dr Dowsett says this accounts with the findings of Glasgow researcher Professor Peter Behan, who has shown that one of the effects of ME can be insulin resistance.

Richards Story: Soon after being diagnosed with diabetes, Richard found late nights left him physically shattered the next day. The tiredness appeared after he had been particularly busy, like mowing the front and back lawns and washing the car along with all the other weekend jobs. He assumed that this was one of the problems of diabetes, but his consultant and other people with diabetes told him it was not so. He hardly had a day off sick during his first three years of diabetes, until September 1989 when his tiredness got so bad that he was spending mornings and sometimes afternoons in bed as well as 12 hours at night. He was off work for 10 weeks.

His diabetes went completely out of control, with readings of 15 mml or even 20 mml which he tried to counteract by increasing his insulin doses (*more insulin should reduce blood sugar levels*). His diabetes specialist prescribed anti-depressants, and a few weeks later Richard started to feel better and returned to work in November. A throat infection soon laid him low, and though he struggled to work in the new year he became so exhausted that he has been off work ever since February 1992. Richard's doctor suggested he see a psychiatrist, which he did and who could not help him because his symptoms were not those of depression. The psychiatrist, whose son had diabetes, knew that the symptoms were not typical of diabetes either. Eventually Richard was referred to a consultant sympathetic to ME sufferers, who diagnosed him as suffering from Chronic Fatigue Syndrome. Since July, Richard has found that he can do a little more each day, but he has to pace himself. He is now back in the position where after a little exercise his blood sugar goes down and he can eat a little extra. But if he overdoes it, he starts feeling very tired, and notices that his blood sugar is 17 mml instead of 7 mml. (*Normal blood sugars are 4 to 7mml/l*) After some rest it returns to normal again. Richard's company has been supportive and he is still on full pay. He hopes to start work again soon for one or two days a week, but is very conscious how tiring mental activity and stress can be, and how important it is not to do too much too soon.

Annes Story: "Extreme fatigue is not something that doctors take seriously in single women," says Ann. She started getting the ME symptoms in 1981 after an attack of summer flu, and in the following months her diabetic control became erratic. She had periods of high blood sugar which would last for days, and which she could not control by increasing her insulin or by eating less - interspersed with days of frequent hypos. She had not heard of ME, and continued to fight the tiredness without resting. She had further flu attacks every three months, but did not take time off work. Eventually, increasing muscular pain in her feet and legs forced her to rest at all possible times. Her sugar balance improved but her quality of life did not. In 1985 she retired, and though she has had every opportunity to rest and recover over the last few years she finds her 'fit' periods are becoming shorter.

Could insulin dependent diabetes and ME be related? Virologist Professor Banatvala of St Thomas' Hospital says there is no evidence but points out that both may be caused by viruses. "The virus that we know can cause diabetes is rubella: mothers may develop it and transmit it to the

foetuses," he says. "The baby may be born with one or more manifestations of infection by rubella but the diabetic state doesn't develop until the second or sometimes third decade." Another possible cause of diabetes, and a virus well known to be involved with the development of ME, is the Coxsackie B virus. "A great deal of excitement occurred many years ago following the publication of a few cases of infants who were known to have had a Coxsackie B virus infection who then went on within a short time to develop diabetes," says Professor Banatvala. "But I think this is an unusual and un-expected finding which we mustn't put too much emphasis on because we know that the incubation period is a long one."

The Barts-Oxford Family Study is endeavouring to find out whether the Coxsackie virus initiates the train of events that subsequently result in the diabetic state developing, or whether it only precipitates the disease in people whose pancreatic tissue is already damaged for one reason or another. As research discovers more about the "" ability of enteroviruses to cause long term conditions like ME and diabetes" as well as short term infections, some link between the two disorders may well emerge. In the meantime, those who suffer from both struggle to cope.

Carol has lost her job and had to give up most of her interests. While she was upset at being diagnosed diabetic as a young mother many years ago, she r says, she found it easy to adjust and, cope. Not so now: "ME/CFS is not so much an illness as a devastation of normal life. With diabetes and ME I sometimes feel like a time bomb ready to go off." She has to go to bed at night with particularly high blood sugars in order to avoid waking early with a hypo.

Vivian's Story. Vivian has found that as her ME has got worse she has had to increase her twice daily insulin to cope with her lack of exercise. It has also caused extreme mood changes, and when she gets hugely depressed she needs to take more insulin still. At present she is virtually housebound and almost totally inactive. She has not been to the diabetic clinic since developing ME, partly for fear of what the specialist might say and partly because she finds clinic visits too tiring and is unwilling to make herself worse.

