



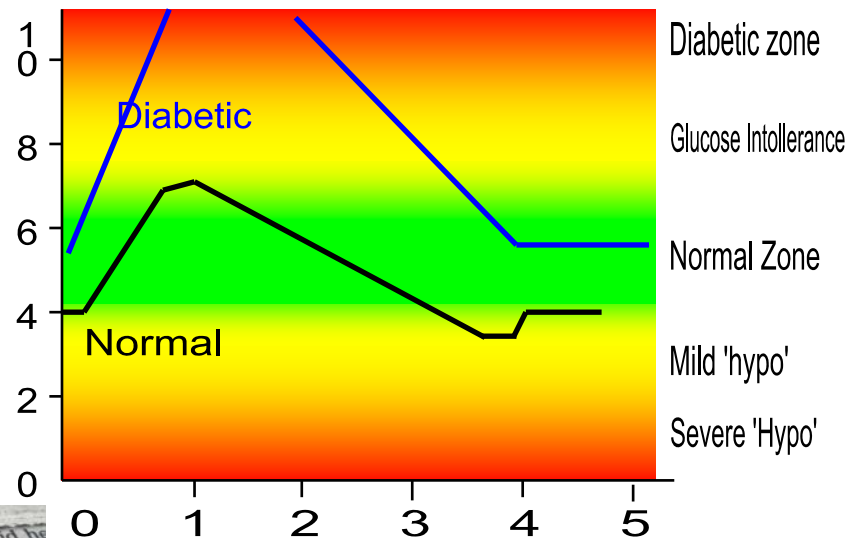
Pathways

Price £ 2.50 (Free to members)

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

The World of Diabetes and ME/CFS

The Diabetic clinic at DRI is one of the biggest clinics in the hospital. Not all people with ME get diabetes. When they do, it multiplies the problem. Far more is known about diabetes than ME. About 10% of group members are diabetics. On page 18 we give an insight into the everyday issues of those with this problem. **See page 18**



Swine Flu

Swine flu is still around, and there is a threat of a second wave. We have produced a digest of issues related to ME/CFS incorporating general advice given by the NHS with a digest of the thoughts of several well known doctors.

See page 8



Dial Doncaster

Dial is a national disability support organisation which originated in Doncaster. A very interesting meeting took place on the 4th August at the Redmond Centre. Read all about it.

See page 15



New Group printer Colour Laser Printer.

We have taken delivery in July of a new printer HP 2820. It is useful because it has a multiple document scanner attached, and it can also be used as a photocopier. The printer is exactly the same mechanically inside as the HP 2550 laser printer, so our existing stock of cartridges and drums will fit. A fuser-unit fault in the HP 2550 delayed the last Pathways 20, and was fixed with parts cannibalised from a scrap printer, because a replacement unit would have cost about £150. A new printer normally costs about £300. Some money had already been raised by Sharon last year in a raffle and a donation had been received from Tony and others. A lot of research and web-browsing traced a brand new printer to a company in Cornwall at the right price of £250.

Matthew writes: Wondered if you could help with the following queries?

1) I am on 1.25mg Olanzapine and am a bit concerned about long term side effects....the drug affects me cognitively and I feel generally dumbed down. Will these effects subside once I discontinue taking the drug or could it cause any long term cognitive problems even after withdrawal?

If you discontinue the drug, the condition that it is intended to control/treat will re-emerge. People who stop taking this kind of medicine often experience a short rebound 'high'. Usually after a short while the condition returns—with a vengeance. If side effects are a problem, you really need to sort this out with your doctor. There are always options. Sometimes a minor dosage adjustment, change in medicine, or specific adjuvant (other medicines) helps. But this is really your doctor's job.

2) There are some supplements that contain animal extracts (e.g. pancreatic, bile etc) that are known as "glandular". Are there any problems with taking things like these?

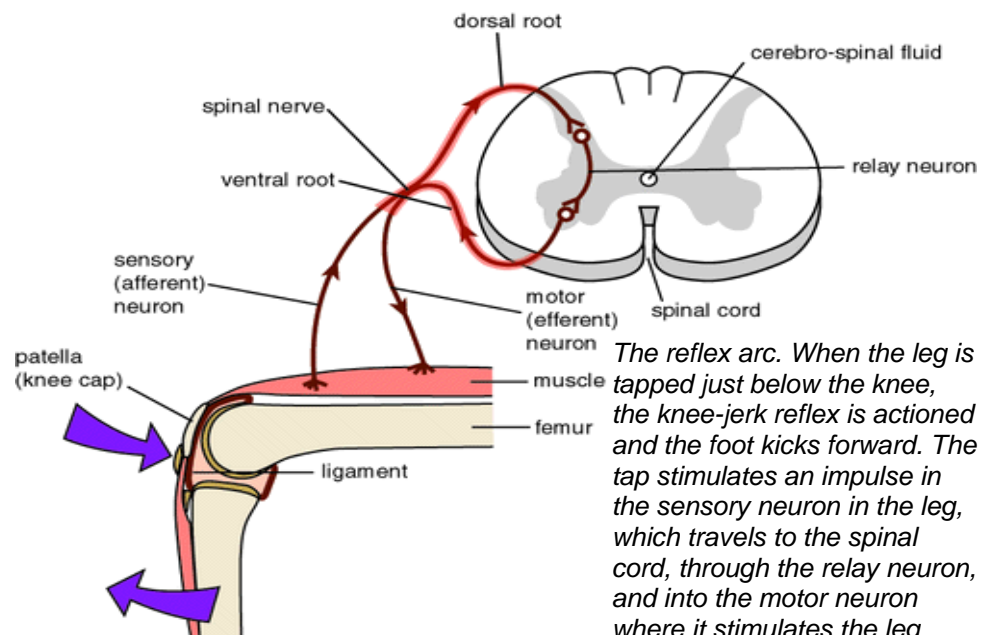
Yes, they are dangerous. Thyroid, pancreas, adrenal, pituitary, and neurological tissue sold as food supplements is illegal, has been so since 1933, and still is. This is because they are a natural source of hormones, which are unreliable on potency, and are usually contaminated. Bile (pancreatic juice) is used to treat certain medical conditions. Also many of these products can pass prion based diseases on. Prions cannot be sterilised as bacteria and viruses can. The biggest example is of course (BSE) Mad Cow Disease, (CJD) Cruetzfeldt Jacob Disease and Scrapie (in sheep). These diseases are always fatal in humans and animals, and cannot be treated. A complaint about a company in Derbyshire selling these types of products has been sent to the Medicines Control Agency.

3) By the way, a point about swine flu: when it is said that it could pose risks to those with underlying health conditions, do we put ME in this category?

Depends. If you have a weekend immune system, and catch everything that is going, yes. Some people with ME don't get flu or colds possibly because of an overactive immune system. There is no vaccine for H1N1 available yet (but one is in development). The only medicine treatment is 'Tamiflu' or similar antiviral drugs, which would shorten the episode of flu by about 1½ days. These may have positive effects on ME. I'm awaiting with interest the reports from other members.

Sarah Writes: Could anyone help with a query regarding muscles, in particular leg muscles please? I am wondering why, even with severe M.E., we don't tend to have as much visible muscle wastage as would be expected. Has anyone seen any research that shows it could be because the muscles twitch and spasm and therefore retain their tone?

Yes, it is well known to doctors and researchers. The leg muscles are controlled by a reflex loop which relies on feedback via the spinal cord from receptors within the muscle. The normal setting for this reflex loop is to keep the muscle taught—on tick over ready for action. Everyone has seen when a doctor hitssomeone's knee it kicks up. That is what doctor does to test the reflex function. The nerves from the brain which control muscle movement control the reflex loop, rather than the muscle directly.

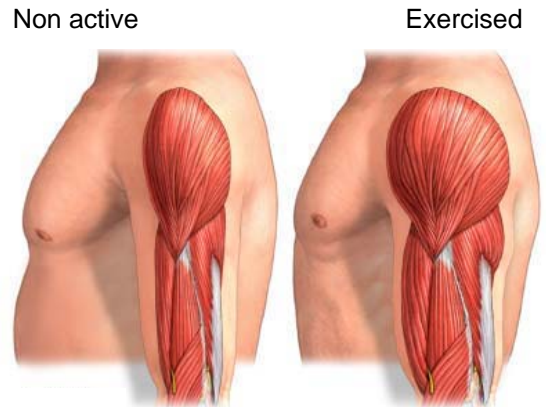


In the case of polio, MS or spinal injury, where the reflex loop is broken, the muscles become flaccid and wasted, losing bulk because they have not been used. This also happens with long term bed confinement and astronauts. In cases where there is overstimulation of a muscle e.g. Parkinson's (constant tremor) the muscles retain their bulk and integrity because they are 'exercised' in a similar way to the working of some electrical muscle simulation machines used in gymnasia.



In ME/CFS the reflex loops are usually oversensitive, and twitchier, and so are 'exercised' without being exercised and this is confirmed by research. When reviewing medical reports after state benefit refusal, I very often see doctors' comments about the presence of a reflex, and muscle bulk, as a reason for (for example) DLA mobility refusal. I've seen people with ME, with normal looking muscles, unable to walk. Sometimes the muscle goes into weak spasm (twitching) called fasciculation which lasts for a few seconds and which feels like a ripple under the skin. When fasciculation occurs it is usually an indication that someone is reaching the end point before ME/CFS kicks in and therefore they need to back off and rest. i.e. the pacing has gone wrong.

Lynn writes I have had ME/CFS for over 7 years and although not severely affected I am predominantly housebound, bedbound at times, and my condition is deteriorating. Prior to the onset of my illness I was employed in a major public sector organisation which permitted me to take a career break to see if the time off work would enable me to make a recovery and return to work. The time they permitted me to take is due to expire at the end of this year and, barring some sort of miracle, I have accepted that it will not be possible for me to return to my job. I am therefore thinking about asking my employer if they would permit me to take early retirement on medical grounds and access my pension thus giving me some sort of financial life line.



