OXFORDSHIRE MYALGIC ENCEPHALOMYELITIS GROUP FOR ACTION
OMEGA ME

Omega Newsletter

Volume 85 Spring 2014

No Myths, No Buts

This edition of the newsletter has a special focus on health – always an important issue for someone with ME and/or CFS. It examines some of the myths about ME (page 3), as well as providing a detailed explanation on blood tests and what the results can mean (page 7). One of our members has referred to a previous newsletter article, *The Art of Letting Go*, and has described what letting go means for her and her health and well-being (page 2).

If you are looking for support and healthcare, OCCMET has a new name and new programmes (page 13). Anne Silk's article (page 2) also provides some hints and advice for getting a better night's sleep.

We would also like to draw your attention to Paul Davies' sponsored walk, which is being done to raise funds for OMEGA. Please see page 15 for more information, and use the provided sponsor forms if you would like to show your support.

There is plenty more to discover in this edition – we hope you enjoy it. Happy reading!

Contents

Report from OMEGA Committee Plus Meeting of 22nd Feb 2014

Children and Young People's Campaign

This committee is sending packs to sixth forms, further education colleges and private schools. Volunteers Una and Matt are helping with this, and a briefing from TYMES Trust will be included. The online survey about experiences with services (see www.oxnet.org.uk/omega) is still continuing.

OMEGA Vacancies

There was a lot of interest expressed in the Committee Plus meeting. However, none of the members present felt able to take on any of the vacant posts, so we are still looking for:

- **Chair of OMEGA**
- **Commissioning Editor for Newsletter**

Luisa has been doing a brilliant job as Commissioning Editor. Unfortunately she has moved to Suffolk and is unable to continue. We wish her well, and are very grateful for her efforts.

- **Treasurer**

Thanks to Cathy for stepping in to fulfil this role for the time being.

Date of Next Committee Plus Meeting:

Saturday 6th September 2014 2-4pm at North Oxford Association Community Centre in Summertown.

Pat Williams

Digital Enhanced Cordless Telecommunication System

We are all familiar with allergic response – for some it is to peanuts, to others it may be pollen, and there are many other triggers. But there is as yet in medicine, a little considered response to pulsed or iterated signals which comes under the heading of 'Resonance Migraines' or 'Migraine Variants'. In the USA this is known as 'Flicker Illness'. However in this 21stC we are not only subjected to visual flicker from fluorescent lights, computer screens, certain linear patterns but also pulsed signals generated by much modern electronic equipment from radio frequency and microwave sources, for example DECT phones.

Do you have a DECT phone as well or instead of the BT land line phone? This stands for Digital Enhanced Cordless Telecommunication System and it consists of a fixed part (FP) known as a base set and a Portable Part (PP) known as a cordless handset. The DECT base set continually transmits 24 hours a day Ultra High Frequency radio signals (UHF) up to 300m from the set itself. Further, it will adjust its power to the reception conditions in a room, on a desk, in a bedroom, or wherever.

The human body acts as a half wave dipole and in addition the human brain will resonate at specific frequencies.

So if you are not sleeping too well, or children get irritated for no reason, try these two simple experiments.

Take a small compass and place on a flat surface. Note where North is. Now bring the hand set over the compass, first holding it flat then vertically – watch the compass needle spin and oscillate between 45° and 180°. Then make a call and again watch the effect of the magnetic field on the dial. See how far away the effect can travel.

Try reverting to the BT landline only for a month – disconnect the DECT. Note how sleep improves, especially in those where the DECT is in a bedroom.

Very similar effects can be seen with other electronic hand-held systems, smartphones, laptops, iPads. Do you really want a pulsed magnetic field by your head? Especial caution should be used charging mobile phones near the bed – don't do it! Melatonin levels can be affected also REM sleep brain waves. You have nothing to lose by trying the two experiments above – 18 cases known to me were happily surprised by the difference a DECT-less house made to sleep, head pains and well-being.

The electronics company Siemens have produced a new ECO-DECT phone system which has severely reduced the emissions from the unit when it is not in use and this type should be considered when purchasing new equipment.

Anne Silk

The Art of Letting Go

I really enjoyed Lisa Lorden Myers' article *The Art of Letting Go* in the Winter issue of the Newsletter. I'm sure it's key to coping with the illness and I only wish I'd understood it 25 years ago. Exhausted muscles and brains cry out for rest – that is exactly what they are trying to tell us. No one in their right mind expects to do a full day's work while in the grip of full-blown flu.

What interests me is why we don't or can't 'let go', and I think there are a number of good reasons for this. We all know how difficult it is to have to drop out of everyday society – to lose work, friends, identity: which is what 'letting go' can often mean. The current cultural cliché is one of 'fighting' illness, of not 'languishing' on benefits and of 'pulling oneself together'. Once you've worked through all these layers you're left with the psychological and physical reasons for not being able to 'let go'.

Of course doing little is very boring, but it also opens one up to the grief and loss that the illness brings, and I know I kept pushing myself because it was hard just to sit and let the dark flood in. But there was something worse than this: ME kept me wired. It made me tense, anxious, sensitised – totally reactive (I suppose all these come under the umbrella of 'depression', but I think it sometimes helps to separate out the individual elements). I couldn't let go because I was tense with exhaustion. I was anxious at losing my grip, and so I did more. And the more I did, the harder I found it to relax because I was so wired* and, losing all

objectivity through exhaustion, I went on doing more. Physiologically, as we know, ME is a total own goal.

I came to understand better what was happening a couple of years ago, when I had treatment from Frank Ludlow (frankatmead@aol.com) in totally detoxifying my body. In one treatment the asthma virus was killed off and I could breathe. And all the parasites, viruses and what-have-you that I had been battling were eliminated. The tension, depression, gut pain and flu-like feeling left, and I was able to relax, to 'let go', almost for the first time. I had forgotten what it was to walk around without a stifling dark overcoat over my head. That, and the pain of course.

The neurological symptoms remain (photo-sensitivity, weakness, poor memory), but the ill feeling that had arrived in me and stopped me from letting go had gone. So now it's *all* about letting go... Well, I'll try.

*My adrenal glands were overworking and sometimes flooding me with 'fight or flight'.

Susie Geddes

Shooting Down the Top 10 Myths from the NHS Online Clinic

From the Phoenix Rising website. (See the Winter 2014 edition of the Newsletter for Part 1). September 6, 2013.

