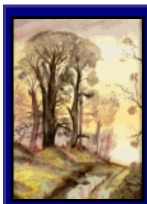


Pathways

Price £ 2.00 (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.

Dietary Issues and ME/CFS.

In this issue of Pathways I am going to deal with dietary issues that I believe are relevant in ME/CFS. As was quite clear from a conference that I attended in the Sheffield ME/CFS clinic, there are many diverging opinions, and no common consensus. Many believed that dietary issues can have a big impact on Me/CFS. Being a health professional and having passed several postgraduate course in dietary and nutrition issues I feel that I am in a position to filter out the more credible issues from the dubious ones.
I have adapted much information with permission from the British Dietetic Association and other sources where acknowledged. *Mike*.

Linking Up Contact Service:

Linking Up is a very user-friendly Contact Service, and it is free to all members of the Support Group. Be in contact with other members of the Group by telephone, letter or email by becoming a member of the Linking Up Contact Service. Every person who becomes a fully paid up new member of the group will find a form to fill in and return to Mike Valentine within their membership package, in order to join Linking Up. Linking Up is open to everyone, all ages welcome. It is a great way to contact people, compare experiences, and more importantly make new friends! Feel free to contact Carolyn via 01302 787353 (after 1pm) or email her at carobee@bt.internet.com

Leger ME Bulletin Service

Due to financial limitations Pathways is produced quarterly, but is not frequent enough to give short notice information about group meetings and activities. For example, the last Pathways was in the early days of December, but was too early to give notice of meetings arranged for January, February and March. For this reason Pathways will no longer carry details of group activities. The regular meeting slot is the last Friday afternoon in the month at the Redmond centre, stating at 1.30 p.m.

Based on the experience of other groups, we have decided to start a bulletin service based on email and the Leger ME Website. The bulletins will be emailed to members who have enrolled into the service. They will also be displayed on the Leger ME website under Stop Press. Members who do not have internet access can receive email via the cable/satellite digital TV platforms, and through various telephone devices. Internet access is available through most libraries and at the Redmond Centre. For further details see our website at www.leger.me.uk or telephone 01302 787353.

You Write

Julie writes *Is there a test for ME/CFS ? My doctors says there isn’t, but my mother has met some who says there is*

A test for ME. There is no litmus paper test, like for diabetes etc that is 100% reliable. The nearest is a Mitochondrial Function Test done by Acumen laboratories. It's reliability is not proven to the satisfaction of the NHS, but is good enough for many private doctors. You could pay £300 + for the test.

In ME people, almost all of the results have come back abnormal except in the case of one that I am aware of. That lady definitely has ME. Dr Myhill says the test is not 100% reliable, as she is aware of some false positive results, but reliability is possibly higher than 95%. The test may give an answer about the cause of the ME, and may be useful is assessing how effective any treatment is. The tests measures about a dozen different things, and the results are expressed as a number worked out by a mathematical formula. (Please see early issues of Pathways). Most of the results I've seen are completely different to mine.

I think we have to be careful about ME. Most diseases come in subtypes or varieties. Diabetes for example has two main types A and B. Although the results of the disease are similar, the root cause and treatment objectives are completely different. The same applies to Arthritis and MS. Gene expression studies have shown that there are at least two different sorts of ME. Although the symptoms are the same, the root causes are completely different. It would be prudent to assume that any effective treatments would have to be different as well. Most researchers and doctors have assumed ME/CFS is one disease. I'm convinced that there could be as many as six subtypes. When clinical trial results are assessed, the typical success rates for treatment are between 30-40% for ME/CFS. The existence of subtypes would explain this. To be accepted as positive, the success has to be at least 70% before drug companies would be interested in marketing a product.

In practical terms you will know yourself if any treatment or intervention is working. The Mitochondrial Function Test will not lead you to a cure, but may help identify a treatment strategy. For me and others it was the first piece of paper that produced hard lab evidence that something physical was wrong.

Jane Writes *I was just wondering whether or not I have to notify the DVLA that I have ME. Do you know what the regulations are on this? Should I declare it to the insurance companies?*

A similar question came up at the Sheffield ME Conference in October last year. Marcus Windle who is a welfare rights advisor in Sheffield responded as follows:

“You do have a legal responsibility to tell the DVLA if you have an illness which will affect your safety in driving. You have the same duty to report, whether you are an existing driver with a new diagnosis, or whether you are applying for the first time. The list of notifiable conditions is published by the DVLA, called the At a Glance Guide for Medical Professionals, and is easily found on their website .The conditions listed are: Neurological disorders (long list specified, does not include ME/CFS), Sleep disorders, Diabetes Mellitus, Psychiatric disorders, Drug and alcohol misuse and dependency, Visual disorders, Renal disorders, Respiratory and sleep disorders, Miscellaneous conditions (includes deafness, malignant tumours, HIV/AIDS, age over 70). M.E is not on the list of notifiable illnesses. Sleep disorders are, though, and this could be the case with someone with ME/CFS”.