At the relatively young age of 42 I would anticipate that this would be something my employer will strenuously oppose, so I am trying to gather as much information as possible in support of my case. I do not know how to approach this and was wondering whether you or anyone in your local ME support group had any experience of applying for medical retirement which might be helpful to me in approaching this task. For example, did anyone have success in something like this and what do they think contributed to that success? Did anyone try to access their pension, but fail and what problems or obstacles did they encounter? Would any of your members be able to recommend a doctor who would prepare a suitable expert medical report in support of such an application? Were there any websites or other resources which they found particularly helpful in dealing with something like this?

Yes I've been in the same boat as yourself, and I got medical retirement in 1992. What you are after is easier to get with some organisations and almost impossible with others. There are a few hints and tips I can give. OK, you are in Scotland but that is not a problem. The system is similar to that in the rest of the UK but there are differences.

Firstly, DO NOT RESIGN OR GIVE YOUR NOTICE otherwise you may lose out. Let your employers make the decision. You need to know whether the pension pot is contributory (i.e. you have paid into it) or discretionary i.e. paid honorarium for being a good employee. Do you get an annual pension or contribution statement?

Secondly we need to estimate what you may be entitled to, and if there are any options in your

employers scheme. If you have a trade union or trade body you can contact for help you need to be in contact with them, but don't tell your employer yet. There is a threshold below which early retirement is not worth chasing because sometimes it can prevent you accessing other sources of private and state income. There may also be tax issues.

Thirdly Almost all early retirement cases of your age need a doctor to say that the condition is 'permanent'. That usually is best coming from at least two doctors, one your own, and the other a consultant or equivalent. Usually NHS opinions are not disputed; private ones are. Some insurance companies and pension schemes dispute findings and tend to refuse the claim.

You have usually got to 'construct a case' before you even apply. A good starting point is your medical history and a list of other current conditions. If you have complications, that also counts. You have also to be prepared for an emotional battle. Most pension schemes are designed to pay out at 65, and you are going to draw on that for possibly 30-40 years, so they are going to throw barriers in the way, and you have to be persistent. It may take some time. My case took 15 months. I have been dealing with one case for 4 years - and they are only just beginning to open up. The other issue is that you may have to live on state benefits or insurance income for several years. I think that is about the most I can tell you without going into details and knowing a bit more about your circumstances.

Lisa writes We are researchers at Sheffield Hallam University who are looking for individuals with a diagnosis of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) to help with our online research study. Lisa Hinds also works as a senior occupational therapist at the Leeds and West Yorkshire CFS/ME Service. We are studying an approach that has been used in the past to look at how people cope with a range of neurological and physical health problems, such as breast cancer. The approach looks at how different styles of coping influence someone's ability to manage their illness. Applying this to coping with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is new. The research is not intended to suggest that CFS/ME is due to specific character types or coping styles. This study will explore factors which can help people cope better with their diagnosis and treatment. On completion of the study, we will make a link to the results available on the website from which you were recruited. For further information about the study please contact:
 Lisa Hinds – lhinds2@shu.ac.uk, or Professor Ann Macaskill – a.macaskill@shu.ac.uk or
 Dr Tria Moore – t.j.moore@shu.ac.uk. Follow this link to start the questionnaire:
<http://ds.shu.ac.uk/survey2/?q=4A4618D500VQ>

I've had a look at the survey, and I'm a little concerned about some of the questions. In particular they do not seem to acknowledge the recent research into sub typing. I was surprised that I had not heard something about it from the Sheffield ME/CFS clinic, so I just wonder how well the researchers have done their background research.

DIAL writes Could you please warn your members of a MOBILITY EQUIPMENT SCAM. Recent reports state that a mobility company is currently targeting customers trying to sell them large pieces of mobility equipment. Reports have been received that the calls appear to follow this pattern:

- Continually ring customers until they agree to a visit.
- Arrange a time – usually between 4 – 6 pm and do NOT turn up.
- They then arrive the next day unannounced – usually 2 men
- Advise customers that they have some connection with 'Social Services'
- Pressures customer to buy large pieces of equipment such as stair lifts and beds

We advise you are advised to be cautious of uninvited callers. If you feel you have been targeted by this company, trading under either name, you should contact Consumer Direct on 08454 04 05 06.

DIAL Doncaster wishes it to be known that we have no connection with these companies in any way. DIAL, Unit 9, Shaw Wood Business Park, Doncaster, DN2 5TB 01302 327 800.

Most of these type of salesmen don't have any occupational therapy, medical or nursing training. SYCIL have a facility at Kirk Sandall to try things out free under qualified supervision without pressure, as they don't sell appliances. My advice is to shop around like Anne Fisher did (Pathways 20, page 8), and don't let salesmen into your home.

Damien Downing writes With reference to the following from Pathways 20.

3) Dr. Downing's clinic in York provides a similar service to that of Dr. Myhill. As a new patient, it would cost you just under £500 for the same thing (it is the York branch of a private Harley Street practice).

There's a difference between the two offered services, they are not the costs for the same deal. I established in York first, so London is an extension of that not vice versa really. With respect to the £500 issue, I don't want to be crabby, but would like to point out that Myhill's price is probably based on doing the CFS profile at Acumen, which is what she always used to do - £125 (*SM £195 + £50). This is valuable but doesn't identify the toxins doing the interfering; that requires the Fat cell pesticides (£75) (*SM £95) and/or the Translocator studies (£90) (*SM £110). So if I did all the above tests, for £390, and saw the patient twice, I guess that is £500-ish, but it's a different deal to having half the tests and a phone consult.

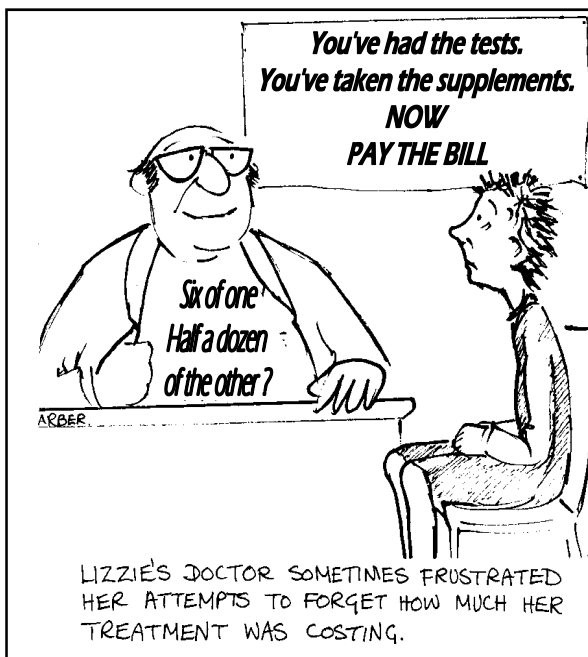
** Myhill's website prices as of August 2009. We suggest you check for yourself:*

Dr Downing can be contacted on 01904 691591, enq@naltd.co.uk or at Nutrition Associates, Galtres House, Lysander Close, York, YO30 4XB.

Dr Myhill can be contacted on 01547 550331, office@doctormyhill.co.uk, Dr Sarah Myhill, Upper Weston, Llangunllo, Knighton, Powys, Wales LD7 1SL.

Jude Writes I have been hired by SYCIL to research a Social Enterprise model of delivering complementary therapies to our client base. This includes a study of existing models in the UK, proposing a model to progress our idea, preparing a business case and planning and implementing the operation. My background is in business, (mainly telecoms, business process management) and I have recently worked in External Funding at an FE college. Apart from this I am also a qualified and practicing homeopath. I am passionate about addressing health inequalities, personal choice in healthcare, and about the fundamental idea of social enterprise.

SYCIL is dedicated to providing support for independent living, and our new service aims to address self management of health and wellbeing issues. At this point in the development of our Total Wellbeing Service, I am putting together focus groups of both (potential) service users and service providers (therapists) to ensure we have a good match and will be able to fulfil the needs and wants of the client. Exploring barriers to access is an important step of this process. We would like to know what types of complementary therapies your client group have tried, what seems to help, and what they would like to have more of, or try for the first time. Some examples may be aromatherapy, acupuncture, Alexander technique, Yoga, homeopathy, etc... With this information we can explore the possibility of putting on 6-12 week courses of activities and therapies designed to improve wellbeing. We are also looking at setting up taster sessions on a regular basis at SYCIL premises. This would allow people to come and try a therapy to see if it might be something they feel might help them if enjoyed on a more regular basis. It would also provide an opportunity, in a safe environment, to meet qualified, carefully chosen therapists who have an understanding of the client's needs and possible limitations.



I invited Jude to meet with some members of Leger ME at the meeting of the 21st August. We had an interesting discussion, and it was agreed that some therapies may be better than others for ME/CFS. However in order to ascertain what members would like we've decided to attach a questionnaire to this edition of Pathways. You can fill it in at a meeting or send it to me by post. You can also email it back to me. Mike.

My Experience of Fairlawns.

(The South Yorkshire and North Derbyshire Chronic Fatigue Syndrome/ME Service)

By Ann Fisher



I have just finished my first course of treatment at the Sheffield clinic for ME/CFS sufferers. It has been wonderful to meet professional people who take the condition seriously and understand what we are going through. The amount of help they can give is limited by funding, which is very often the case for many illnesses, but I feel they are trying to do their best for the sufferers in South Yorkshire. My first appointment came through quite quickly and I was taken by my husband to see Anne. She was very thorough in taking a history and very understanding of the condition. I was given a short break during the appointment as answering all the questions was quite tiring, as was sitting in the chair provided which soon became uncomfortable, (even the recliner chair was hard). On returning home I was completely exhausted and very grateful that I had not driven as I don't think I could have driven back.

I received a phone call a few days later to book my appointments for advice on 'Pacing', as we had agreed on this form of treatment, rather than CBT, Group Therapy or Graded Exercise, at the meeting. I was informed that there would not be an appointment for over 4 months, I hadn't realised until that moment how desperate I had become for someone to help me. I have had ME for 18 years and had helped myself for most of that time. I was referred to Sheffield after having a severe relapse. On hearing this news I started crying which I think surprised both myself and the lady on the phone. My desperation must have come across quite clearly as she found me a single appointment in 5 weeks time and 1 a month later, they like to book a series of appointments but agreed to break mine up. She chatted to me until I was calmer then reminded me to read the information I had already been given and to start trying to pace my lifestyle. I needed to also start daily activity diaries. Although I found doing these quite difficult it helped me to realise on how my activities affected me. I did also find that after doing these for a few weeks it was quite depressing constantly focusing on the things I couldn't do and how tired I felt but I persevered to see what common denominators it might show up.