PART II – The Top 10 Myths, In Reverse Order

Myth #10: Everything in The Lancet can be trusted

Jessica Bavinton: 'Nothing gets published in The Lancet unless it's very rigorous and checked out thoroughly.'

It is indisputable that controversial papers have been published in The Lancet in the past, with content which was later seen to be less than trustworthy. This casts considerable doubt upon the basic premise that everything in The Lancet has been thoroughly and rigorously reviewed. The most famous example is the 1998 study by Andrew Wakefield suggesting a link between a vaccine and autism.

And for an example directly involving the PACE Trial, a successful complaint against the Lancet was brought before the Press Complaints Commission (PCC) by the Countess of Mar. Regarding the report of a 30% recovery rate, the PCC found that '[t]he journal had failed to take care not to publish inaccurate or misleading information in breach of Clause 1 (i)'. While this breach had already been corrected via the publication of an external letter addressing the point, the case illustrates that The Lancet can and does err.

It also illustrates the importance of carefully reading the entire publication, instead of relying on headlines and summaries, and the importance of permitting civil debate regarding publications.

Myth #9: TYMES Trust recommendations do not follow NICE guidelines

Dr Caroline Grayson: 'I note that there has been previous recommendations to consult the TYMES Trust and I want to clarify that the recommendations from this organisation do not follow NICE guidelines and I do not endorse their approach'.

This statement originated after the parent of a child asked for an expert opinion about his daughter, previously diagnosed with CFS, having that diagnosis removed by a paediatrician. The child had been diagnosed with CFS several years earlier, but the paediatrician was now claiming that she had cured the child of her CFS, and what remained must be a dissociative disorder. The parent was rather confused by this, as the child's symptoms had not changed.

Someone suggested contacting the Association for Young People with ME (AYME), and then someone else suggested the TYMES Trust when the father of the child responded that AYME was unhelpful in the past.

That is when the accusation was made that the TYMES Trust are not in line with NICE. Unfortunately this is too large of a subject to explore completely, but Executive Director Jane Colby of the TYMES Trust came to the clinic to post a response, claiming that NICE had actually taken the advice of the TYMES Trust in its section regarding education and related issues for young ME/CFS patients. Indeed, the sections (1.4.5.5 and 1.4.5.6) of the NICE ME/CFS Clinical Guideline relevant to children, seem to be very

similar to what was being suggested by the TYMES trust.

While it is possible that there is some material elsewhere indicating a deviation from the NICE guidelines by the TYMES Trust, it is not readily apparent. Furthermore, the expert did not specify what might be the specific subject of such a disagreement, despite being asked for clarification. But if NICE has followed the recommendations of the TYMES Trust, it seems unlikely that any such a rift exists as was claimed by the expert.

Myth #8: Muscle function is normal

Jessica Bavinton: 'However, once scientific studies have taken into account deconditioning and abnormal perception of effort, muscle function is in fact normal'.

This seems to be a common argument by those who favour psychological explanations and treatments for ME/CFS. And, indeed, some studies have found that some aspects of muscle function are indeed normal for ME/CFS patients. However there are many more studies which have repeatedly found indications of various abnormalities in the muscles of ME/CFS patients.

These abnormalities include excessive intracellular acidosis, Type II muscle fibre predominance, Type II muscle fibre dystrophy, muscle fibre necrosis, "bizarre tubular structures", mitochondrial abnormalities, enterovirus RNA in skeletal muscle, decreased intracellular RNA suggesting "impaired capacity to synthesise muscle protein", mitochondrial pleomorphism, and accelerated glycolysis. Many of the authors of these studies have made statements indicating that these abnormalities are not compatible with deconditioning models.

Myth #7: PACE shows that CBT and GET are as safe as pacing or standard specialist medical care

White, Sharpe, Chalder: 'There were no significant differences in any of these safety measures across the four treatment arms'.

This is somewhat difficult to answer, as the people making this claim have also been successfully fighting to withhold the deterioration data from the PACE trial since publication. However, the initial results of the PACE Trial state that GET patients experienced significantly more Serious Adverse Events (SAE) than the patients in the pseudo-control group receiving only specialist medical care (SMC). But the trial arms of the participants experiencing SAEs were then unblinded, allowing the researchers to determine if they felt that each SAE was related to the treatment, and thus constituted a Serious Adverse Reaction (SAR) to the therapy. Rather oddly, at that point GET went from producing 2.4 times as many SAEs, when compared to SMC, to producing exactly the same number of SARs as SMC.

While there is a vague promise to eventually publish more detailed deterioration data in response to Freedom of Information requests, it is doubtful how useful that information will be. Essentially PACE created two categories, one for SAEs, and one for non-serious adverse events (NSAE). A sizable flaw is apparent with the definition of these categories: to qualify as an SAE there must be a death, hospitalization, or drastic decrease in condition lasting at least a month. Everything else would be classified as an NSAE, ranging from feeling a little sore after exertion to being bedbound for several weeks. Thus there is currently no way to know how many of the CBT and GET participants with NSAEs had multiple severe episodes of post-exertional malaise.

Fortunately the harmful effects of CBT and GET have been studied elsewhere, and illuminate the issue. Tom Kindlon discusses the problems with the PACE Trial's adverse events reporting in great detail in his Harms paper. Dr Shepherd posted the results of a large ME/CFS patient survey at the clinic forum, which shows that 56.5% of respondents felt worse after GET, compared to 4.7% feeling worse after pacing.

Myth #6: Muscle pain is presumed to be harmless

Jessica Bavinton: 'There is no evidence to suggest that the muscle pain associated with CFS/ME is as [a] result of any harm being done to the muscles themselves'.

A lack of evidence of harm is not evidence of a lack of harm. Indeed many studies have found indications of potentially painful abnormalities in processes which might result in harm, and

abnormalities in structures which might or might not have resulted in pain.

As a specific example, the expert's claim can be disputed by a study conducted by Jammes, et al, which found "lengthened and accentuated oxidative stress" in ME/CFS patients after incremental exercise, compared to controls. This oxidative stress could be responsible for both pain and cellular damage, which suggests that the muscle pain experienced by ME/CFS patients after exertion may very well not be harmless after all.

Myth #5: If you have any abnormal blood tests, you don't have ME/CFS.