There was a legal case a few years ago where an award was made because ME was made worse as a result of an accident. If you had an accident, and it was is be found out that you have ME then your insurance cover could be void because of non disclosure of material facts. You have to disclose to DVLC any medical condition which could affect your ability to drive if it last longer than three months. That's on the driving licence.

The best way to deal with the issue if you are OK to drive is to firstly ask your GP is there is any problem with you driving with ME/CFS. Usually there isn't unless other medical conditions are present. Tell DVLC by telephone, who will then write to your doctor for a report. The expenses are paid by DVLA. Usually you will receive a letter telling you that are OK to drive. Send a copy of this letter to your insurers, who will then usually accept this without question. If you tell your insurers without a DVLC letter, you may lose cover or have to pay for a private medical until the issue is sorted. Normal private car licences are generally no problem with ME/CFS. However Heavy Goods and Public Service (e.g. bus) licenses are usually withheld on safety grounds.

I personally have followed this procedure without any problem for ME/CFS. I tend to think that the DLVC medical advisors do not consider ME/CFS a problem. I've had no experience in 15 years of anyone with ME/CFS in the Doncaster Group being refused a driving licence. The decision to stop or restrict driving is usually taken by the ME/CFS sufferer. A car with an automatic gearbox reduces the effort and concentration needed to change gear, while leaving more attention time to deal with road conditions. Many people find power steering beneficial. P.S. Jane subsequently contacted DVLC, and they confirmed there was no problem in her case.

Tandoori salmon with mango salsa and boiled rice

(Serves 4)

4 small salmon fillets ·
1 teaspoonful tandoori paste
1 lemon, quartered
For the salsa:-
1 mango diced
1 red onion diced
1 red pepper, diced
4 tomatoes, chopped
Juice of one lime,
¼ red chilli, deseeded and finely chopped
Tilda Basmati Rice for 4 people

Preheat oven to 200C/180C Fan/Gas 6 Spread the surface of each salmon with a little tandoori paste, place in a baking tray, skinside down. Add the lemon wedges and bake for 20 minutes until the salmon is just tender. Meanwhile, mix all the salsa ingredients together and serve with the salmon, lemon wedges and boiled rice.

Each serving provides:-
287 calories 12g sugar 15g fat 2.5g saturates 0.2g salt.

Trevor Writes *Every driver thinks they are a good driver, me included but something one day led me to take a look at my driving ability. So I decided to try a RoSPA Advanced Driving Course. So going to a meeting paying my joining fee my name was forwarded for training. I was surprised to find that me tutor was to be an old Windsurfing friend. So off we went, me thinking I had driven well only to have my ego deflated as he pointed out my shortcomings, highlighting them by taking me out in his car and showing how it should be done.*

So then came a course of weekly hourly lessons, the old way of driving had to be got rid of, and a new style of driving, new skills to be learned, old skills to be brushed up, as I learned observation and anticipation to a higher level. Driving up to the permitted speed limit when conditions allowed, no more of my 'Sunday driving style'. At times it seemed like I would never get the hang of it, but over the months I did, developing a simple efficient system which would give me time and space to deal with hazards, using a simple technique incorporating such things as the limit point to ensure I can stop safely in the distance I can see to be clear, the power band, where the engine is at its most responsive in the appropriate gear for the conditions. It all came together on Jan 3 of this year when I took my Advanced Driving Test and was awarded a Silver Grade. Quite an achievement when I think my original driving test was over 32 years ago. Still it proves one thing, age is no barrier to learning new skills.

Congratulations on passing your ROSPA driving test, Trevor!.
I think it would be a good topic for a group meeting. I think it is a very good idea is to have a go at an advanced course and driving test e.g. ROSPA or the IAM. This does sharpen up driving skills and give more confidence. The origin of advanced driving started when too many police drivers had too may accidents and damaged cars. The solution of this was the advanced system of car control, which is still the basis of advanced driving today. I passed the IAM advanced driving test a few years ago, I had a two hour test with a police examiner which covered every type of situation. There are two organisations offering free advanced driving tuition and a advanced driving tests. They are ROSPA http://www.roada.org.uk/ and the IAM http://www.iam.org.uk/

ME Paper Clips

£700,000 award for parrot disease man

Pet shop worker caught rare bird illness that robbed him of a normal life

£700,000

ing up a temporary management team at the store in

Very often I get given clippings from the press—usually with the comment " have you heard of ….". Nothing really surprises me about ME/CFS these days. A real surprise was a clipping from the Sheffield Star of 11/1/2007 which Liz sent. The clipping carried a story about a pet shop worker who had been awarded £700,000. The guy caught psittacosis (parrot fever) from a sick bird in his workplace. Psittacosis is a serious bacterial disease which can be fatal in some cases. It can be treated successfully with conventional antibiotics. The tragedy of this case is that the guy developed severe (grade 3) CFS as a result of the infection and is in a wheelchair.