So for the next 2 appointments I was taken to Sheffield and we talked through Pacing regimes and studied my diaries, but one of the main things that came over to me was that I should accept my illness, allow myself to sit and rest and not to struggle for improvement, as I had been, but to allow it to happen. They helped me establish a baseline where my symptoms are at their least, but the pressures of life always seem to interfere with this and it's not very easy keeping to it. It was going to be a few months then to my next appointments, but I had got something to start working with and felt happier for that.

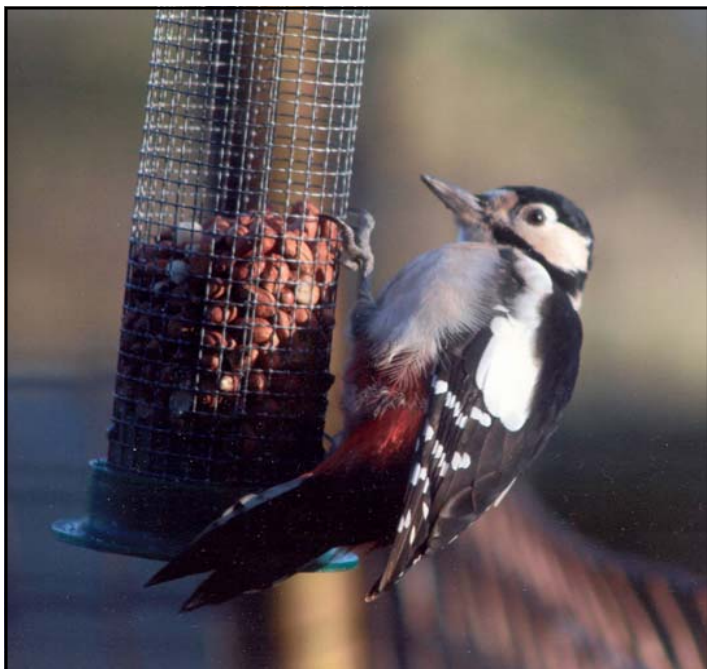
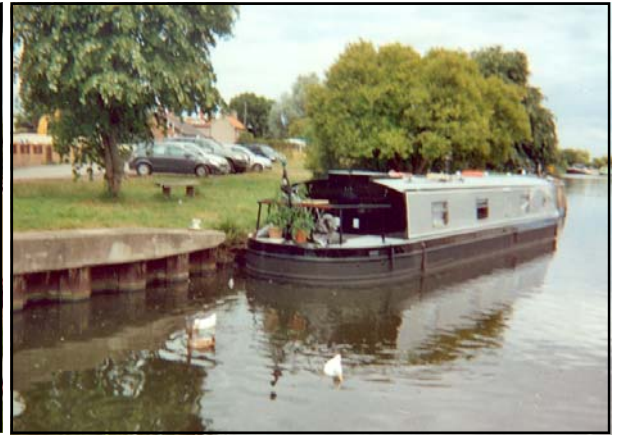
I was also booked in for the relaxation classes that they run, but as I now had to drive myself to Sheffield, these were very tiring; however I have found the techniques useful to introduce into my daily life. Following this I had my next 4 appointments over 5 months, but these were phone appointments so I did not have to do the exhausting travelling. Each appointment discussed my activities, emotional needs and any stressful events and how I could adapt ways of dealing with them. I was given some very practical advice.

Having someone outside my situation looking at the things I was doing was more useful than I thought it would be. I was involved with 3 of the staff and each one was considerate and concerned about my situation and I cannot praise them highly enough for their help. However there are some limitations with the clinic that, if funding was available, I am sure would be dealt with.

I feel it would be better if there was a Consultant involved, able to test, medicate and do research. Also if there were satellite clinics rather than just the central one, as travelling is very difficult and even though the phone appointments are useful I much prefer to see who I am talking too. I recommended to them that they start with 2 appointments initially to start Pacing so that intervention isn't delayed, then, there can be longer gaps between appointments as it takes a few weeks to assess if any changes to life style are effective. So overall it was useful going to the clinic and I will probably have myself re-referred next year if my symptoms haven't improved, or I may consider Graded Exercise if they have. One thing I will do if I go again though is—take a cushion!

Your Photographs

My name is Celia, and I have been a member of Leger ME for many years. After five years of trying I managed to make it on an Ethel Trip. On the 12th July. Here are some of the memories of that great day for you to share.



Greater spotted woodpecker



Lesser spotted woodpecker

My Name is Richard, and I moved from Doncaster to Scotland five years ago. We are both enjoying the clean air up here and quite often enjoy watching the birds in our garden. Here are a couple of photographs of visitors for you to share with us.

Comparing Swine Flu Advice of the NHS & ME Doctors.

Well not quite as expected, from pigs instead of birds, but its here. At the time of writing antivirals are being supplied locally and vaccine is in the testing stage. Most of what I last featured (Pandemic Flu in Pathways No. 6, Autumn 2006) still applies. The specific advice for Doncaster by Dr Tony Baxter's team at NHS Doncaster team is:-

If you experience a sudden fever, cough or shortness of breath, or have a headache, sore throat, tiredness, aching muscles, chills, sneezing, runny nose or loss of appetite you may have swine flu. For most people this is a mild illness and you should start to feel better after a few days without needing to go to your GP or A&E. Help yourself and others by not spreading the virus. The best thing you can do is stay at home, rest, drink plenty of fluids and take over-the-counter flu remedies to help relieve the symptoms. It is particularly important that you talk to your doctor if you think you have swine flu and are pregnant, are young, over 65, or have long-term conditions such as asthma or diabetes. If people think they have Swine Flu, they should first go online and check their symptoms on www.nhs.uk, call NHS Direct (0845 46 47) or call the Swine Flu information line on 0800 1 513. If they are still concerned, they should then call their GP, who can provide a diagnosis over the phone. People should not go to A&E if they suspect they have swine flu, unless they are seriously ill.

Every house in Doncaster will have received an advice leaflet by post. Further information can be seen on http://www.direct.gov.uk/en/Swineflu/DG_177814. Many members have enquired regarding the outlook for people with ME/CFS. Pathways asked Dr. Layinka Swinburne (a retired infectious disease specialist) her thoughts.

I only have unofficial thoughts! Some people say they never had flu or similar infections whilst they had ME and may be in the group whose immune function is hyperactive and are thus naturally partly protected. Others, at the opposite end of the scale, get everything that is going so it is hard to give general advice about protection. The other aspect is that some folk date their ME to some sort of immunisation - again an over-reaction. Hep B and 'flu vaccines were amongst the culprits blamed in my experience. Any one who suspects that have had an over-reactor in the past should think twice about having any sort of vaccine. In general people with ME seem very prone to suffer side-effects from drugs. What does the Association (i.e. Charles Shepherd) say about vaccines before travel for instance? At the moment the risk of getting swine flu seems fairly small and the offers of vaccine and anti-viral drugs seem to be based on herd statistics rather than individual needs.

My experience is similar. Basically most people with ME/CFS fall into two based on immune system categories:

More susceptible reactor are usually those who get everything infection that is going around. Should they become infected, then a typical bout of 'flu should be expected.

Less susceptible reactor usually have overactive immune systems (usually grade 2 or above) and may experience a masking effect, in that the flu will not show in the usual way. In the past some people have experienced a remission with flu that has lasted a number of days. This is thought to be because the immune system is fighting off the flu, and has reduced ability to cause ME/CFS symptoms.

The basic problem is that many of the ME/CFS symptoms are flu like, so even a doctor with ME expertise would have difficulty in distinguishing between ME/CFS and Swine Flu.

The ME association and Action for ME have updated advice on their websites. However there are specific issues for people with ME



1) Body temperature. Body temperature for people with ME/CFS is a good barometer of how the ME/CFS is behaving. Some people with ME/CFS have definite patterns, and some have abnormally low body temperatures, especially in bad periods. An abnormally raised body temperature is above 37 deg centigrade (100 degree Fahrenheit). Flu-like illness symptoms: cough, sore throat, congestion, runny nose, limb/joint pain, headache suggests flu rather than ME/CFS.

2) Generally people with chronic diseases, diabetics, asthmatics, chest, heart, kidney disease, liver conditions, suppressed immune systems (e.g. asplenia, neoplastic disease, chemotherapy) need to take extra care and be vigilant. This applies also to higher grades of ME/CFS.

3) A high proportion of people with ME are diabetics. Abnormally or unexpectedly high blood glucose readings (BM's) may precede onset of flu symptoms by 6-12 hours. The advice from Diabetes UK is *"Whether you catch swine flu or not, any illness can raise blood glucose. If you develop an infection follow these steps at home:*

- *Make sure you rest and drink plenty of additional sugar-free and decaffeinated fluids. Keep taking your tablets or insulin injection even if you are not eating—you may even need a higher dose than usual. Make sure you contact your GP or a member of your diabetes team if you are in any way unsure how to do this.*
- *Aim to stick to your normal meal pattern. If you are not able to eat normally try to replace some food with snacks and/ or drinks that contain carbohydrate, such as soup, milk, fruit or sugary drinks.*
- *If you already monitor your blood glucose levels, testing at these times is even more important.*
- *Make sure you have a good supply of blood or urine testing strips around, just in case. Write down the results which will be useful to inform yourself and/ or your healthcare what to do regarding your medications.*
- *If you have Type 1 diabetes and it is not correctly managed during this time, you could raise the risk of developing diabetic ketoacidosis (DKA), which requires urgent medical attention."*

4) A high proportion of MEs have asthma/COPD. The latest information I have is that the virus may make those susceptible more prone to an asthma attack. If you are asthmatic, be sure to use your preventer inhaler (if you have one) and keep a record of your peak flow meter reading. An increased need to use a reliever inhaler, or reduced peak flow, needs to be reported to your asthma nurse or doctor.