Dr Caroline Grayson: 'I am unsure what the specific abnormalities in your son's blood tests are but for a diagnosis of CFS/ME there has to be no evidence of any other cause for the symptoms such as infection or inflammation'.

Dr Caroline Grayson: 'I am unsure what the abnormalities are in your son's blood tests are as I would expect that blood tests should be normal for a diagnosis of CFS/ME'.

It's hard to imagine how such ignorance has managed to survive for so long, in a licensed ME/CFS paediatrician. First of all, it should be obvious that there can be abnormalities in the case of co-morbid disorders. This means that someone has two or more illnesses for the symptoms of ME/CFS. A co-morbid illness would present symptoms separate from, and in addition to the symptoms of ME/CFS. But the ME/CFS symptoms would remain after the other illnesses were successfully treated.

Then we have the thousands of research papers actually finding indications of various objective abnormalities in ME/CFS patients, a great many of them showing up in blood tests – albeit usually not the blood tests on the rather abbreviated list recommended by NICE. Common issues pop up like vitamin D levels often getting low, possibly due to reduced exposure to UVB resulting from decreased mobility in housebound patients. Hence when the side effects of being very disabled result in an abnormal blood test, it wouldn't make much sense if the blood test excluded an ME/CFS diagnosis.

Now that we've covered the basics, let's set down the Oxford Handbook for ME/CFS Denialism and look at some internationally recognized definitions of ME/CFS to see what they say about abnormal blood tests. Even the Center for Disease Control (CDC) admits that there are co-morbid diseases which ME/CFS patients are more likely to have, some of which are diagnosed by blood tests. And if you look at the definitions favoured by many ME/CFS patients and most experts, the Canadian Consensus Criteria (CCC) and International Consensus Criteria (ICC) primers each list dozens of common abnormalities, many of which are found via blood testing.

Myth #4: PACE shows that 60% of patients improve with CBT or GET

White, Sharpe, Chalder:' About six out of ten patients made a clinically useful improvement in both fatigue and functioning after CBT or GET'.

Unfortunately this is rather misleading. While 59% of CBT patients and 61% of GET patients in the PACE Trial did give minimally better responses on two of the questionnaires used, so did 45% of the control group, which received only standard specialist medical care (SMC).

Because the CBT and GET patients also received SMC, determining the rate of improvement solely attributable to GET and CBT requires an accounting of the rate of improvement attributed to the SMC-only group. Therefore the improvement in only 14% of the CBT patients and only 16% of GET patients can be attributed solely to those therapies, after SMC is removed from the equation.

Another problem is that PACE used the Oxford definition of ME/CFS when recruiting patients. Because that definition only requires unexplained chronic fatigue for a diagnosis, it cannot be extrapolated that the PACE trial is applicable to ME/CFS patients as defined by more rigorous criteria.

It's also important to note that the modest rate of "improvement" for chronic fatigue patients was completely subjective and quite small. Instead of using objective measurements like actometers, a walking test, welfare benefits, or employment outcomes, the authors chose to

rely solely on responses to questionnaires when determining improvement.

And on those questionnaires, a difference of only two points was needed on one scale (range of 0-33), and 8 points on the other scale (range of 0-100). Thus it would be much more accurate to say that CBT or GET results in about 15% of chronic fatigue patients saying that they feel marginally better after a year of treatment.

Myth #3: Muscle pain is due to deconditioning.

Jessica Bavinton: 'Muscle pain can be, as in your case, a significant issue for people with CFS/ME. People tend to find it may have a generally constant impact, but gets worse: . . . When resting too much, or being 'under-active' as the muscles weaken considerably making it much harder to do things'.

As usual, this claim as applied to ME/CFS is a baseless theory favoured by a small group of researchers. From a patient perspective, it is generally easy to distinguish between ME/CFS muscle pain and the pain which comes after exerting muscles which have not been used recently. The deconditioning pain is generally quite brief, localized, and even pleasant compared to the muscle pains caused by temporarily exceeding limitations or coming down with post-exertional malaise. So although it is not disputed that deconditioning does cause pain when muscles are re-engaged, it is almost certainly not causing the chronic muscle pain most associated with ME/CFS.

Furthermore, some of the studies investigating muscle abnormalities have made discoveries which indicate an alternative and more plausible source for the cause of ME/CFS muscle pain. One such study shows patient muscle cells producing 20 times as much lactic acid in vitro as the muscle cells of sedentary volunteers, an abnormality which has been observed repeatedly to some degree over the past few decades.

Another study shows that ME/CFS patients have increased sensory, adrenergic, and cytokine gene expression corresponding with pain and fatigue after moderate exercise, compared to controls who had no such abnormalities. There is no indication that all of these abnormalities can be attributed to deconditioning.

Myth #2: A child with ME/CFS who is having seizures primarily needs psychological treatment

Paediatric Medical Question: 'He started having seizure-like episodes early in 2012, with whole-body convulsions etc. . . .'.

Dr Caroline Grayson (entire initial response): 'From your post I am unsure whether your son is accessing any specific psychological support with his symptoms. I have certainly seen similar presentations in young people and in these cases I have sought psychological support'.

Although the expert did eventually qualify her initial statement after it generated considerable outrage, it is still incomprehensible that the first reaction to someone asking about convulsions is to suggest psychotherapy. Exactly what does this expert think that ME/CFS is?

Even NICE (1.2.1.4) concedes that: '[s]igns and symptoms that can be caused by other serious conditions ('red flags') should not be attributed to CFS/ME without consideration of alternative diagnoses or co-morbidities. In particular, the following features should be investigated: . . . localising/focal neurological signs . . . signs and symptoms of cardiorespiratory disease. . . .'

And a response from Dr Miller in the Adult Medical section of the clinic forum was also rather topical: 'the important thing is to have any new symptom assessed on its own merits and not just attributed to –"'of, of course, it's due to the ME" '.

Myth #1: GET increases activity levels.

Jessica Bavinton: 'GET is exactly designed to support people becoming more active over time. We know that becoming gently and sustainably more active seems to be an important component in any therapy that has shown effectiveness in CFS/ME'.

No studies support this claim. PACE and most other trials involving GET or CBT-including-GET do not use actometers or other objective measures to determine if activity levels increase. A notable exception to this is a series of three Dutch studies where many ME/CFS patients were declared to be improved based on questionnaire responses after CBT-including-GET.