Other bacterial infections like Lyme disease can cause CFS in a similar way. ME/CFS has many causes: infections, accidents, stress, poisonings etc., but all lead to the same problems as many of us know only too well. There are two body systems with memory, the brain and the immune system. The immune system remembers what infections it has encountered from birth, in order to defend the body. Vaccinations are a means of programming the immune system. Sometimes events lead to misprogramming, as in MS, or arthritic autoimmune diseases where certain tissues in the body are mistakenly targeted. My guess is that in this case, during a severe infection, somewhere in the confusions the guy's immune system was misprogrammed, and is causing ME/CFS. It is almost certain that many ME/CFS cases are autoimmune damage, but as yet the actual site of the damage and mechanism by which it occurs are unknown. In layman's language, there are plenty of smoking guns, but we have yet to find who pulled the trigger.

Bird Flu

I don't think that anyone will not have heard about the out break at the Norfolk turkey farm. (I dealt with this issue in Pathways no.6). I recently attended a meeting where the plans for emergency arrangements were discussed. It reminded me of the late 50's and early 60's where the cold war threat was seen as real. My father was in the civil defence, and the issues discussed were very much of that nature. Every health authority in the country is making individual arrangements. What is quite clear in Doncaster is that in the early stages of an outbreak, access to antiviral drugs will be through G.P.'s. As far as our members go, that same advice applies for seasonal flu. Although bird flu issues have receded into the background, behind the scene it is still seen as a major threat. So far we have only seen the H5N1 strain, which is not transmissible human to human. Let's hope that things stay that way.

People's Day 12th May 2007.

The annual M.E. People's Day Event to mark M.E. Awareness Day is being held on Thursday 10th May 2007, and will include deputations to No. 10 Downing Street, the Department of Health and to lobby Parliament at the House of Commons. It is expected that representatives of M.E. organisations will give a presentation with a focus on any M.E. related matter which they wish to bring to the attention of the Government. Last year, eight organisations were represented: 25% M.E. Group, MEACH, MERGE, CHROME, CO-CURE, Tymes Trust, BRAME and a research paper was presented by Dr Betty Dowsett. Conspicuously missing were Action for ME and the M.E. Association.

If you wish to join in, contact M.E.PeoplesEvents2007@hotmail.co.uk. For those wishing to spend the duration of the day, the following is recommended: folding chairs; food & refreshments; extra clothing/ umbrellas/sunblock. Scooters and wheelchairs welcome although, please inform us beforehand, where possible, to ensure available space. Restaurants and WC nearby, along Whitehall—and of course, don't forget your placards! Details will be on the website shortly. Kind regards to Di Newman Event Organiser & Peterborough M.E. & CFS Self-Help 01733 552872.

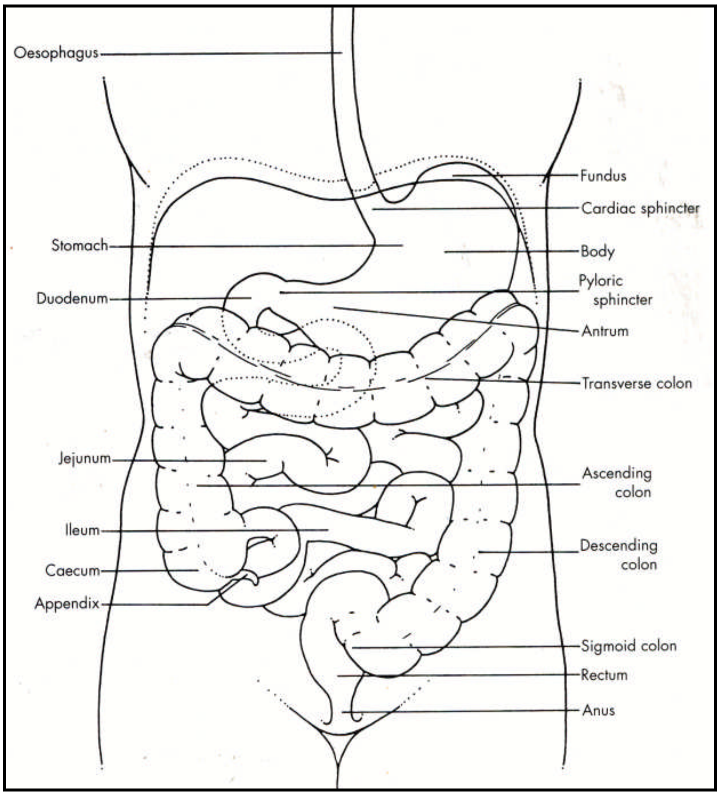
Leger ME Photo News

On the 10th December, all ME was cancelled for the day while the Christmas Party took place at the Church Hall in Kirk Sandall. As in past years the usual organised chaos was expected, but this year we had a plan. We booked a professional entertainer.