If you suspect flu, contact your doctor by telephone first for instructions. If appropriate, a prescription will be issued with instructions for collection. Tamiflu (capsules) or Relenza (inhaler) will be given. To be effective, the treatment needs to be started as soon as possible after onset of symptoms.

Summary of the advice from the private doctors.

Dr Myhill's information sheet for her patients points out that in all flu pandemics only about half of the population actually get flu. If you get it she advises to avoid contact where reasonably possible, rest, keep warm, and allow yourself to run a temperature. People who tend to run cold all the time are more prone to picking up infections and indeed this is the basis of the age old adage to "wrap up well in cold weather or you will catch a chill". People with low basal temperatures may have borderline hypothyroidism which could present as recurrent infections. The body reacts against viruses with inflammation and the result of inflammation is either directly toxic to the virus, or helps to physically expel virus from the body. For example, viruses are very temperature sensitive. For the body to run a fever is a good thing. Fever kills viruses (and bacteria). A good snotty nose helps to wash out virus from the nose and a hacking cough blasts the bugs from the lungs. Symptoms may be uncomfortable but should be welcomed as an appropriate way to get rid of the virus. This is why she hates to see the use of symptom-suppressing cold remedies such as paracetamol, antihistamines, alcohol, and decongestants, cough mixtures which interfere with the body's natural mechanisms of killing and expelling virus.

Do not symptom suppress!

If the symptoms of a virus do not improve after 3-4 days, then it is possible that a secondary bacterial infection has developed. A healthy body and immune system can deal with most bacterial infections, but for less than healthy people such as the very young, old, smokers, diabetics, heart failures, and people with a history of chest infection, call your G.P. The only exception to using paracetamol for fevers is in some children who tend to get fits if their temperature goes up too high. In this event paracetamol and tepid (have you ever had a fever and had cold water splashed on you?) sponging should be used to prevent this happening. Dr Downing's information for his patients warns that Tamiflu on average reduces the duration of flu symptoms by 1 to 1½ days, but at the cost of common gut side-effects (nausea, stomach-ache, vomiting). Both doctors believe that vigorous supplementation can prevent or moderate the impact of viruses.

The major recommended food supplements

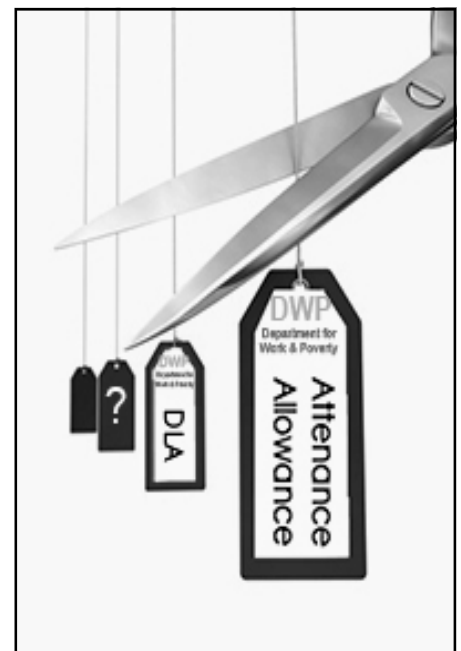
Vitamin C can reduce the risk of and the severity of viral infections. The normal recommended daily dose as a food supplement is 50mg. But just as for vitamin D, the dose is critical, and sometimes scientists have ignored this and used the wrong dose, guaranteeing negative results. One study that did things right found that 500mg of C a day cut the risk of catching a serious respiratory infection by 50% another found that 2000mg cut it by 85%. Excess vitamin C can cause diarrhoea.

Vitamin D Widespread vitamin D deficiency due to lack of sunlight was proposed as one reason that vaccines haven't worked better over the last 20 years. And why has influenza mortality in the aged not declined with increasing vaccination rates? Influenza vaccines effectively improve adaptive immunity; the most likely explanation is that the innate immunity of the aged declined over the last 20 years due to medical and governmental warnings to avoid the sun. While the young usually ignore such advice, the elderly often follow it. We suggest that improvements in adaptive immunity from increased vaccination of the aged are inadequate to compensate for declines in innate immunity the aged suffered over that same time. Flu pandemics are much more virulent during the winter months than the summer months. Indeed it is already being predicted that swine flu will flare up in the autumn. Vitamin D is the sunshine vitamin and so the more sunshine you can get without actually burning, the better your vitamin D levels. Indeed a recent paper in the Lancet confirmed that vitamin D is indeed highly protective against viral infection. Roughly speaking one hour of Mediterranean sunshine will produce 10,000 IU of vitamin D. Most pills in shops provide only 400 IU of vitamin D—furthermore, this is often as the inactive vitamin D2 rather than the active D3. People are recommended to have at least 2,000 IU of vitamin D3 daily and for people who may be particularly susceptible, a once weekly dose of 50,000 IU of vitamin D3 is recommended.

Zinc is probably the most common deficiency resulting in poor immunity. It is necessary for so many things, including brain enzymes, growth, tissue healing and immunity; this trace mineral can reduce your risk of respiratory infections. 10mgs four times daily into the mouth kills microbes.

Threat to DLA *Tristana Rodriguez from Policy Officer, Action for M.E.*

You may be interested in the communication below which gives details of Action for M.E.'s new survey in relation to the Government's new Green Paper. This is of particular importance to those who claim Attendance Allowance and Disability Living Allowance, and you can find supporting information on how the new proposals could affect people with M.E. detailed below. The survey can be completed online, or if you are unable to access the internet, please call Action for M.E. on 0845 123 2380 to request a paper copy. If you did not receive the update below previously, and would like to receive updates in the future, you might like to visit the Action for M.E. website: www.afme.org.uk which features a section on the right hand side where you can register.



Versatile Vinegar

Historical curiosity.

Vinegar is produced when a wine or beer fermentation goes wrong. The French call it *vin aigre* meaning 'sour wine'. It is believed to have been discovered quite accidentally some 10,000 years ago by wine makers. A roman legionaries' drink was Posca, vinegar mixed with water and honey. In the middle age during the Black Plague, four thieves were able to rob the houses of plague victims without being infected themselves. When finally caught, the Judge offered to grant the men their freedom, on the condition that they revealed how they managed to stay healthy. They claimed that a medicine woman sold them a potion, made of garlic soaked in red wine vinegar.



What is Vinegar?

Vinegar is basically about 5% dilute acetic acid. Vinegar is made by the fermentation of pretty much anything including sugar or starch. The most common starting material, due to its low cost, is malt vinegar. Balsamic vinegar is traditionally made with Trebbiano grapes and rice vinegar is made with rice. Distilled vinegar is a colourless solution of about 5% to 8% acetic acid in water, and is sometimes known as distilled, spirit or white vinegar, and is used for medicinal, laboratory and cleaning purposes as well as in cooking, including pickling. Glacial acetic acid is almost 100%, and is produced by fermentation or distillation or chemically. A wartime recipe for substitute vinegar is composed of 3% glacial acetic acid and burnt sugar, and is rumoured to still be used by some chippies. Vinegar, available to consumers for household use is between 5% and 8% and is relatively safe, but solutions above 10% need careful handling since they are corrosive and damaging to skin.

Scientific, Technology and Educational

When vinegar is added to sodium bicarbonate (baking soda), it produces a volatile mixture of sodium acetate and carbonic acid. The carbonic acid rapidly decomposes into water and carbon dioxide, which makes the reaction fizz. This is often used to illustrate typical acid-base reactions in school science experiments. Diluted vinegar can be used as a homemade stop bath during photographic processing. Vinegar can be mixed with heated milk to create a casein-based plastic. Acetic acid is used to preserve animal and plant specimens.

Household and In the Home

A mixture of salt and vinegar will get those difficult tea and coffee stains off your china cups when rubbed on gently. Give the colour of your carpets and rugs a new lease of life by brushing them with a mixture of 1 cup vinegar to 1 gallon water. A small bowl of vinegar left in a room will help remove tobacco smells and other odours. Vinegar is great for making spectacles and drinking glasses really sparkle. White and apple cider vinegar can be used for general surface cleaning such as kitchen worktops; bath tubs and so forth, and will also make your taps shine, especially if you wrap cling film around them while the vinegar soaks in. Wipe your oven with a cloth dipped in distilled vinegar and water to prevent grease build-up. Clothes will rinse better if vinegar is added to the final rinse water. Hot white vinegar can be used to remove traces of glue; for example, if you have removed a sticker from a flat surface. Leather will shine better if wiped over lightly with distilled vinegar.



Vinegar is also great for creating a fruit fly trap: Pour 2/3 vinegar, 1/3 sugar and 1 drop of washing-up liquid (but not alkaline or ammonia based) into a high narrow glass. By combining vinegar and syrup you create that smell of decay that these flies love so much - and the drop of washing

up-liquid breaks the surface tension. When trying to land on the surface, the flies will drown. Remove kitchen odours that come from burnt pots or when cooking certain foods by boiling a small amount of water with 1/4 cup white distilled vinegar so that the steam circulates throughout the room

Cooking

If your vegetables are wilting, freshen them up by placing them in 2 cups of water and a teaspoon of vinegar. Tenderise your meat, killing germs in the process by marinating it in vinegar with added herbs of your choice. Help prevent your boiled eggs from cracking by adding 2 teaspoons of vinegar to the water before boiling. The acid coagulates egg proteins.

The acidic nature of vinegar is useful for pickling. A little vinegar will stop fruit (e.g. apples and bananas) from going brown, and also adds to its freshness. If your vegetables are wilting, freshen them up by placing them in 2 cups of water and a teaspoon of vinegar. When boiling or steaming cauliflower, beets or other vegetables, add a teaspoon or two of white distilled vinegar to the water to help them keep their colour. This will also improve their taste, and reduce gassy elements. This also works when cooking beans and bean dishes. Make pasta less sticky and reduce some of its starch. Add just a dash of white distilled vinegar to the water as it cooks. Turn out great rice by adding a teaspoon of white distilled vinegar to the boiling water.