Little mention was made of actometers in these studies, until a fourth paper was released, showing that the "recovery" on questionnaires was not matched by any improvement in activity levels as measured by actometer in any of the three trials.

Brain Fog!

Three ME/CFS patients were discussing the travails of brain fog.

One said, 'Sometimes I catch myself with a jar of mayonnaise in my hand in front of the refrigerator and can't remember whether I need to put it away, or start making a sandwich'.

The second chimed in, 'Yes, sometimes I find myself on the landing of the stairs and can't remember whether I was on my way up or on my way down'.

The third one responded, 'Well, I'm glad I don't have those sort of problems, knock on wood', as she rapped her knuckles on the table. Then she said, 'That must be the door, I'll get it!'

Submitted by Tricia Barnett

Blood Tests Explained

This article by Dr. Charles Shepherd originally appeared in the winter 2014 edition of The ME Association's magazine, ME Essential, and is reproduced here with their kind permission. Copyright remains with the ME Association and no further reproduction is permitted without their express consent.

Human blood contains red cells, white cells, platelets and plasma. Red blood cells carry oxygen around the body – so a deficiency or abnormality will probably cause anaemia.

White blood cells help to fight off infections and respond to allergies. They are sub-divided into cells called basophils, eosinophils, lymphocytes and neutrophils – each with a slightly different function.

A rise in the overall number of white cells usually indicates the presence of infection or inflammation somewhere in the body. A decrease in the white cell count may mean that your body isn't so good at fighting infections. Causes of a low white cell count include drug side-effects and diseases involving the bone marrow, where white blood cells are made.

Platelets help to form blood clots and prevent bleeding. So a platelet deficiency can cause a problem with excessive or prolonged bleeding from a wound site.

Human blood also contains a wide variety of immune system products (e.g. antibodies), enzymes, hormones and proteins that are made or excreted by various organs and tissues in the body.

Laboratory analysis of a small sample of blood can, therefore, reveal a great deal of basic information about your state of health and the function of various organ systems.

Is there a diagnostic test for ME/CFS?

The simple answer is no. An "ME blood test" seems unlikely to be developed in the foreseeable future.

Minor blood abnormalities can occur in ME/CFS but none of them are sufficiently consistent or robust to turn them into diagnostic markers.

When we understand more about the basic underlying pathology of ME/CFS, possibly as a result of new research taking place at the ME Biobank, it is possible that a diagnostic test will then emerge.

Blood tests and ME/CFS

Everyone should have a number of routine blood tests before a diagnosis of ME/CFS is confirmed. This is to help rule out conditions that can also produce fatigue and other ME/CFS-like symptoms. The routine tests that make up this list are:

* Full blood count: red cells, white cells, platelets etc.

* ESR and CRP (C-reactive protein).

* Biochemistry screen – including electrolytes, calcium and urea.

* Blood glucose – for diabete.s

* Coeliac disease screening – IgA anti-tissue transglutaminase antibodies.

* Creatine kinase – for muscle diseas.e

* Creatinine – for kidney function.

* Liver function tests.

* Thyroid function tests

* Adrenal function – 9am cortiso.l

Depending on the results and/or the type of symptoms that are occurring, a number of other tests may be also necessary. These include tests that check for:

* Infections such as HIV, hepatitis B or C, Lyme disease.

* Rheumatic conditions such as lupus/SLE.

* Vitamin D deficiency – which can occur in people with ME/CFS who lack exposure to sunlight.

There are also a number of private (i.e. non-NHS) tests that are promoted to people with ME/CFS. These can be quite expensive and current medical consensus is that most of these tests are unproven or unnecessary as they are not helpful in either the diagnosis or management of ME/CFS.

Two tests that fall into this group are the RNAse-L test (for antiviral activity) and CFS urinary markers (CFSUMs) – both of which have been assessed in research studies funded by the ME Association.

Blood tests and children

Doctors are more reluctant to carry out extensive testing on children. Even so, it is also important to rule out other possible explanations before the diagnosis is confirmed in a child. There are also some other blood tests that may be recommended in the case of children and adolescents.

These include:

* Viral studies that could help to confirm a recent or current infection with Epstein-Barr virus (glandular fever).

* Tests for other types of infection which can sometimes cause an ME/CFS-like illness in children. Examples include Lyme disease and toxoplasmosis.

* Serum ferritin level – a measure of iron status in the body.

* Tests for some of the rare disorders of childhood that can produce fatigue.

The results – what do they mean?

After a blood sample is taken by your GP, it is sent to the hospital laboratory for analysis in a machine. The results should be back within a few days.

Each test will have a numerical result giving the level in the blood. If this measurement falls within what is called the normal range, there is usually nothing to worry about.

In some cases, an abnormality occurs when the result is higher than normal. If it's just outside the normal range, this may be acceptable and all that needs to be done is for the test to be repeated after an interval.

Results that are significantly higher than normal usually indicate the need for further assessment and/or investigation. Results that are significantly lower than normal are also important – an example being a low level of thyroid hormone or haemoglobin.

When should blood tests be repeated?

Once a diagnosis of ME/CFS has been confirmed, further investigation isn't usually necessary. But it's worth noting that new symptoms shouldn't just be automatically linked to ME/CFS as they may need to be investigated.

If ME/CFS persists, especially if you are over 40, there is a strong case for repeating some of the routine tests, such as thyroid function, every few years. This is because conditions such as diabetes and hypothyroidism often appear very gradually – so they can be easily missed when you already have ME/CFS.

Specific tests

Full blood count and differential

Checks the level of haemoglobin, white blood cells and platelets as well as providing information on the size of the red blood cells and a breakdown of the white count into its components.

Anaemia is not part of ME/CFS and if present must be investigated further – as it always has a cause. One of the commonest situations is iron deficiency due to bleeding (sometimes menstrual) but a number of conditions with ME/CFS-like symptoms can also cause anaemia. These include coeliac disease and low thyroid function (hypothyroidism).

Anaemia can also be caused by dietary deficiencies and is sometimes found in teenage girls with ME/CFS who do not eat enough iron-containing foods.

Minor abnormalities in the white cell count – such as what are called atypical lymphocytes – are sometimes found in ME/CFS, especially in the very early stages when the illness follows a viral infection such as glandular fever. More persistent or significant abnormalities in the white cell count will need to be investigated, especially when accompanied by physical signs such as enlarged glands.

The platelet count should be normal in ME/CFS.