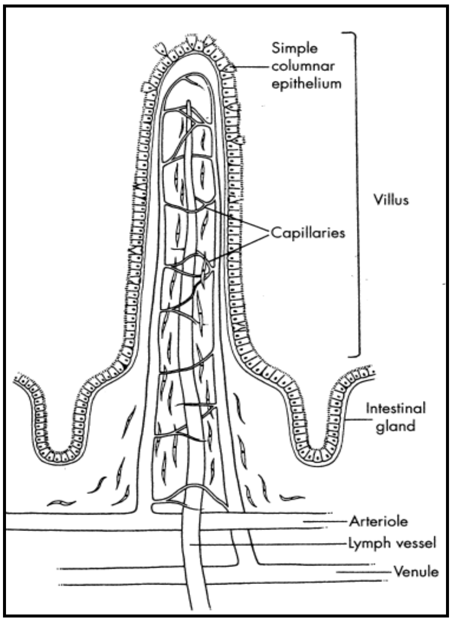
On entering the Hall guests were greeted by Dan Dylan, who literally was larger than life. Raffle tickets were sold by our three charming ladies at the door. Dan entertained us with his circus style skills which kept all the children entertained, including some of the grown ups. Justin and Stephen sang excerpts from ’Phantom of the Opera’. Dan then did a further slot, juggling knives while balancing on a massive ball. Dan then brought out his plate spinning kit, and let everyone have a go. He also showed us his tightrope kit, and after showing how it was done, let the children try it. Even some of older kids tried their skill. By special arrangement, Santa paid a visit, and all the children were given selection boxes.

Strangely enough, some older kids were seen at the back of the queue to see Santa, presumably vying for Santa’s treats. Throughout the party, raffle tickets had been sold, and tombola stalls had been operating. There was the usual helping of prizes. Dan had also been entertaining the kids individually with his magic tricks. On the whole, everyone had a great afternoon. Remarkably, after all that fun, we had raised £156.14.

The Digestive system



The digestive system breaks down food which is then absorbed into the bloodstream from the small intestine. The nutrients are then carried to every cell in the body. The digestive tract begins at the mouth and ends at the anus. It can be thought of as a long, muscular tube about 30 feet long with digestive organs attached along the way. Digestion begins in the mouth. The food is ground up by the teeth and moistened with saliva. Saliva also has a special chemical, called an enzyme, which starts breaking down carbohydrates into sugars. Once swallowed, muscular contractions of the oesophagus massage the ball of food down into the stomach. The food passes through a sphincter or small muscle ring into the stomach, where it is mixed with gastric juices. The stomach is a muscular bag and it churns the food to help break it down mechanically. The food is then squeezed through a second sphincter into the first part of the small intestine, called the duodenum. Once in the duodenum (small intestine), the food is mixed with more digestive enzymes from the pancreas and bile from the liver. The liver has a number of different roles in the body, including: breaking down fats, using bile stored in the gall bladder; processing proteins and carbohydrates and filtering out impurities and toxins. The food is squeezed into the lower parts of the small intestine, called the jejunum and the ileum. Nutrients are absorbed from the ileum, which is lined with millions of finger-like projections called villi. Each villus is connected to a mesh of capillaries which absorb nutrients into the bloodstream. The waste is moved into the large intestine, or bowel where water is removed and the waste (faeces) is stored in the rectum, before being voided through the anus.



What is the difference between a dietitian and a nutritionist?

The title ‘dietitian’ is protected by the Health Professions Council. All registered dietitians (RDs) have a university degree or post-graduate qualification which involves nutrition science theory and supervised training in both clinical and community settings. Many dietitians work in hospitals and clinics, advising individuals in need of therapeutic diets, but dietitians also work in many other areas supporting public health through improved food choices. Dietitians are expert in both the science and the communication of nutrition, and registration ensures that dietitians practice to a code of ethics, and maintain professional development. Most dietitians are also members of their professional body, the British Dietetic Association. The title ‘nutritionist’ is less defined, and is not protected. There are several degree level courses in nutrition, and upon qualification, many register as nutritionists (RNutr) or as public health nutritionists (RPHNutr) with The Nutrition Society. Nutritionists work in government, industry, sports, education, media and for charities, supporting the collection and communication of information about food and health. Some provide general guidance to individuals about eating to support good health. There are many general courses on nutrition and diet. Some of these are for other professionals e.g. doctors/nurses or those working in catering. Some are in response to those with an interest in optimum nutrition and nutrition therapy. When seeking the services of a nutrition professional, the length of relevant full-time study, and the authority of the registering body should be considered, as an indication of the competence of the practitioner to be assumed.