To make basic vinaigrette salad dressing use 1 part wine or cider vinegar to 4 parts oil. Make creamy vinaigrette by adding some plain or whipped cream to a mixture of 1 part white wine vinegar to 3 parts oil. Give some extra zest to your white sauce by adding 1/2 teaspoon of white wine vinegar. Make onion odours disappear from your hands by rubbing with white distilled vinegar. Add moistness and taste to any chocolate cake—homemade or from a box—with a spoonful of white distilled vinegar. To keep icing from sugaring add a drop of white distilled vinegar. It will also help keep white icing white and shiny. Make perfect, fluffy meringue by adding a teaspoon of white distilled vinegar for every 3 to 4 egg whites used.

Health and Beauty

Drinking a mixture of 2 teaspoons of apple cider vinegar in a cup of water will help to settle an upset stomach and is reputed help to relieve arthritis symptoms. Some insect bites and stings (wasp stings, but not those from bees and ants), sunburn and rashes such as urticaria (hives) can be relieved by applying a little vinegar directly to the affected area. Soothe hot swollen feet by putting a little apple cider vinegar in a foot bath. A teaspoon of vinegar swallowed straight down rarely fails to cure hiccups. Help keep dandruff at bay by rinsing with vinegar and warm water after shampooing. A little vinegar in your bath water will help to relieve dry skin.

A dilute solution of vinegar is an old cough remedy when mixed with lemon and honey. Medicinal vinegars are made by infusing herbs and natural medicines in vinegar. Squill vinegar is an Edwardian era cough remedy used, up to 25 years ago on the NHS, in 'Gees Linctus'. Aromatic vinegar is an old remedy for treating warts.

In the Garden

Full strength vinegar makes a good weed killer when sprayed on directly. In hard water areas you can add a cup of vinegar to a gallon of tap water to increase soil acidity. Freshen up and prolong the life of cut flowers by adding a little vinegar to their water. Vinegar can be used as an herbicide. Acetic acid is not absorbed into root systems, so vinegar will kill top growth, but perennial plants will reshoot. Vinegar made from natural products classifies as organic and so there is interest in its being used on farms, orchards, and gardens which are certified as organic.



So when you put vinegar on your fish and chips, it's more than just a bit of extra flavour!

More on local water fluoridation issues

By Elizabeth A McDonagh, Chairman, National Pure Water Association

Two of Yorkshire's Primary Care Trusts, 'Bradford and Airedale PCT' and 'Kirklees PCT' have asked the Strategic Health Authority for Yorkshire and the Humber to commission a feasibility study as the first step in a proposal to fluoridate parts of Yorkshire's water supply.

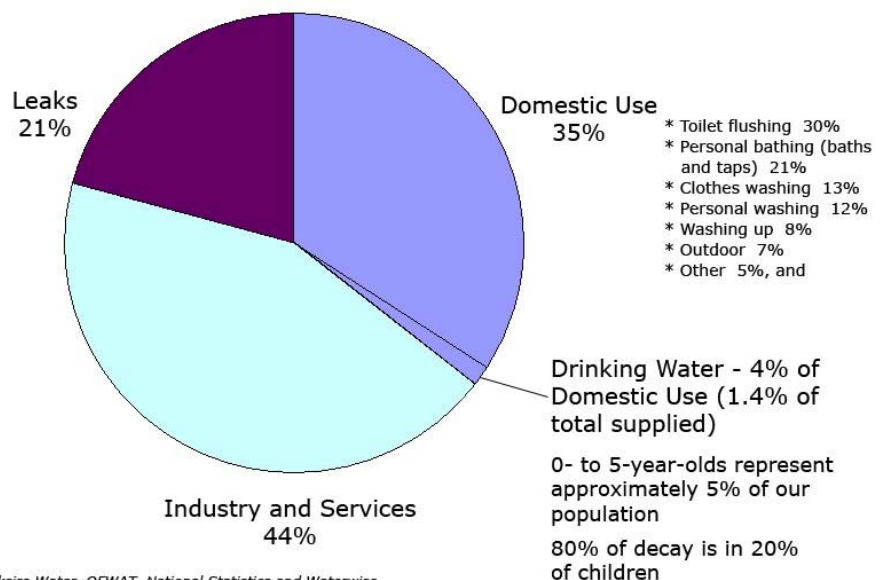
Yorkshire Water declined to fluoridate in 1995, stating that the Government did not offer the Company adequate indemnity against the risks involved; their customers did not want it and that fluoridation does nothing to enhance water quality but adds to the complexity and risk involved in water treatment. As a result, water currently supplied by the Company is not fluoridated. Some Yorkshire customers do receive fluoridated water because their water supplier is Severn Trent. Bawtry and parts of South Sheffield are in this category.

The Water Act 2003 took away a water company's discretion as to whether to fluoridate or not. Two Statutory Instruments are attached to the Act. One indemnifies the companies; the second makes a three-month 'public consultation' obligatory before any new fluoridation scheme is introduced. Such a consultation is conducted by a Strategic Health Authority (SHA) which can order a water company to fluoridate if "it considers the health benefits outweigh the objections". There is no requirement for a majority of the population to be in favour.

The first Consultation under the 2003 Act took place in Southampton and Hampshire in Autumn 2008. 72% of written local responses rejected fluoridation. A telephone poll of 2060 people also rejected fluoridation by a 6% majority. While a majority of Southampton councillors supported fluoridation, Hampshire County Council held a rigorous investigation and voted unanimously against it. The unelected South Central SHA decided to impose it on the population, dismissing every argument presented by the opposition.

The Strategic Health Authority for 'Yorkshire and the Humber' is unlikely to restrict any consultation to the areas of the two PCTs ('Bradford and Airedale' and Kirklees) which have asked them to commission feasibility studies. As in South Sheffield, the configuration of the pipework for water will largely determine which households are fluoridated. For the same reason, in Hampshire some areas with high tooth decay will not be fluoridated while areas with low tooth decay will be.

Where Yorkshire's water goes



Sources - Yorkshire Water, OFWAT, National Statistics and Waterwise

Only about 1.3% of a fluoridated water supply is drunk. More than 98% is used for other purposes or lost in leaks. Can this profligate use of scarce NHS funds be justified, especially when the evidence that fluoridation reduces tooth decay is extremely weak? Studies show that tooth decay is highest among deprived children and that topical application, (e.g. use of fluoride toothpaste) not swallowing fluoride, is most effective in reducing it. This, not a blind belief in fluoridation, is the evidence that should inform public policy and clinical practice.

Only repeal of the nonsensical and undemocratic legislation regarding fluoridation will protect the people of Yorkshire from having fluoridation thrust upon them. The forthcoming General Election is an opportunity to cleanse Parliament not only of the abusers of the expenses system but also of those MPs who support compulsory medication via the water supply.

Getting the best from National Health Service appointments

The NHS is notorious for waiting and appointments. When you do get one, it's usually one of many and you are limited to 3-6 minutes. Compare this with private doctors or therapists who will take time to explore and listen to what you have to say.

Before

Write down your two or three most important questions.

List or bring all your medicines and pills - including vitamins and supplements.

Write down details of your symptoms, including when they started and what makes them better or worse. Ask your hospital or surgery for an interpreter or communication support if needed.

Ask a friend or family member to come with you, if you like.

During your appointment.

Don't be afraid to ask if you don't understand. For example, "Can you say that again? I still don't understand." If you don't understand any words, ask for them to be written down and explained.

Write things down, or ask a family member or friend to take notes.

Ask questions before you leave your appointment - make sure you know the following:

1. What might be wrong?

You could ask the following questions:

"Can I check that I've understood what you said?"

"What you're saying is...."

"Can you explain it again? I still don't understand."

"Can I have a copy of any letters written about me?"

2. What about any further tests, such as blood tests, scans and so on?

"What are the tests for?"

"How and when will I get the results?"

"Who do I contact if I don't get the results?"

3. About treatment, e.g. which, if any is best for you

"Are there other ways to treat my condition? What do you recommend?"

"Are there any side effects or risks?"

"For how long will I need the treatment?"

"How will I know if the treatment is working? How effective is this treatment?"

"What will happen if I don't have any treatment? Is there anything I should stop or avoid doing?"

"Is there anything else I can do to help myself?"

4. What happens next and who to contact

"What happens next? Do I come back and see you?"

"Who do I contact if things get worse?"

"Do you have any written information?"

"Where can I go for more information, a support group, or more help?"

Before you leave your appointment -

Check that: you've covered everything on your list

Check that you understand, for example "Can I just check I understood what you said?"

Make sure you know what should happen next and when. Write it down.

Ask who to contact if you have any more problems or questions, about support groups and where to go for reliable information and for copies of letters written about you - you are entitled to see these.

After your appointment,

Write down what you discussed and what happens next.

Keep your notes.

Book any tests that you can and put the dates in your diary.

Don't forget, ask the following: "What's happening if I'm not sent my appointment details and can I have the results of any tests?" (If you don't get the results when you expect - ask for them.)

Ask what the results mean.

Group Meeting: 4/8/2009. Dial Doncaster

In the past DIAL has been a useful resource to Leger ME members in help with supplying information and support with welfare rights problems. In order to get an update and introduce members to DIAL, I asked John Burke, Community Development Manager, Dial Doncaster to come along to one of our afternoon meetings.

DIAL Doncaster was formed in early 1983 when John Gaskell was seconded by ICI (Imperial Chemical Industries) to the Doncaster District Association for the Welfare of the Disabled under a Government sponsored scheme. His role was to visit disabled people in Doncaster to ascertain what they thought was needed most. An Information and Advisory Service covering all aspects of disability was the result of his survey. DIAL's service began in Bentley Library with two paid workers and, after various moves, transferred in 1995 to shared premises at The Disability Resource Centre. During this time DIAL's staff increased to nine paid workers and 20 volunteers with the quality and range of services improving dramatically. In November 2004, DIAL relocated to its own premises based at Shaw Wood Business Park and currently employs 20 paid workers and 25 volunteers.

DIAL provides information, advice and support to people with any disability (including physical, sensory, learning disability and people who have mental health problems) and those with ill health (e.g. Cancer or heart disease). DIAL also provides a service for families, carers and friends of disabled people and for professionals working within healthcare. DIAL's funders are as Doncaster Local Authority, NHS Doncaster, The Big Lottery Fund, Department of Health, Doncaster NDC, Coalfields Regeneration Trust and Department of Health (RADAR).