Biochemistry screen

Checks the level of salts/electrolytes in the blood (i.e. sodium, potassium), calcium and urea.

An increase or decrease in the level of calcium suggests that there may be another cause for symptoms. One condition that can cause a raised level of calcium is sarcoidosis – this would need to be considered if you also have chest symptoms. Thyroid disease can also raise the level of calcium in the blood.

The levels of sodium and potassium provide vital clues as to how your body is dealing with fluid load and how your kidneys are functioning. An increased level of sodium could indicate lack of water intake (dehydration) or an unusual hormonal condition called diabetes insipidus.

A decreased level of sodium could indicate an excessive water intake or Addison's disease, where there is a serious fall in the output of the hormone cortisol. A decrease in the level of potassium could be caused by drugs (including diuretics, liquorice and carbenoxalone), diabetes, kidney problems or malabsorption of potassium in the gut.

The level of blood urea gives a rough guide to kidney function.

Blood glucose

A raised level of blood glucose indicates that you may have diabetes – an illness that can come gradually with increasing fatigue and urinary symptoms. If so, more specific tests will probably need to be arranged.

Creatine kinase (CK)

This is an enzyme that passes into the blood from damaged or inflamed muscle. Although CK is usually within normal limits in ME/CFS, there are occasional reports where it is raised. Any significant increase in the level of CK will need to be investigated, possibly with a muscle biopsy (where a small sample of muscle is removed for examination under the microscope) to exclude a primary muscle disease.

ESR and/or CRP (C-reactive protein)

These are two tests that simply pick up whether there is inflammation or infection somewhere in the body. Results of these tests should be normal in people with ME/CFS. If raised, further investigations are likely to be necessary.

Hormone function tests

The only hormone levels that need to be routinely checked in people with ME/CFS are thyroid and adrenal gland function – where cortisol is produced. If symptoms, or electrolyte results, are suggestive of Addison's disease – a very rare condition where the adrenal glands produce dangerously low levels of cortisol – this will require further hospital-based tests.

In some circumstances, other hormones may need investigation. One possible example is serum oestradiol and FSH levels in women who have a significant exacerbation of symptoms at period time. This is because they may benefit from treatment with hormonal supplementation if levels are low (reference: Studd J and Panay M. Chronic fatigue syndrome. *Lancet,* 1996, 348, 1384).

Immune function tests

The white blood count gives a rough idea of how your immune system is functioning. There are also specialised tests of immune system function that show how the various different components are functioning. Although abnormalities do quite often occur in ME/CFS involving different components – e.g. autoantibodies, cytokines, immunoglobulin levels, natural killer cells – the changes are not sufficiently consistent to be helpful in diagnosis. And, in most situations, the results are not going to affect the management of your illness. So a more comprehensive investigation of the immune system is not normally required.

Liver function tests

These measure the level of various chemicals, proteins and enzymes produced in the liver.

Minor abnormalities can occur in ME/CFS for a number of reasons. These include the type of infection that triggered the illness and drugs (e.g. antidepressants) or herbal remedies that affect liver function. A benign condition of the liver called Gilbert's syndrome is more common in ME/CFS and this can cause an intermittent rise in the level of bilirubin – a pigment that causes jaundice. And a condition called primary biliary cirrhosis, which can cause debilitating fatigue, should be considered when liver function is abnormal – especially where someone also complains of skin itching.

Screening for Coeliac disease

Anyone with irritable bowel-type symptoms – i.e. abdominal pain, bloating, changes in bowel habit – must be properly checked for coeliac disease as this is a fairly common disorder that has a number of symptoms in common with ME/CFS. An antibody screening test (i.e. IgA antitissue transglutaminase) is commonly used.

If the result suggests coeliac disease you may then be asked to have a biopsy of the gut lining. Coeliac disease symptoms, including the fatigue, often respond very well to a gluten-free diet.

Screening for infection

Antibodies, which are part of the body's immune system response to infection, often remain in the blood for a period of time after the acute infection. So looking for antibodies to specific infections can provide clues as to what triggered your ME/CFS.

Unfortunately, this sort of information isn't usually of any help in diagnosing or managing ME/CFS – so most doctors believe that looking for antibodies to past infections isn't normally of any practical value. And these types of antibodies can be present in perfectly healthy people.

Even so, there are a number of specific and treatable infections that do sometimes need to be checked for if your clinical history suggests that one of them could be involved. Examples include hepatitis B and C, HIV, Lyme disease and Q fever.

Autoantibodies are antibodies that the body sometimes produces against its own tissues and this type of abnormal immune system response can sometimes follow an infection. This may explain why low levels of autoantibodies are sometimes found in people with ME/CFS.

Screening for rheumatic conditions

ME/CFS can produce pain in the joints. If this is more pronounced, or accompanied by inflammation, swelling or deformity, you will probably need to be investigated for some of the rheumatic diseases that can produce fatigue. This will involve immunological tests that are positive in conditions like lupus/SLE.

Thyroid function tests

As both underactivity (hypothyroidism) and overactivity (hyperthyroidism) can produce an ME/CFS-like illness, testing thyroid function is essential before a diagnosis of ME/CFS is confirmed.

The most sensitive test of thyroid function involves measuring TSH – thyroid stimulating hormone. As the name suggests, this is a hormone (produced in the brain) whose function is to stimulate thyroid hormone (thyroxine) production.

If thyroxine output is low then the TSH level rises. If too much thyroxine is being produced, then the TSH level falls. Thyroid hormones that are measured in the blood are T3 (occasionally) and T4.

Some private doctors prescribe thyroid hormones to patients with ME/CFS who have normal thyroid function test results. However, this is inappropriate and potentially dangerous because even small extra amounts of thyroxine can trigger serious heart rhythm disturbances.

Charles Shepherd

Disclaimer:

Medical information contained in this article is not intended to be a substitute for medical advice or treatment from your own doctor. The ME Association recommends that you always consult with your own doctor or healthcare professional about any specific problem. They further recommend that any medical information provided by the MEA is, where appropriate, shown to and discussed with your doctor.

"Your blood sugar is high, but your salt, pepper, ketchup, mustard, and grated cheese levels are fine."