Understanding more about Diet and CFS/ME

From the DBA information sheet.

CFS/ME is classified as a neurological illness by the World Health Organisation. It can affect children as young as five years, but mostly it affects teenagers and adults. Diagnosis is made by excluding other causes of the symptoms, as presently there is no specific diagnostic test.
Symptoms include:

- Overwhelming fatigue, present for six months or more, not refreshed by sleep.
- Muscle pain and/or weakness
- Headaches, poor concentration, poor memory
- Nausea and irritable bowel like symptoms
- Increased sensitivities to foods, drugs, household chemicals, alcohol etc.
- Depression/anxiety

The symptoms and their severity vary greatly. Some, who are mildly affected, will still be able to go out to work, attend school, or university. The very severely affected can be completely bed bound, unable to carry out any daily selfcare such as feeding or washing, or tolerate any sensory input such as light and noise.

Are there any diets that will help recovery? The body needs a balance of healthy foods to ensure optimum health. Eat regular meals and snacks. Foods to choose include:

- Bread, other cereals including rice and pasta and potato; eat these at every meal.
- Fruit and vegetables; aim to eat five or more portions a day.
- Meat, fish and alternatives-such as chicken, fish, egg, nuts, quorn, beans, pulses, soya alternatives. Include these at two meals throughout the day
- Milk and milk products including cheese and yoghurts

There are many diets, (such as the anti-Candida diet), that claim to improve CFS/ME symptoms. However, there is very little scientific evidence to support these claims. Such diets can be very restrictive and can create a lot more work and effort for the sufferer and their carers. Care needs to be taken that the diet remains healthy, nutritionally adequate, and there is no unwanted weight loss or gain. Also, consideration must be taken that benefits outweigh extra demands on the sufferer and carers.

Weight changes and concerns. It is common for there to be weight changes in those with CFS/ME.
1) Weight increase may result from a much reduced activity level, when appetite remains unchanged. Typically, exercising can make muscle-pain worse, so restricting the ability to be active. To counteract a lower activity level, choose healthy foods with a good intake of fruit and vegetables (5+ portions). Energy-dense, (high fat/sugar) foods such as biscuits, chocolate, cake, crisps and sugary drinks need to be kept to a minimum.
2) Weight loss can occur if the appetite is poor and nausea is present, or if it is difficult to buy and prepare foods due to fatigue. To help minimise this, eat regularly. Try small, quick and easy meals and nourishing snacks such as beans or egg on toast or a bowl of vegetable soup.

Food allergy and intolerance. CFS/ME may affect or be affected by the immune system, but exactly how is unknown. The number of those affected by food allergy or sensitivity is unknown, but likely to be relatively few. Some sufferers report that symptoms do improve by excluding certain foods such as milk and/or wheat. Your doctor can refer you to a dietitian if you would like further advice on food allergy or hypersensitivity.

What about supplements? Further research is urgently needed in this area. There are many nutritional supplements, including vitamins, minerals and essential fatty acids, (omega 3), and co-enzymes claiming to help tiredness. Some are very expensive and contain mega-doses of the active ingredient. Large doses of some vitamins, for instance Vitamin A and B6, can be harmful.
If you are concerned about nutritional intake, keep to a multivitamin and mineral supplement with no more than 100% of recommended daily intake.

Eight Tips for Eating Well *adapted from the Food Standards Agency Website.*

The base of any health problem is correct management. For ME/CFS, dietary modifications can make a big difference in many cases. The following guidance is general guidance to help you make healthier choices. Please bear in mind that many people will need to modify this general guidance to manage their allergies and sensitivities. The two keys to a healthy diet are eating the right amount of food for how active you are and eating a range of foods to make sure you're getting a balanced diet. A healthy balanced diet contains a variety of types of food, including lots of fruit, vegetables and starchy foods such as wholemeal bread and wholegrain cereals; some protein-rich foods such as meat, fish, eggs and lentils; and some dairy foods.