Currently DIAL's aim is to provide an easily accessible Information and Advisory Service for people who live in the Doncaster Borough. By providing this service we aim to raise awareness of disability issues in order to influence change. We aim to empower and enable disabled people to live a more enriched and independent life. DIAL Doncaster covers the Doncaster Metropolitan Borough. Dial is confident that they provide a service that is second to none. The DIAL Network is one of the leading disability information and advice organisations. DIAL Doncaster is a registered charity, Company Limited by Guarantee and a voluntary organisation. It is managed by a Management Committee of 15 people who are responsible for making sure that the organisation is working effectively to meet the needs of its service users. The majority of DIAL's Management Committee, staff and volunteers are either disabled or have had experience of disability, which means, as an organisation, they are close to the needs of their service users. It takes a lot of people with many skills to make DIAL Doncaster work. All play an important role but the spirit and commitment of DIAL's volunteers is invaluable.

What DIAL Doncaster does?

DIAL provides information, advice and support to people with any disability (including physical, sensory, learning disability and people who have mental health problems) and those with ill health (e.g. cancer or heart disease). They also provide a service for families, carers and friends of disabled people and for professionals working within healthcare.

- Advice where it's needed
- Telephone advice
- Drop-in advice and support
- Outreach advice
- Producing fact sheets
- Home visiting service
- Information available in other languages upon request
- Text-phone
- Braille, tape and large print information upon request
- Promotion through local groups of disabled people
- Talks to community groups and hospitals
- Disability Awareness sessions in local primary schools and after school clubs
- Information via *Touchscreen* kiosks in GP surgeries

Dial Doncaster Welfare Benefits Service

DIAL Doncaster's Welfare Benefits Team help over 6000 clients every year with all issues relating to State Benefit entitlements. Last year they helped claim over £2 million pounds in unclaimed benefits for disabled people and their carers. They represented at over 200 Appeal Tribunals and answered questions on entitlement to Disability Benefit criteria. They have helped to realise over £14,000,000.00 in benefit claims, much of which will be spent within the local economy.

Provision of a 'Quality' service.

DIAL Doncaster is an Investors in People organisation. It was the first voluntary group to achieve this accolade in 1997 and has been reassessed every 3 years. The organisation has the Community Legal Services Quality Marks - "Specialist in Welfare Benefits" and "General Help and Casework in Disability". DIAL Doncaster also has the DIAL UK Quality Mark - "Positive About Disabled People" Award and has recently achieved the ISO 9001:2000 quality mark. This is an

Internationally recognised award, a standard Quality Management system that demonstrates that an organisation can provide a consistent standard of quality.

How DIAL administers benefits help

- Benefit Advice help line
- Assessments against DLA/AA eligibility
- Assistance with form/claim filling
- Revisions and Supersessions
- Appeals and further Appeals to Commissioners representation
- Other Services include:
- Wheelchair Hire Service
- Debt Advice
- Blue Badge/Passport photographs
- Sale of Radar toilet keys
- Sale of car stickers for disabled drivers/passengers
- Access Audits for various services
- Charity Shops
- Holiday Lodge

Members Question Time to DIAL.

Having known that through the recession many disability support organisations were having their funding cut back or withdrawn altogether. DIAL was feeling the pinch. John Burke said that DIAL's charity shops at Woodlands and Armthorpe were busier than ever - in effect they were providing another service stream, but also had their own income. They were opening a third.

The lead of the meeting was passed over to Susan, a Welfare Rights officer working for DIAL. She explained she suffered from Myasthenia Gravis, and because of this, it helps her understand the issues around ME/CFS. A member questioned whether DIAL employed disabled people, she had been an unpaid volunteer for DIAL, and had eventually been employed. John had followed a similar path, after being unable to work in the engineering industry.



Myasthenia gravis (MG) is an autoimmune disease, where auto antibodies are produced by the disease process that damages the motor end plates, the connection between muscles and nerves, making them less effective. The course and symptoms are similar to grade 2-3 relapsing and remitting ME. However unlike with ME, the disease process is well known to all health professionals, and there are drugs which are effective in treatment. There seems to be no issues regarding rebound, unlike with ME.

Roseanne is a former health worker in her late 40's. I had helped her with her first ESA 50 form, which was complete and due for submission. She expected to be summoned to Crossgates House for a medical examination. She asked is there any advice with reference to attending the medical or if DIAL could help her with her medical if the outcome was unsatisfactory. As very little is known about the way the DWP assess ESA, Susan could not offer any detailed advice, but offered support, should it be a problem. Obviously ESA forms should be treated with the same scrutiny and cautions as DLA and IB forms. Susan went on to explain that she holds a welfare rights surgery by appointment at Tickhill hospital. DIAL do their own assessment before committing their time. She told us that she watches people as they walk to the appointment, and has seen cases where a client has hobbled in, and run out. The DWP clearly do a similar thing for medical examinations.

One member raised the issue about Crossgates House being in the middle of town, and a fair walking distance from the bus station. Parking is very limited, and I explained that many members go by taxi, and take a chaperone. An early question in medicals reported by clients is "how did you get here?". It's quite clear that if someone has put that they can't walk 50 yards in an ESA 50 or IB 50 form, and they walk from the bus station - the DWP is going to be very sceptical about that statement and the rest of the form.

John, in his late 50's had been recently refused Incapacity benefit for the third time. His two previous refusals had gone to tribunal, both of which he had eventually won. John was looking for someone to help him with an appeal and tribunal, as the previous organisation he had used had lost its funding. Susan reassured John that he had not been singled out, and was not the only victim of a general purge. However DIAL Doncaster could not offer support, as John lives in the Rotherham area.

Cedric, in his late 50's, had recently submitted DLA & ESA applications. He had been awarded DLA, but was still expecting to be summoned for an ESA medical. He was concerned that if the ESA 50 medical outcome was unfavourable, he would lose his DLA. Really at present there is no way to predict the outcome, as ESA and DLA are two separate benefits with deferent criteria, and require different medical examinations, although both are carried out by Altos. I quoted a couple of cases where information contained on a IB85 form (IB results form, not given to the client) had been accessed by DLA adjudication officers, and used as evidence to deny DLA. Susan explained that there is no way to predict DLA awards. She quoted a case of identical twins, one receiving the full DLA award, the other receiving nothing. There is also a DLA jeopardy rule. If someone received DLA mobility, and subsequently applies for the DLA care component, then, the whole case is reviewed, and it would be possible to lose the DLA mobility component. We don't understand the relationship between ESA and DLA though clearly there seems to be one.

Another issue was that DIAL can arrange short term hire of wheelchairs, e.g. for holidays & airports.

Website: <http://www.dialdoncaster.co.uk/> Helpline Telephone 01302 327 800

Open 9:30 - 4:00 (Monday to Thursday), 9:30 - 3:00 (Friday)

Answer phone all other times. E-mail: advice@dialdoncaster.co.uk

What have members reported about DIAL's Service?

1) Where people have been accepted under DIAL's criteria for services, the outcome has been satisfactory in almost all cases. There have been the odd couple of DLA cases where other services have produced a better outcome after DIAL has tried to help.

2) DIAL's Doncaster Services are limited to the Doncaster MBC area. So anyone outside the area is denied access to these services, and the service boundaries do not cover the same area as the Doncaster Health or NHS boundaries. There are equivalent DIAL branches in some adjacent areas, but not all the services are provided or are available. Members from the former Dearne area have had difficulties as that area is covered by Doncaster MBC which is fine, but Barnsley MBC and Rotherham MBC provide no support. There is a similar problem with the small villages to the north of Doncaster.

3) Some members referred by me to DIAL in the past have been refused service, because DIAL has a policy of 'closing' to new cases, if they have a heavy case load. This is annoying and irritating for me because usually it is because a tribunal or some other urgent issue has been raised. I don't like this policy. I have avoided referring to DIAL, and resorted to using other service providers. Also members refused service have not been referred back to us.

4) One of the requests I made to DIAL Doncaster for the meetings was for further information and support on Employment and Support Allowance, particularly the ESA 50 form. The only information they provided to me was a factsheet from the Disability Alliance, which is on file available to members. I am very disappointed with DIAL considering that ESA has now been going since October 2008, and it is now August 2009. (See Pathways no 18 for further details on ESA).

The World of Diabetes and ME/CFS

In our ME group there are about 10 members who are diabetic. Normally it's bad enough dealing with ME, but as a diabetic it's just adds to our problems. Diabetes, sometimes known as diabetes mellitus, is a long-term (chronic) condition caused by too much glucose (sugar) in the blood. Diabetes affects two million people in England and Wales. It is also thought that there are a further 750,000 people who have the condition but are unaware of it. Normally, the amount of sugar in the blood is controlled by a hormone called insulin, which is produced by the pancreas (a gland that is located behind the stomach). When food is digested and enters the bloodstream, insulin helps to move any glucose out of the blood and into cells, where it is broken down to produce energy. However, in diabetes, because there is either not enough insulin, or because there is a poor response (resistance) to insulin, the body is unable to fully use the glucose in the blood stream. While mistreated ME usually results in inconvenience, ignoring diabetes is dangerous leading to blindness, loss of limbs usually legs, kidney disease, stroke, heart attacks and death. That is why the NHS treats diabetes with a firm hand. If the diabetes is well controlled, a normal lifespan can be expected, if not, it takes a least 10 years off one's life and leads on to misery. There are two types of diabetes:

Type 1 diabetes occurs when the body produces no insulin. It is often referred to as insulin-dependent diabetes mellitus (IDDM), and sometimes known as juvenile diabetes, or early-onset diabetes, because it usually develops before the age of 40, often in the teenage years, and accounts for 5-15% of all people with diabetes.

Type 2 diabetes occurs when not enough insulin is produced by the body for it to function properly, or when the body cells do not react to insulin. This is called insulin resistance. It is far more common than type 1. Around 95% of all people with diabetes have type 2 diabetes.

Gestational diabetes is diabetes in pregnancy which usually clears after the birth, and affects approximately 2-7% of pregnant women. Pregnancy makes existing type 1 or type 2 worse.

Diabetes insipidus is not true sugar diabetes, but a completely different problem affecting water balance caused by kidney or pituitary abnormalities.