Christopher's Story: Balance reader Christopher recounts his own experience of living with ME and diabetes. As a fairly well controlled diabetic for nine years, I had always thought of myself as a fit and active 22 year old. So why, after a night out with friends, did I suddenly feel so exhausted and ill? My blood sugars were unexpectedly high and I felt physically and mentally drained. My girlfriend, Donna, claimed it was a combination of drinking too much and too many late nights. Over the next two weeks, I began to feel increasingly worried that maybe something a little more serious than a flu bug or infection was the problem. The symptoms were more pronounced - extreme dizziness, headache, nausea, muscle pain, rapid mood swings, total exhaustion and the feeling that I was actually going mad.

To actually describe what I was going through proved difficult, because I simply didn't know where to start. The doctors were confused and a simple solution seemed to be to blame my diabetes for the problem, but I knew from day one that the problem lay elsewhere. My symptoms seemed to be worsening and my blood sugars were high one minute and low the next. Donna was getting very worried and came along to see my GP with me, because I felt as though I was there in body but not in mind. I remember thinking that the lights in the doctor's room and the noise outside would make my head explode. Little things like a baby crying or cars driving past would send me into disarray. Eventually, three months later, the emergency doctor had to be called as I awoke one morning feeling so ill that I could hardly move. When he arrived, all he did was reprimand me for calling him out. Apparently I was only suffering from post-viral syndrome, and on that note he hurriedly left

Feeling like death, it seemed to me that I had been totally deserted by doctors. Donna was furious so the next day she went with me to the doctor again to find out what exactly post viral fatigue was. This time I was seen by a very nice locum doctor who told me I had classic symptoms of ME, which is otherwise known as post viral fatigue or chronic fatigue syndrome. I came out of the clinic feeling somewhat happier as I finally knew why I had been feeling so dreadful. I then began the process of reading and talking to as many people as possible to try and find out more about ME. Whilst visiting the library I met a lady who had had ME for seven years. When she told me that I had a good chance of recovering within two years, I was totally stunned. The thought of possibly having ME for a further year and a half, seemed unbearable. Now, eighteen months on, I hope she is right. One mistake I

made was to think that all medical professionals would be aware of ME and know how to treat it. On one occasion an ambulance had to be called as I was being violently sick and had severe pain in my muscles. On arriving at the hospital, a nurse asked me what the problem was. I told her I had ME and diabetes. She asked me what ME was and placed me in a cubicle to wait for someone to see me.

I started to feel very sick and tried to stand up to get the nurse's attention, so she could find me something to vomit into. I simply could not stand and I fell to the floor. The nurse marched up to me and told me to stand up and to stop making a fuss. As the result of a blood test she had taken showed that my diabetes was fine, she said there was nothing she could do. She ordered me to leave as she had a lot of people waiting. Donna and my flatmate, John, had to help me to the car. At times like this, when you are made to feel like a timewaster and a hypochondriac, you need someone around you to tell you that what you are feeling is not just in your imagination, and to give you support.

My self-confidence was probably one of the first things to be "destroyed", but despite these setbacks, I think I have just about managed to regain it. My diabetes specialist has changed me over to a different insulin pen (a syringe in the form of a pen for patient convenience) which has helped my diabetic control, as I sometimes need to inject nearly twice as much as I did the previous day. Even so, I now feel I am coming to terms with having both ME and diabetes even though occasionally it is still difficult.

Work is not yet possible. I was training to be a hairdresser, but wouldn't dream of trying to cut hair as I am now. Any work plans I had will have to be put on hold until I am well again. I had hoped to be getting married this year, but felt it would be rather unfair to expect Donna to start married life looking after me and struggling for money.

As conventional medicine has not helped me much, I have also tried complementary therapies. I found aromatherapy particularly useful. For the first six months the Bristol based ME charity, Westcare (Now *adsorbed into of Action for ME*), gave me invaluable help with counselling and made me appointments with a private ME specialist. All this was on a donation only basis. Finally, there is still far more that the medical profession could be doing to help people with ME. I feel that they need to be more aware and accepting of the condition and understand that the combination of diabetes and ME can be dangerous. So, a big thank you goes to my family and friends who must also come under the heading 'ME sufferers', especially Donna, who has put up with so much and wants so little in return. "

For me personally, when this feature appeared, it gave me the key to dealings to many of the problem I was experiencing. Mike.