1 Base your meals on starchy foods

Starchy foods such as bread, cereals, rice, pasta and potatoes are a really important part of a healthy diet. Try to choose wholegrain varieties of starchy foods whenever you can. Starchy foods should make up about a third of the food we eat. They are a good source of energy and the main source of a range of nutrients in our diet. As well as starch, these foods contain fibre, calcium, iron and B vitamins. Most of us should eat more starchy foods—try to include at least one starchy food with each of your main meals. So you could start the day with a wholegrain breakfast cereal, have a sandwich for lunch, and potatoes, pasta or rice with your evening meal. Some people think starchy foods are fattening, but gram for gram they contain less than half the calories of fat. You just need to watch the fats you add when cooking and serving these foods, because this is what increases the calorie content. Wholegrain foods contain more fibre and other nutrients than white or refined starchy foods. We also digest wholegrain foods more slowly so they can help make us feel full for longer. Wholegrain foods include: wholemeal and wholegrain bread, pitta and chapatti; wholewheat pasta and brown rice; wholegrain breakfast cereals.

2 Eat lots of fruit and veg

Most people know we should be eating more fruit and veg but most of us still aren't eating enough. Try to eat at least 5 portions of a variety of fruit and veg every day. It might be easier than you think. You could try adding up your portions during the day. For example, you could have: a glass of juice and a sliced banana with your cereal at breakfast, a side salad at lunch, a pear as an afternoon snack and a portion of peas or other vegetables with your evening meal. You can choose from fresh, frozen, tinned, dried or juiced but remember potatoes count as a starchy food, not as portions of fruit and veg.

3. Eat more fish

Most of us should be eating more fish – including a portion of oily fish each week. It's an excellent source of protein and contains many vitamins and minerals. Aim for at least two portions of fish a week, including a portion of oily fish. You can choose from fresh, frozen or canned—but remember that canned and smoked fish can be high in salt. Oily fish rich in certain types of fats, called omega 3 fatty acids, which can help keep our hearts healthy as well as helping ME/CFS. (See Pathways no 10.) Four portions is the recommended maximum number of portions for other adults. Examples of oily fish are salmon, mackerel, trout, herring, fresh tuna, sardines, pilchards, eel. Examples of white or non-oily fish are cod, haddock, plaice, coley, tinned tuna, skate, hake shark, swordfish and marlin. Don't have more than one portion a week of these types of fish. Anyone who regularly eats a lot of fish should try and choose as wide a variety as possible.

4. Cut down on saturated fat and sugar

To stay healthy we need some fat in our diets. What is important is the kind of fat we are eating.
There are two main types of fat:
Saturated fat—having too much can increase the amount of cholesterol in the blood, which increases the chance of developing heart disease.
Unsaturated fat—having unsaturated fat instead of saturated fat lowers blood cholesterol Try to cut down on food that is high in saturated fat and have foods that are rich in unsaturated fat instead, such as vegetable oils (including sunflower, rapeseed and olive oil), oily fish, avocados, nuts and seeds. Try to eat foods high in saturated fat less often or in small amounts so avoid meat pies, sausages, meat with visible white fat, hard cheese, butter, lard, pastry, cakes, biscuits, cream, soured cream and crème fraîche, coconut oil, coconut cream and palm oil. For a healthy choice, use just a small amount of

vegetable oil or a reduced-fat spread instead of butter, lard or ghee. And when you are having meat, try to choose lean cuts and cut off any visible fat.

Most people in the UK are eating too much sugar. Try to eat fewer foods containing added sugar, such as sweets, cakes and biscuits, and to drink fewer sugary soft and fizzy drinks. Having sugary foods and drinks too often can cause tooth decay, especially if you have them between meals. Many foods that contain added sugar can also be high in calories so cutting down could help you control your weight. To identify a food is high in added sugar look at the label. The ingredients list always starts with the biggest ingredient first. But watch out for other words used to describe added sugar, such as sucrose, glucose, fructose, maltose, hydrolysed starch and invert sugar, corn syrup and honey. If you see one of these near the top of the list, you know the food is likely to be high in added sugars. Another way to get an idea of how much sugar is in a food is to have a look for the 'Carbohydrates (of which sugars)' figure on the label. .

5. Try to eat less salt – no more than 6g a day

. Try to eat less salt—no more than 6g a day. Lots of people think they don't eat much salt, especially if they don't add it to their food, but don't be so sure! Three-quarters (75%) of the salt we eat comes from processed food, such as some breakfast cereals, soups, sauces, bread, biscuits and ready meals. So you could easily be eating too much salt without realising it. Eating too much salt can raise your blood pressure. However, I know of one doctor who specialises in ME/CFS who advocates more salt. Some people takings antidepressants, especially SSRI’s may have low Sodium (salt) levels. (See ME Drugwatch)