Tell me lies about ME

I was run over by the truth one day
Ever since I've had ME I've thought this way;
So you stop my mouth with CBT
Tell me lies about ME

Heard the alarm clock while screaming in pain
Couldn't get up, fell asleep again;
So you splint my legs with GET
Stop my mouth with CBT
Tell me lies about ME

Endless Forms are all I see
Blatant persecution by the DWP;
So you fill my ears with ATOS lies
Splint my legs with GET
Stop my mouth with CBT
Tell me lies about ME

I smell something burning, suspect it's just my brain
GP says it's my imagination - another bogus claim;
So you ignore the evidence before your eyes
Fill my ears with ATOS lies
Splint my legs with GET
Stop my mouth with CBT
Tell me lies about ME

Where was the government at the time of the crime?
Drafting NICE Guidelines – what a waste of time;
So you falsely claim that nobody dies
Ignore the evidence before your eyes
Fill my ears with ATOS lies
Splint my legs with GET
Stop my mouth with CBT
Tell me lies about ME

You send your psychiatrists in, you take your conscience out
You take the human being and you mangle it about;
So you Section me to stop my cries
Falsely claim that nobody dies
Ignore the evidence before your eyes
Fill my ears with ATOS lies
Splint my legs with GET
Stop my mouth with CBT
And pray to hell you don't get ME!

Carol Rosier, December 2013
Based on the Poem *'To whom it may concern'* by Adrian Mitchell (1964)

Videos from 'Exercise and ME/CFS'

Presentations from the Exercise and ME/CFS event in Bristol on Feb 5th 2014, following a screening of 'Voices from the Shadows', can be now be watched here:

http://voicesfromtheshadowsfilm.co.uk/exercise-mecfs-event/

under the screenings tab.

Prof Mark VanNess from the Workwell Foundation explains how damaging aerobic exercise can be for patients with ME/CFS. Their two day testing protocol demonstrates an astonishing post exertional amplification of symptoms in ME patients; a hallmark symptom of ME. This damage to the aerobic energy system means that it is utterly counter productive to try to use aerobic exercise to improve health in these patients.

Dr Nigel Speight talks about some of the kinds of cases where he is asked to try to protect children from being mistreated by professionals who are misinformed about ME, or abdicating responsibility. He is the medical advisor or paediatric medical advisor for five charities, including the ME Association, TYMES Trust and significantly the 25% Group who have been unable to find anyone more suitable to help in severe cases.

Erinna Bowman is part of the Cure ME team at the London School of Hygiene and Tropical Medicine. She explains about their new research projects funded by the USA's NHI which will involve immunological, virological and gene expression analyses and describes the previous work on the biobank and its further development as a result of the new funding.

http://voicesfromtheshadowsfilm.co.uk/exercise-mecfs-event/

The trailer for 'Voices from the Shadows' can be found at:

http://voicesfromtheshadowsfilm.co.uk/2011/trailer/

Submitted by Pat Williams

Action for ME Patient Reference Group

Join our ME/CFS Patient Reference Group

20 January 2014

Action for ME is setting up a Patient Reference Group to be involved in its health and/or research work, and would like to invite you to apply to join.

The group is open to ME/CFS patients, carers and their family members only, and will be facilitated by Action for ME CEO Sonya Chowdhury.

From discussion and consultation with Supporting Members and others, the following have been suggested as a possible focus for the group:

- inputting into Action for ME's strategies: what we do, how we do it, what new things to develop and setting priorities
- overseeing specific projects such as Patients Know Best (when we get funding)
- helping to inform decisions about which research projects we become involved in or support
- contributing ideas, challenges and creativity to help shape our work.

'No terms of reference have been set yet, because I feel very strongly that this should be done by us as a group, through discussion and negotiation' says Sonya. 'The group will meet virtually - by email, phone or teleconference – and we particularly welcome input from anyone affected by severe M.E. We will explore the most appropriate way of meeting to suit individual needs.'

If you are interested in joining the group, please:

- read our Patient Reference Group Q&A for more information
- complete the joining form and return it as soon as possible.

Please see http://www.actionforme.org.uk/ for more information.

Oxfordshire CFS/ME Service

(previously OCCMET)

New name and new programmes

The Oxfordshire CFS/ME Service is a community service for people with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) and their families and carers. It is provided by a team of therapists and a GP who are all specialists in CFS/ME. It also provides a specialist resource to other professionals in health care, social and community care, education and workplaces.

Scope: We see adults and young people (currently those over 14 years old) who have an Oxfordshire GP. We provide a personalised service that assists people to a place of self-management and towards recovery, utilising a range of individual and group programmes (please visit www.oxfordhealth.nhs.uk/cfs-me for more information). Above all, we recognise that treating each person as a unique individual is at the heart of their recovery process.

Referral and pathway: Referral is made by GPs and paediatricians (using a referral/screening form available from cfs@oxfordhealth.nhs.uk). Confirmation of the diagnosis for adults is made by the team's GP and many people report the validation of this experience as an important part of their recovery process. A recommendation for the next best step is agreed at a service triage: one of our own programmes, or referral to our colleagues in Talking Health (part of Talking Space, Oxfordshire NHS Foundation Trust), or direction to another agency. Initial meetings can be arranged in the person's local area or at home if necessary, with the intention for people to become part of a recovery community. As such, we don't provide long-term support but anticipate that people will put their own action plans (developed together during contact with us) into process for continuing independently. We advocate a stepping stone approach to making progress.

Outcomes: We see people across a whole spectrum of presentation. Outcomes are variable, with the majority of people making personally significant improvement; returning to feeling normal and to engaging in their desired everyday activities, including some returning to work and education. Service outcome measures compare favourably with other services on the CFS/ME National Outcomes Database.