Other forms of diabetes. There are subtypes of both type 1 and 2 involving different mechanisms. Of interest is a type of type 2 related to mitochondrial myopathies (dysfunction), similar to that seen in ME/CFS, and for which tests may be carried out. Many people with diabetes mellitus (DM) get it at the same time as ME/CFS, but usually they are diagnosed as two separate disorders. I think there is a link, but further research is needed.

Diabetes Jargon

Honeymoon period is a brief remission after sudden onset of type 1 diabetes; insulin requirement may fall to nil, before the full blown type 1 returns

Hb1ac is a blood test measuring the damage done to blood cells by blood sugar. It is long term index of how well the diabetes is controlled, and most diabetics have it done by their GP 3-6 monthly.

Hypoglycaemia (hypo's) is a temporary condition where the blood sugar level is below 4 mm/l. It is associated with tremor and agitation, at worst unconsciousness or death. It is usually caused by too much activity or diabetic medication usually insulin or sulfonylureas, not enough food or too much activity and cleared by eating carbohydrate (sugar) or with glucagon injections in an emergency. It is usually a major problem with type 1 but less frequent with type 2 diabetes. ME/CFS causes hypos due to impaired activation of the HPA axis. This is not remedied by the usual strategies sometimes confusing health professionals who don't understand.

Hyperglycaemia is too high blood sugar usually above 7 mm/l. It is typical of too little medication, too much food, too little activity, or sometimes, in well controlled people, due to ME itself, or to viral or bacterial infections. It may happen after a meal in most diabetics causing drowsiness.

Ketosis (DKA or diabetic ketoacidosis) is a clinical emergency, usually caused by sudden onset of type 1 diabetes, sudden worsening of type 2 to type 1, or no food, and is the cause of death in many diabetics. Treatment is with insulin and IV glucose drips. Low carbohydrate diets like the Atkins type can induce ketosis; these are dangerous for this reason and can cause artery damage.

Mild Diabetes is a misleading term, formally used to describe Type 2 diabetes, because insulin is not needed. It is far from that because of problems related to high blood pressure, obesity and cholesterol.

Comparison of Type main types of Diabetes and M.E./C.F.S.

Characteristic	Diabetes Mellitus Type 1 (IDDM)	Diabetes Mellitus Type 2 (NIDDM)	M.E./C.F.S.
Prevalence	0.15%	1-2% may be higher	0.15–0.2%
Age at onset	Any, but mainly in children and younger people	Usually later life, but can occur in teens especially Asian. Sometimes pregnancy	Any, mainly 30-50
M:F Ratio	1:1	1:1	1 : 3
Disease Process	Pancreas stops producing insulin.	Pancreas cannot produce enough insulin. Cell insulin resistance, & metabolic syndrome	Mitochondrial abnormalities & other mechanisms.
Glucose intolerance	Not usually present.	May be present years before DM2 onset.	Erratic in some cases.
Origin	Auto immune disease, damage or after surgical removal of pancreas	Auto immune damage, obesity, induced metabolic changes due to age& lifestyle	Auto-immune.
Onset experience	Usually sudden and a medical emergency. Ketosis (nail polish breath). coma	Gradual. Symptoms minor. Many be present years before diagnosed. Usually and unexpected finding in routines tests.	80% sudden after life event or 20% gradual
Management	Daily insulin injections Cocktail of short (soluble), medium (zinc) or long Proamine acting, insulins. Balanced with food and activity	1) Dietary restriction 2) Control weight if necessary 4) a) Metformin, (s/e GI) sulfonylureas, (s/e 2→1) acrobiose (s/e IBS) glitazones (s/e CV) Gliptin, exanidie inj (insulin stimulant) Insulin(s) if all else fails.	Pacing ,lifestyle restriction avoidance of known stressors, Nutritional, Analgesics,. NSAIDs, TCADs
Weight	Most DM1s are thin and have a normal BMI.	Most DM2s have a spare type around the middle waist associated with metabolic syndrome and overweight	Tends to be both
Common Short term issues	Balancing lifestyle, food and insulin. Hypoglycaemia (too much insulin activity or not enough foods) Keto acidosis coma	Diet retractions are the cornerstone, and weight if needed. Metformin may be introduced if these fail o key	Balancing lifestyle with limitations & pacing .
Common Long term issues	In later life, if blood sugar control is good and balance is right, long term complications are about the same as a healthily person.	DM2 gets worse with age. In later life trouble comes in 3s, weight increase, high blood pressure, high cholesterol. Requires many other drugs to control conditions and strict weight control.	Balancing lifestyle with limitations & pacing .
Testing	GP: HB1ac 3-6 monthly Home BM: 4x daily	GP: HB1ac 3-6 monthly Home BM (NICE says weekly)	Annual general health check.
Micro vascular Complications Retinopathy (blindness) Nephropathy (kidney failure) Neuropathy	If well controlled about the same as a normal person if uncontrolled can progress very quickly	Risk increases with age, but minimised by good diabetic control otherwise disastrous	Changes are immune & neurological with variable involvement of other body systems.
Macro vascular Complications Stroke Heart Attacks Thrombosis	Risk about the same as a normal person if well controlled, otherwise potentially disastrous	Risk about the same as a normal person if well controlled, otherwise potentially disastrous	about the same as a normal person if weight cholesterol and blood pressure are well controlled,
Soft Tissue	Muscle weakness Cramp especially at night	Muscle weakness Cramp especially at night	Sore weak muscles Morning Stiffness
Fatigue/Malaise	If blood sugar is high	If blood sugar is high	Always on exertion
Exercise	Beneficial can have normal ability if well controlled	Beneficial, but very often limited	Rebound always present, sometimes delayed

Good diabetic housekeeping

Join Diabetes U.K. they are like the ME Association, and produce a magazine called *Balance* which gives a wealth of information. **Once a year**, or more frequently if needed, have an MOT with a diabetic nurse or hospital.

BM's Use a blood glucose meter to check your level before and after food.

Diary. Record your readings, doses and other events like hypos. People with ME should record body temperature as it can help explain abnormal blood sugar, hypos, infections or other problems often encountered by PWME.

Diet. Follow the advice of your dietician or doctor. MEs usually fair better using a glycaemic eating strategy consistent with a diabetic diet.

Insulin. Keep in a fridge

Hypos keep a supply of sugar or e.g. *Hypostop* etc to stop a hypo.

Blood pressure should be checked every few months, treat if raised. Start with ACE inhibitors e.g. enalapril.

Cholesterol. Ensure it is checked and treated if above guidelines.

Try B3 or fish oil first. Statins make some MEs worse. Avoid simvastatin; atorvastatin seems OK or use fibrates.

Weight. Keep within ideal limits. Loss of excess weight reduces the severity of diabetes as well as helping ME.

Feet Diabetics may lose sensation in feet and pick up limb or life-threatening injuries without knowing it. Follow foot-care guidelines

Eye. Have your eyes checked once a year by an optician and have a retinal scan if available.

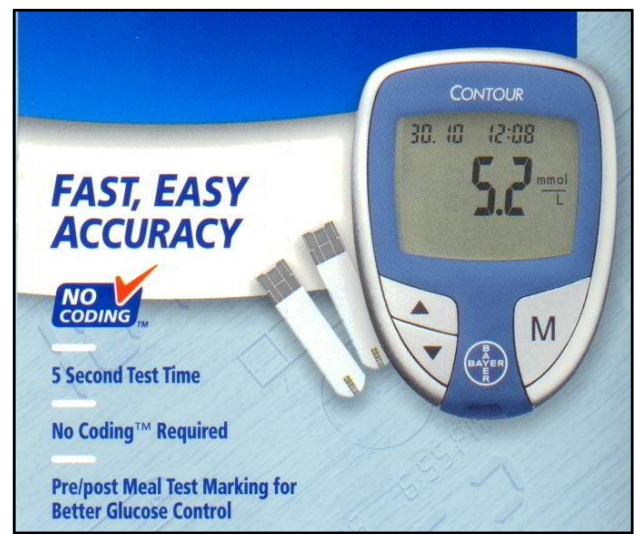
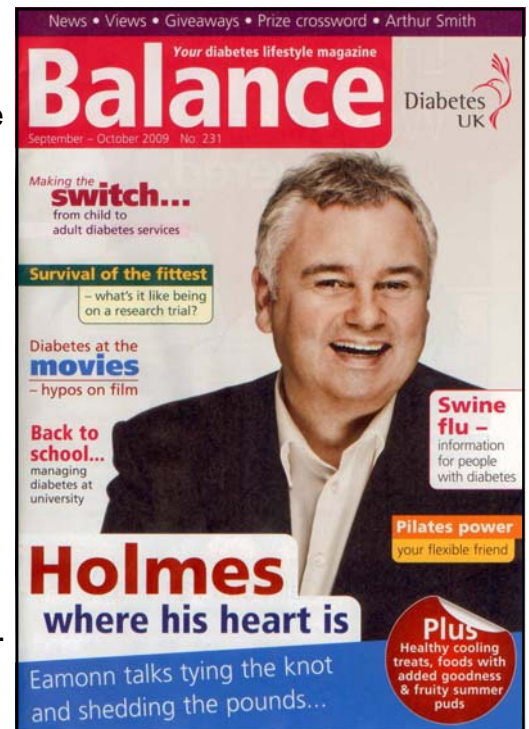
Skin may be prone to fungal infections. Keep warm wet places dry e.g. watch armpits, crutch and feet. If necessary, treat and treat vigorously.

Infections may increase need for insulin three fold. Watch BM, seek medical help if raised.

Healing cuts, wounds and injuries may take two or three times longer to heal than a normal person.

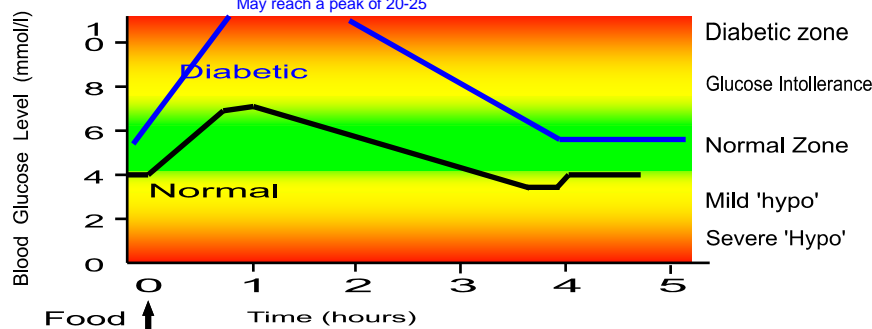
Driving Tell your insurance company and DVLA you are diabetic

Prescriptions All diabetics get free prescriptions, except those type 2 controlled by diet alone.