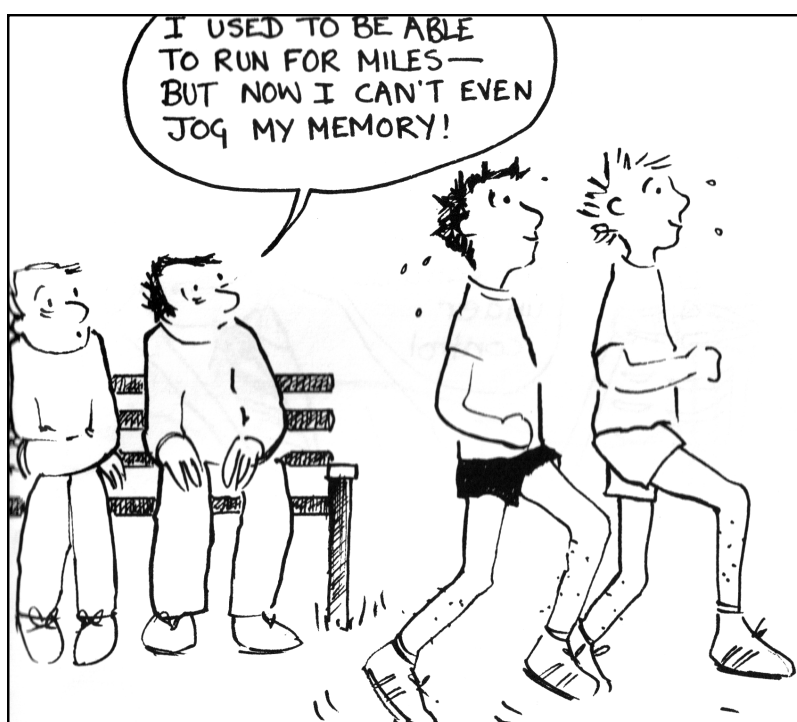
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email our Information and Support Officer:
For information about M.E. www.actionforme.org.uk



Out and About: A Review of Belsay Hall Castle and Gardens

On a July afternoon while on holiday we decided to visit Belsay Hall Castle and Gardens. Belsay is not local to us but around 14 miles NW of Newcastle, on A696. We put the postcode NE20 0DX into the satnav system in the car to get us to the gate of the Belsay estate. After that it was a long uninteresting drive to the Hall site which is badly signposted. The main car park is located next to the entrance to the site, as well as two overflow car parks which are located further away from the main entrance. Blue Badge Parking is available in the main car park, which is close to the tea shop. Overall we were unimpressed by the arrangements. Although the disabled car park was next to the tea room, the actual entrance to the estate was through the stable block complete with uneven cobbled paving which did not help our cognitive problems. There is then a long walk of several hundred yards to the Hall itself.



The hall itself has features similar to the local Brodsworth Hall; but unlike Brodsworth there is no golf buggy type shuttle. The biggest disappointment was on entering the magnificent hallway complete with Greek style columns. The rooms were bare, devoid of contents and much of the wood panelling had been removed. It was



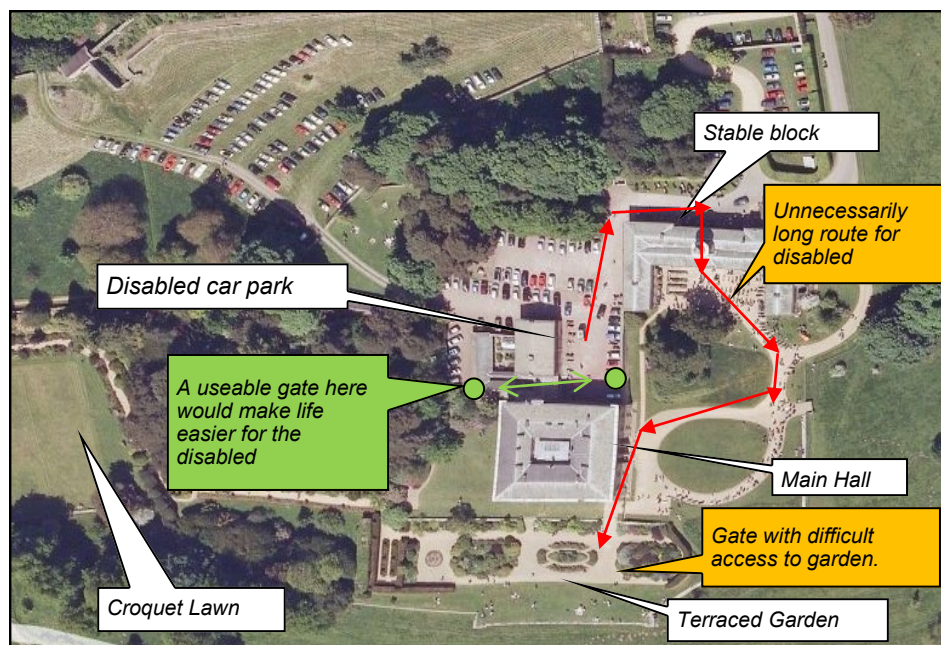
nothing like the pictures in the glossy full colour guidebook we had purchased from the stable shop. We were told that this is a conservation measure to stop dry rot.