Contact:
Office only at:
Orchard Health Centre 5A Cope Road
Banbury
Oxon OX16 2EZ

Tel: 01295 819191 Fax: 01295 819111
Email: cfs@oxfordhealth.nhs.uk
Web: http://www.oxfordhealth.nhs.uk/cfs-me

Oxford Health NHS
NHS Foundation Trust

OMEGA Accounts 2013

OMEGA Accounts 2013					
Bank Credits at 1/1/2013					**£3,437.38**
Income	**General income**	**Poetry book income**	**Children's Campaign income**	**Total income**	
Subscriptions	£765.00			£765.00	
Donations	£537.19			£537.19	
Bank interest	£3.98			£3.98	
ME Awareness 2013 / Children's Campaign *			£640.28	£640.28	
Quiz nights	£140.00			£140.00	
Poetry book sales		£496.06		£496.06	
Total	**£1,446.17**	**£496.06**	**£640.28**	**£2,582.51**	
Expenditure	**General expenditure**	**Poetry book expenditure ******	**Children's campaign expenditure**	**Total expenditure**	
ME Awareness 2013 / Children's Campaign			296.72	£296.72	
Newsletter	412.86			£412.86	
AGM	£100.61			£100.61	
Subscription to Oxfordshire Neurological Alliance	£20.00			£20.00	
Poetry book		£803.11		£803.11	
Room hire	£10.00			£10.00	
Volunteers expenses	£84.82			£84.82	
Summer social	£141.26			£141.26	
Total	**£769.55**	**£803.11**	**£296.72**	**£1,869.38**	
Surplus/loss	**£ 676.62**	**-£ 307.05**	**£ 343.56**	**£ 713.13**	
Bank closing balance					**£4,150.51**
Notes					
* we had two substantial donations from Waitrose Community Matters for raising awareness of the needs of children with ME/CFS					
** new poetry book surplus is £1075.51					

"We found the accounting error. Somebody printed all the zeroes upside down."

Paul Davies' Sponsored Walk for OMEGA

Paul Davies walks for ME Awareness in May, walking to our support groups i

n aid of funds for OMEGA.

Paul has two friends with ME, a mother and daughter and he has kindly offered to do three walks to our support groups in May 2014 – ME awareness Month.

1. **Tuesday 6th May**

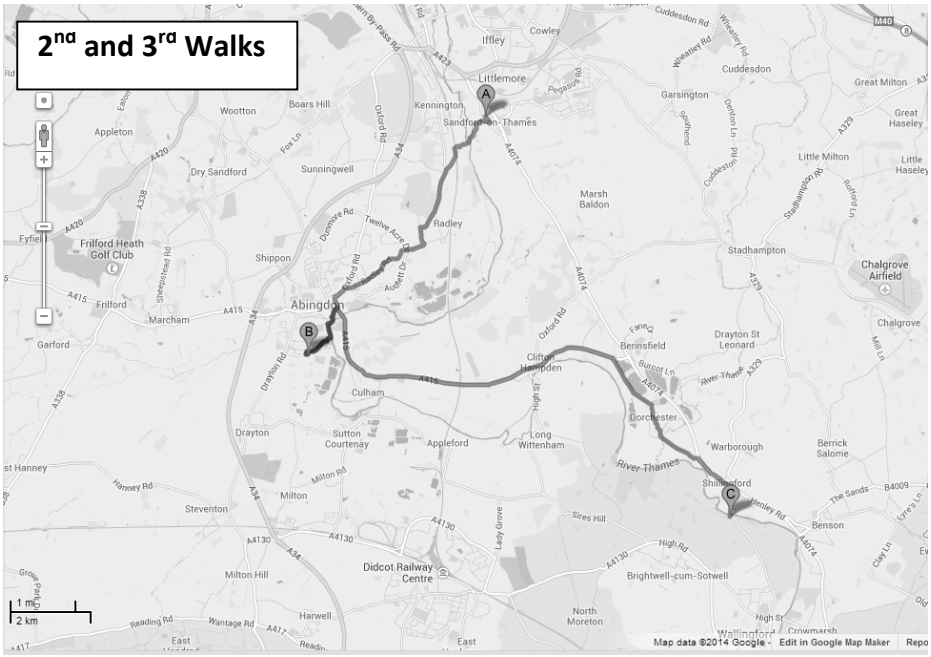
From Bloxham to Debenhams in Banbury, OX16 5UP, or weather permitting along Oxford Canal towing path from Twyford Bridge to Banbury, approximately 5 miles. Arriving between 11am and 1pm.

2. **Monday 12th May (ME Awareness Day)**

From Abingdon to Four Pillars Hotel, Sandford-on-Thames, OX4 4GX, approximately 6 miles, or weather permitting, along the Thames towpath to Sandford. Arriving between 1.30 and 2.30pm.

3. **Thursday 15th May**

From Abingdon to Shillingford Bridge Hotel near Wallingford, OX10 8LZ, approximately 9 miles or along the Thames towpath, weather permitting. Arriving between 12noon and 2pm.



It would be good if some friends or family members could join Paul for some of the walks. Please sponsor him if you can. Please see separate pages for sponsor forms.

We would like some help with transport especially the Banbury Walk.

Please telephone Tessa on 01491 838727 if you can help or would like to join the walks.

Sponsor forms enclosed. Total (approximately) 20 miles.

Please send cheques made payable to OMEGA to: Cathy Brocklehurst, 41 Lytton Rd, Oxford, OX4 3PA. Please write "WALK" on the back of the cheque.

Submitted by Tessa Keys

Notices

Music Recital Donation

On the evening of 15th February a music recital was held at the Hall of St Michael at the North Gate in Oxford, organised by and featuring Dolly Thompson and some of her musical friends and family with proceeds going towards OMEGA's work. A couple of our members went to what was an enjoyable and well attended event. We'd like to thank Dolly for raising over £300.

International ME Conference 2014: IIMEC9 – *Synergizing research into ME*

Friday 30th May 2014 - Westminster, London

Full details of this conference are at http://www.investinme.eu. As in previous years OMEGA will sponsor any Oxfordshire GP or other health professional recommended by any OMEGA member to the extent of a £20 reduction in the registration fee. If you can persuade your GP or therapist or any other health professional to register, have them do so at the reduced fee and inform Norman Booth at 01235 833486 or norman.booth@mansfield.ox.ac.uk who will validate the reduction in registration fee. Note that the health professional will receive CPD accreditation as well as a valuable insight into the latest biomedical research into ME.

2014 Subscription Reminder

Thanks to those that have already paid their OMEGA membership for the year but we still have a fair few members outstanding with their payments. If you receive a subscription form with this newsletter either through the post or via email then your payment is due for renewal.

So if you'd like to continue your membership please fill out the form and post it back with your cheque (payable to OMEGA) to

Cathy Brocklehurst, 41 Lytton Road, Oxford, OX4 3PA.

Mike Shepherd's North Pole Marathon for Invest in ME

Run a marathon at the North Pole

Why would anyone be mad enough to do such an extreme challenge?

Race Date : April 2015

Runner : Mike Shepherd

http://www.shepherdfitness.co.uk/

'This is the challenge of a lifetime and it is the result of my daughter having ME since September 2008. I have seen firsthand how damaging ME can be to a person's life, their prospects and their family', - Mike Shepherd.