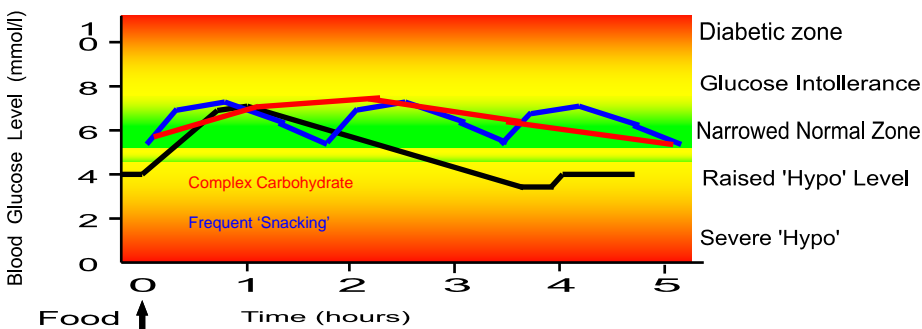


Home testing equipment for blood sugar level in diabetics. Left is Diastix, for urine testing -sugar appears in the urine if BM 's are greater than 20 ish, the diabetes is untreated, or you got it wrong by missing treatment or eating too much. Reading is by comparing the colour of the stick to a chart on the side of the bottle. Anything but blue means trouble. Middle is a older type blood-glucose meter with reagent strips which gives a digital reading. Right is a more updated model. These meters are not supplied by the NHS, and patients are expected to buy them. The test strips are quite expensive, but are supplied free on prescription.

The Normal Blood Sugar Response

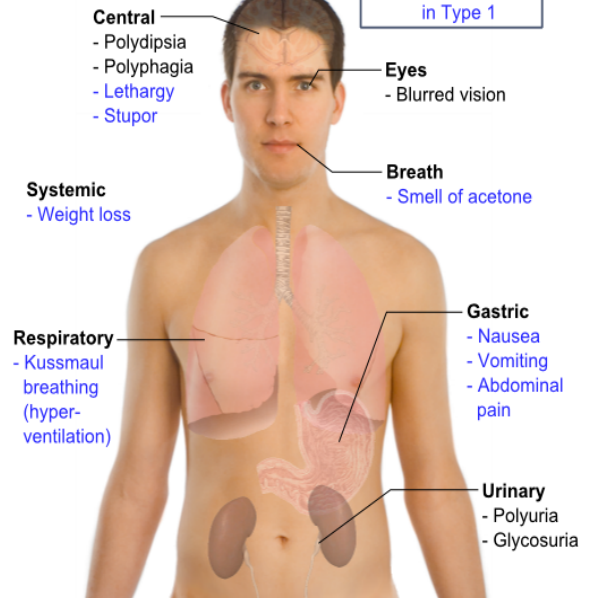


The M.E. Blood Sugar Response

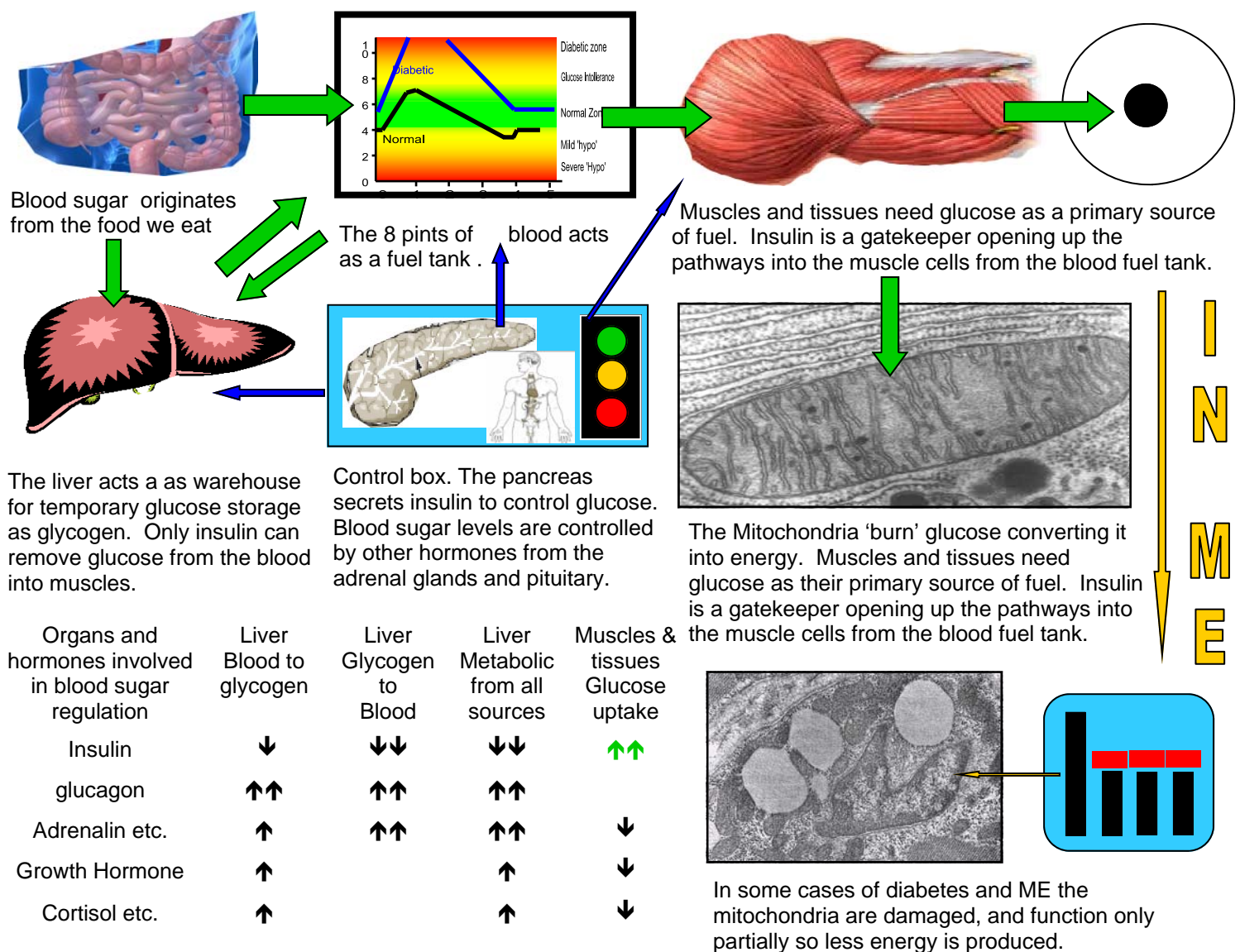


Main symptoms of

Diabetes



Blood-sugar pathways Diabetes is all about lack of control of blood sugar and controlling it. Here is a graphic representation of the issues involved.



North of Doncaster

Personal Comment by Trevor Wainwright

HIV – ME – A PARALLEL: CONCLUSION

Well this is it three issues later than planned, you may recall I ended North of Doncaster (Pathways 18) with: So what of the ME /AIDS Parallel? I'm saving that for the next issue along with a previous article 'The Wesseley'. First a poem dedicated to a sufferer who initially wrote it for the poetry book with her poem in it then turned against it on hearing of the HIV connection. I'm saving 'The Wesseley' for the next issue - something to look forward to.

On a happier note my eyes are continuing to improve, I did have a scare with my left eye showing the same symptoms as before but it turned out that I had had a haemorrhage which they laser-treated there and then. It only hurt for the afternoon. I was told, however, that if I noticed a shadow appearing in the bottom of my eye get straight to casualty. This means that due to the set up of the eye, there will most likely be a tear in the upper part of the retina, something for us all to bear in mind.

Another symptom is floaters accompanied by what can be described as flashes of sheet lightning on the periphery of the eye. Again get straight to casualty. I was told take a taxi as using the bus and walking may cause further damage so I now carry an emergency taxi fund in my wallet. *Trev*

The Monster Within

There is in me a Monster within,
Though I've committed no visible sin.
This monster will go to many a length
To rob me of my strength.
Yet if you will stand by my side,
And in my hour of darkness abide.
Giving me a shoulder to cry on,
And be there for me to rely on.
From this so called modern day scourge,
I may one day emerge.
Out of the darkness of tormented body and
mind,
and with your support, one day may find,
I've left the Monster called ME behind.
(Trevor Wainwright)

Now the Parallel

HIV - ME - A PARALLEL

There is no cure only management
Both illnesses carry a stigma
Both have been the subject of ridicule
Both have been given ridiculous names
Both attack the immune system
Both screw peoples lives up
Both can affect anyone
Both illnesses are severely debilitating
Both require further research
Both require someone's help
Both require someone's understanding
Yours



Energising ME Research

Up to 240,000 people in Britain wake every day with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a condition involving debilitating malaise, pain and neurological symptoms. Across the world, millions are affected. Yet, research into this illness is meagre, given the scale of the problem.

ME Research UK is a national charity with the principal aim of funding biomedical research into the causes, consequences and treatment of ME/CFS.

Medical research is, by its very nature, expensive. Help us to continue our work by purchasing Christmas cards from our range.

You can view a larger version of each card on our website at www.mereseach.org.uk.

The wording inside each card reads "Sold in aid of ME Research UK, registered charity number SC036942" (inside left), and "with Best Wishes for Christmas and the New Year" (inside right).

The back of the card has the MERUK logo at the bottom, with the words "ME Research UK commissions and funds scientists and clinicians to undertake high-quality research into the causes and consequences of ME/CFS. We rely exclusively on donations from the general public to advance our work", followed by our address and website.

Energising ME Research by Energising Christmas
ME Research Group for Education and Support
Charity Number SC036942



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