6. Get active and try to be a healthy weight

Being overweight can lead to heart disease, high blood pressure or diabetes. Being underweight could also affect your health. Check if you are the right weight for your height. If you’re worried about your weight, ask your GP or a dietitian for advice. But if you think you just need to lose a little weight, the main things to remember are: only eat as much food as you need make healthy choices—it’s a good idea to choose low-fat and low-sugar varieties, eat plenty of fruit and veg and wholegrains and get more active. It’s also important to eat a variety of types of food so you get all the nutrients your body needs. Physical activity is a good way of using up extra calories, and helps control our weight but is not appropriate for many of our members. Just try to be as active as you can. Whenever we eat more than our body needs, we put on weight. We store any energy as fat. Even small amounts of extra energy each day can lead to weight gain. Fad diets aren't good for your health and they don't work in the longer term. The way to reach a healthy weight—and stay there—is to change your lifestyle gradually. Aim to lose about 0.5 to 1 kg (about 1 to 2 lbs) a week, until you reach a healthy weight for your height.

7 Drink plenty of water and restrict alcohol

We should be drinking about 6 to 8 glasses (1.2 litres) of water, or other fluids, every day to stop us getting dehydrated. There is nothing wrong with the occasional alcoholic drink, but it in excess can cause problems. Alcohol is also high in calories, so cutting down could help you control your weight. Women can drink up to 2 to 3 units of alcohol a day and men up to 3 to 4 units a day, without significant risk to their health. A unit is half a pint of standard strength (3 to 5% ABV) beer, lager or cider, or a pub measure of spirit. A glass of wine is about 2 units and alcopops are about 1.5 units. Drinking heavily over a long period of time can damage the liver. Many people with ME/CFS are intolerant to alcohol.

8. Don’t skip breakfast

Breakfast can help give us the energy we need to face the day, as well as some of the vitamins and minerals we need for good health. Some people skip breakfast because they think it will help them lose weight. Missing meals doesn't help us lose weight and it isn't good for us, because we can miss out on essential nutrients. Research shows that eating breakfast can actually help people control their weight. This is probably because when we don't have breakfast we're more likely to get hungry before lunch and snack on foods that are high in fat and sugar, such as biscuits, doughnuts or pastries. So why not go for a bowl of wholegrain cereal with some sliced banana and a glass of fruit juice for a healthy start to the day ?

Irritable Bowel Syndrome and ME

Irritable bowel syndrome (IBS) is a chronic disorder in its own right. IBS is known by a variety of other terms: spastic colon, spastic colitis, mucous colitis, nervous diarrhoea, nervous colon and nervous or dysfunctional bowel. Often it affects people with ME/CFS. Personally, I think it is a part of the syndrome. The main features are recurrent abdominal pain and intermittent diarrhoea, often alternating with constipation. It most commonly affects people between the ages of 20 and 30 and is twice as common in women as in men IBS is very common and is present in perhaps 60% of patients who see a specialist in gastroenterology. The incidence is around 10%—20%, although it may be higher, because many people with IBS symptoms do not seek medical advice.

Symptoms. IBS features repeated abdominal pain and occasional diarrhoea, often alternating with constipation, rapid transit of food with frequent bowel motions, a sense of fullness (bloating), abdominal tenderness and swelling, an awareness of the bowel action and often headache and anxiety. Peristalsis is how bowel contents are moved along by a succession of rhythmical tightening and relaxation of segments of the intestine. In IBS peristalsis is stronger and more frequent which may make bowel activity much more noisy. Bowel noises —loud abdominal rumblings and squeaking —caused by gases being propelled through the intestines by peristalsis are called borborygmi and may be embarrassing. Pain is usually felt in one of the four corners of the abdomen, especially the lower left corner. It is sometimes brought on by eating, and is often relieved by going to the toilet. The stools are often ribbon-like or pellet-like and may contain mucus. Often, soon after a meal, there is extreme and embarrassing urgency to empty the bowels. Other symptoms include: burping, bad breath, excessive gas production, headache, tiredness, nausea and a sense of incomplete emptying after stooling.

Causes Like ME, the precise cause of irritable bowel syndrome is unknown. The condition often begins during a period of emotional stress and symptoms worsen in stressful situations. Up to 60 per cent of people with the syndrome have psychological symptoms such as anxiety and depression. The disorder sometimes develops after a gastrointestinal infection. An increased sensitivity or intolerance to certain foods may also contribute. It may result from exaggerated contractions of the muscles in the intestinal walls. These abnormal contractions can be tested by placing pressure-sensing devices in the colon. The colon muscles begin to spasm after only mild stimulation and are more sensitive and reactive than usual. Serotonin mediates the change to pressures within the bowel by acting on bowel wall smooth muscle. It is found in the brain also and this could explain the side effects of SSRI and other antidepressant drugs.