Invest in ME are an independent UK charity campaigning for bio-medical research into Myalgic Encephalomyelitis (ME). They have links nationwide and also internationally. Invest in ME are one of the founding members of The European ME Alliance.

Diary Dates

OMEGA's 25th Anniversary Celebration, 27 September 2014

This year is the 25th Anniversary of the foundation of OMEGA and we will be celebrating it at Wolfson College in Oxford on Saturday afternoon, 27th September 2014. OMEGA is organising this celebration in collaboration with the ME Association which will combine its annual Question Time with our Anniversary event. Some details are on p. 5 of the Spring 2014 edition of ME Essential and will be on the MEA website. Also, our local multidisciplinary team, OCCMET, became operational in early 2005 but the first appointments were made in late 2004 so our Anniversary event will also celebrate the 10th anniversary of OCCMET. In view of the MEA participation we expect to be joined by members of support groups from neighbouring counties. We will soon be looking for volunteers to help with this event and perhaps tell us about the early days of OMEGA. In the meantime please put this date in your diary.

Norman Booth

Committee Plus

The next Committee Plus meeting will be on Saturday 6th September 2014, 2-4pm at the North Oxford Association Community Centre in Summertown. All members are very welcome to come and find out more about OMEGA, what is going on and how you can help. North Oxford Association Community Centre – Library, Diamond Place, Summertown, Oxford, OX2 7DP.

Socials

Banbury ME Group

This is an informal ME Group in Banbury. Do you live in or near Banbury?
Are you diagnosed with ME/CFS? Are you family, friend or carer for someone with ME/CFS? Would you like to meet others in Banbury?
We will meet regularly on the 1st Tuesday of the Month.

This will be at Debenhams where the manager and staff look after us very well.
Debenhams, Castle Quay, Banbury OX16 5UP.
Please come to the restaurant upstairs (there is a lift) between 11.00am and 1.00pm. Please drop in for an informal meeting or for more information.

Contact Email :megroupbanbury@btinternet.com
Facebook: Banbury ME Support Group or
https://www.facebook.com/pages/Banbury-ME-Support-Group/160180667482566?fref=ts
Tricia - 07745 385293

OMEGA Oxford Area Social gathering

OMEGA Oxford Area Social gathering takes place on the first Monday of every month from 1.15 pm onwards at the Four Pillars Hotel, Henley Road, Sandford-on-Thames, Oxford, OX4 4GX. An opportunity for OMEGA members and carers to socialise with other ME sufferers. For more details, phone Jo and John on 01993 866610 or Lesh Lender on 01865 766310.

Please note the Meeting in May will be on May 12th as the first Monday is a bank holiday.

The bus services from Oxford is now the T2 leaving St Aldates stop G1 at 12.50 going via Cowley Rd and stops just beyond the hotel entrance .

Wantage and Grove ME/CFS Support Group

All at Cornerstone Coffee Shop, 10 Savile Way, Grove, Wantage, OX12 0PT
For further info phone Annie Kingsbury on 01235 763813 or email annie.kingsbury@talktalk.net

South Oxfordshire ME/CFS Support Group

Shillingford Bridge Hotel, Oxfordshire, OX10 8LZ

Monday 14th April	Thursday 15th May	Monday 9th June
Monday 14th July	Monday 11th August	Monday 8th Sept.

Car parking on site, buses X39, X40 and 139 buses stop near to the hotel
The same time each day: 12.00 midday – 2.00 pm
For further information, email Tessa at tessamary_keys@yahoo.co.uk or phone on 01491 838727

For further details, please see: www.oxnet.org.uk/omega

OMEGA Contact Information, and Roles and Contacts

Oxfordshire ME Group for Action (OMEGA). General Enquiries to OMEGA, 4 Bursill Close, Oxford OX3 8EW, Tel. 01865 766310, Email: ltrl3@tiscali.co.uk

OMEGA Website: www.oxnet.org.uk/omega

OMEGA Facebook page: www.facebook.com - search "Oxfordshire ME Group for Action".

OMEGA on Twitter: Follow @omega_oxon

Membership Secretary	Lesh	01865 766310
Acting Treasurer	Cathy	01865 779031
Volunteers (Organiser)	Jan	volunteers.omega@gmail.com
Clinic Group (research/campaigning/NHS liaison)	Norman	01235 833486
Acting Minutes Secretary	Norman	01235 833486
South Oxon Social	Tessa	01491 838727
Bicester Social	Nicky	07813 942474
Banbury Social	Tricia or Jill	01295 278810 or 01295 271366
Special interest groups:		
Book Group	Nicky	07813 942474
Parent Support Group	Priscilla	01844 213772

Other Useful Contacts

Oxfordshire CFS/ME Service
(Previously known as OCCMET)
01295 819191, or e-mail: cfs@oxfordhealth.nhs.uk

ME Association Support and Information Line 0844 576 5326
Every day: 10.00am – 12.00pm, 2.00pm – 4.00pm and 7.00pm – 9.00pm

Action for ME (Support line) 0845 123 2314
Monday – Friday 11.00am – 3.00pm Email: support@actionforme.org.uk

Welfare rights helpline (AfME Membership only service): 0845 122 8648

OMEGA Newsletter Production Team: Luisa Beck, Jan Seed, Nathan Smith, Pat Williams, Cathy Brocklehurst, Mary Horan, Joanna Breheny, John Porter, Jo Porter, Jill East, Lesh Lender, Catherine Rye and Susie Geddes.

With thanks to: Luisa Beck, Valentijn (Phoenix Rising), Tricia Barnett, Charles Shepherd, Pat Williams, Tessa Keys, Lesh Lender, Carol Rosier, Patricia Wells, Cathy Brocklehurst, Norman Booth, Anne Silk and Susie Geddes for contributions.

The next newsletter copy deadline is **Friday 13th June 2014**, so please send any info, news, jokes, poems etc. to newsletter.OMEGA@gmail.com. Send articles, jokes, cartoons or letters for publication with 'Editor' in subject line.

To receive your newsletter by email, put "email newsletter request" in the subject line.

Disclaimer – Please note that views expressed in this newsletter are not necessarily the views of OMEGA.

"I found 1837 web sites about 'alternative medicine' but none of them recommend pizza or chocolate for lowering our cholesterol."