So we explored the terraced garden on the south front. There were steps and a gate to negotiate. For anyone with a wheelchair there would have been major difficulties. We found nothing impressive in the garden.



Following on to the Magnolia Terrance was equally unimpressive. We reached the croquet lawn and sat and watched the local team play croquet. Further on is the quarry garden and castle—but that was when the ME/CFS kicked in. We just wanted to get back to the car and go home. The map showed a way to the car park. However there was a very heavy padlocked gate blocking the way – so the only way was a long trek back via the terraced garden hall and through the stables.



On leaving, we felt very angry and disappointed. With the bare hall and then the poor state of the gardens and blocked exit to the car park, and poor overall disabled facilities. Had we not been English Heritage Members and got in free I certainly would have been even more livid. I felt that this was the worst property we had seen.

Verdict: ME unfriendly: Avoid if you have any sort of disability.

English Heritage has been forwarded a copy of this feature. If a reply is received it will be published in due course. Mike.

North of Doncaster *Personal Comment by Trevor Wainwright***Travel diary: American 2015 Poetry Tour part 1**

Last year's poetry tour got off to a bad start due to fog at Leeds Bradford Airport meaning a day's delay and a rearranged flight from Manchester. This year I decided to fly from Manchester again, the advantage being it would still be daylight when I got there. This meant I could do my first gig on my first night there and so it was arranged. I flew from Manchester to Heathrow, and then to Austin where I went through the quickest customs clearance ever a matter of 'scan your four answers' No's to four questions pick up the receipt and your luggage. Taking the receipt and on flight declaration to the desk a quick photo and, hand them to another officer "welcome back to Austin" he said, on hearing it was my 5th trip, and that was it, we were through, collect my car and away, it was a Ford Focus.

After dropping my luggage at the motel, the evening began and at last I could recite a poem I had been planning to since last year about an 11 year old boy who was refused entry to Omaha Beach War Cemetery on June 6 so he took his World War II USA flag to Omaha Beach and paid his tribute there, my original plan was to recite it holding the American Flag in my left hand as he did, recite the poem and at the end bring my right hand up in salute. Tom had forgotten the flag so I told the audience to imagine it was in my hand, and began. A silence fell as I recited it; it was as the words were being drawn from me. At the end the applause was fantastic and more poems followed ending with 'Along the Texas Coastline', based on the Yorkshire folk song "Out along the East Coast", like the Saluting Boy it was written last year and also went down great. We had a break, I did a few more poems, and then it was time for me to turn in.

Sunday night was the first of four appearances at what is known as *you are about to witness the best*, the baddest open mic in the ATX, spoken and heard LIVE every Sunday night at Kick Butt Coffee Music & Booze!" and they do a great choice of smoothies for teetotal me. Once again I opened with the saluting boy this time with the flag; once again it went down great as sound man Ernie B said when he passed me "Awesome Trev" patting me on the shoulder.

Monday I began live telephone broadcasts to KPET Radio in Lamesa. I would do these every Monday Wednesday and Friday mornings promoting their 'Forrest Fest' usually about 9:30 from wherever I was. Monday night should have been an open mike at Austin's Irish Bar B D Riley's I had performed there two years ago and gone down great, but sadly it was not to be as my tyre blew out and then the fun began. Getting out of the car to check the damage I shut the door and locked myself out. Luckily help was at hand, some kind passer-by had called the fire department who turned up to help, and on hearing I was a retired firefighter they did everything for me then, it was back to the car hire place to change it, for another Ford Focus. All went well until Wednesday morning when going for breakfast I was rear ended, we swapped details and another car exchange, this time it was a Ford Fiesta

USA radio stations have a four letter designation beginning with 'W' or 'K'. KPET (690 AM) is an independently owned and operated radio station licensed to serve Lamesa, Texas, USA. The station's 280-foot tower is located at the south edge of the

Thursday and after my stint at AWR. I went to register for the Austin Festival and to pick up my badge, programme, and anthology in which was a poem about feeding the smaller animals at AWR, and hopefully some events but we were disappointed as the opening event clashed with others. At the event. The reading I was to be hosting only one other person turned up, the rest seemed to be at the opening event. Other readings fared the same. At the opening event there was nowhere to park so I headed to the library to catch up on my emails. Opening Facebook, I saw a video of Louie out Boston Terrier frolicking on the beach at Filey. I immediately messaged back "he's having a better time than me"! one good thing I did read was that my 'phone broadcasts were having the desired effect in Lamesa the presenter Don was highly amused and people kept mentioning it to Connie.

It would be late that night before I got chance to recite at a place called Mr Catfish where yes they did serve it and as usual it was nice except I'd forgotten my malt vinegar but my poem about the saluting boy went down well. Then it was back to the motel to see what the following day brought.



1. My second car, the first one was similar



2. My third car, the Fiesta



3. Reciting The Saluting Boy.



Closing a recital at Kick Butt



Left. With Minor Keys
Right. Two Austin FD tee shirts I swapped one of my WY Fire Service ones for, not a bad deal
Below. A touch of Texas humour



Cafe 1886 house special "yummy" baked in house using only local produce

This time an internet link up with London, when we finally got the problems ironed out, I featured in the flash round at the end where I was able to acknowledge the Derbyshire Bard and friend Matt Black, who was over on London. Later it was back to another venue and another non-event. Thankfully due to the programme I did find another open mic, and once again was able to perform and hopefully things would improve tomorrow!

No such luck, the first place was double booked, no chance there, the second place a herbal tea Shop the Black Butterfly had been cancelled but the staff asked to hear my work, I was pleased to read it, they enjoyed it so I got a free cuppa out of it. Moving to another venue a short walk away that too was cancelled so it was back to the Black Butterfly where there was supposed to be another event, at least three of us turned up so we had an impromptu jam session and enjoyed it, but the disappointment was still there at the lack of communication.

The problem had seemed to be that the featured poets were given prominence, with meet and greet events; many of us thought all should have been treated as equals. They had brought in a special poet as a featured guest the cost of which was supposed to have been met by ticket sales. Some of us who had received free tickets fancy gave ours away, we weren't into single person events, particularly if we were not that person.

The programme showed an even at a place called 'Dominican Joe's'. I went there and to my surprise it went well, initially outside but, it began to rain so we ended up inside and it proved to be the best open mic yet, I was still writing poetry about the entire festival capturing it all in rhyme. There was even better to come when it was the midnight to dawn event Tom organises it every year. This year it was at the 'Full English', an Austin Cafe based on a cafe in Bradford. It went well, all we had to do was join the queue and wait our turn, this year there was at least 26 remaining by the time the event was over and we had heard a great variety of others poets works, what a shame the rest of the festival hadn't gone like this I thought heading back to my motel.

Later that afternoon after a rest I was off to a place called 'Stomp'n' Grounds'. Another regular event in the calendar and another that went well. This was followed by the final event at Kick Butt which got off to a late start due to the Festival Committee having a meeting there, but for those of us who were dismayed at this year's festival it gave us a chance to put forth our comments with suggestions for next year, then the final event got underway, and finished slightly early as the events of the previous night caught up with us.

Monday and I finally made it to BD Riley's the MC was called Joe I signed up as Trevor, he asked "Trevor who?" I said "from England", he asked "Is that your second name?" but that was it I was on the programme. The featured act were 11 year old twins, a boy and a girl called Minor Keys, the girl was strumming a guitar and it was obvious she had talent, then they started and the moment her brother touched the keyboard his talent was obvious, they were fantastic. I found myself writing a poem about them, and after wards I was able to talk to them and their parents promise to send them a copy of the poem, I was also allowed to have my picture taken with them and given permission to post it. It was my turn to take the stage; I began as usual with The Saluting Boy then the poem about Minor Keys, using the 11 years old denominator to great effect. My third poem was 'Along the Texas Coastline', about my 2012 tour and based on the Yorkshire fold song 'Out along the East Coast', then ended with Mr Poetry Man, a poem based on Billy Joel's Mr Piano Man the song Minor Keys had ended with. I left the stage to great applause, handshakes and comments of "well done" and "awesome".

Wednesday morning was my last telephone link up with KPET in Lamesa. Thursday morning I was on my way there, leaving at 6:30 am I would be there in time for lunch, catch up on the plans and to do a live broadcast from KPET, knowing full well the next event would be better organised.

To be continued in the Next Pathways. Trev

PIANO MAN

Words and Music by
BILLY JOEL

Moderately

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