Diagnosis. The diagnosis is made after full investigation has failed to reveal any underlying cause and the symptoms are strongly suggestive of irritable bowel syndrome. Full medical investigation, including a rectal examination, a barium meal X-ray, and sometimes a gynaecological examination, shows no other abnormalities. Sometimes the colon is seen to be in a state of unusual activity, contracting and relaxing in an abnormally rapid manner. Diagnosis, as with ME, is a matter of exclusion. The person should also show at least two of the following three features: pain is relieved by defaecation (opening the bowels); pain is associated with a change in the frequency of bowel movement, either an increase or a decrease; there is a change in the form of the stool—it is watery, loose or pellet-like.

Treatment. Diet changes can help. Record what you eat over a couple of weeks and identify the foods that seem to trigger IBS. Avoiding these foods may help. Cutting out spicy and fatty, as well as gas producing vegetables such as beans may help. Try to drink less alcohol and swap tea and coffee that both contain caffeine for herbal teas such as peppermint and chamomile. Avoiding sorbitol can help. Try to eat more fruit and vegetables to increase the amount of dietary fibre (roughage) in your diet - this helps to prevent constipation. It's also important to drink plenty of water to flush waste products out of your body. Special exclusion diets may help some people but should be undertaken only with the supervision of a medical professional. Several drugs are effective in quieting down the excessive bowel activity and relieving the pain. Antispasmodics slow contractions in the bowel, which helps with diarrhoea and pain. Antidiarrhoeal drugs can be used when necessary. For constipation, an osmotic laxative is preferred over stimulant laxatives like lactulose. For severe pain, antidepressants, can help. Complementary therapies like acupuncture and peppermint oil capsules may be useful.

***Gut Dysbiosis/Fermentation** (sometimes known as Candida & auto brewery syndrome)*
Information from Dr. Myhill.

The symptoms it causes are very similar to ME/CFS. Gut Dysbiosis means that the wrong bugs are in the gut, the common offenders being overgrowth of yeasts, unusual bacteria or parasites. The gut is not sterile but full of bacteria, especially the colon. The stomach is supposed to be sterile and it is kept this way by dint of producing acid. However, some acid resistant bacteria can survive there, in particular helicobacter pylori which can cause ulcers. Eradication of H pylori (by antibiotics) can cure ulcer disease. The duodenum, jejunum and small intestine are supposed to be sterile, but it is believed that the jejunum is where yeasts may flourish to cause so called "Candida". Conversely, the lower bowel, large intestine or colon, is full of bacteria which have many beneficial functions. Normally the gut flora is in balance, but sometimes it is disturbed because of:-

- depletion of the gut's friendly bacteria, long term antibiotic treatment or gastric infection
- compromised immune function, as in the case of M.E., chemotherapy or HIV
- excess female hormones, HRT, the Pill, during a pre-menstruation phase or the menopause
- high blood sugar levels caused by a high sugar diet, stress or diabetes
- drug therapy mainly antibiotics, steroids, hormone therapies or immune-suppressive drugs

If however the gut flora balance goes towards yeasts, then we have a problem. Yeasts ferment carbohydrates, but the fermentation is not clean and toxic products can be produced. The following are measured in a gut fermentation test. The presence of ethyl alcohol suggests yeast overgrowth in the gut. Acetate, if raised, suggests bacterial fermentation due to excess carbohydrate reaching the colon. If propionate, butyrate, succinate, butanol and 2,3-butylene glycol are raised, this suggests bacterial fermentation due to excess fibre reaching the colon. Excess carbohydrate or fibre reaching the colon suggests either intestinal hurry or failure to break down carbohydrates due to inadequate enzyme production by the pancreas. An example of this in practice is the reaction to having baked beans for supper. Beans are poorly digested (humans don't have the enzymes necessary to break them down fully) get to the large bowel where they are fermented by grateful bacteria generating large amounts of wind!

If the cause is treatable then treating the cause will resolve the problem. Antifungals like nystatin and fluconazole, as well a certain food supplements can help. If there are enzyme deficiencies, supplementing with enzymes can help. Diets avoiding simple carbohydrates can also help. Probiotics are useful. Dr. Myhill says " I don't do this test very often. I suspect "candida" problems on the basis of a history and response to antifungals. I might do the test in order to help persuade a GP to prescribe expensive antifungals. It can be a helpful test, if the patient has a lot of wind, to determine whether antifungals should be used or pancreatic enzymes, FOS, probiotics etc."

Probiotics

Probiotics are live bacteria, mostly lactic acid bacteria, which are thought to be beneficial to health, especially gut health. They can be cultivated and added to foods, such as yogurts and milk drinks or in dietary supplements. These bacteria need to be robust enough to survive the journey through the digestive system, so that they can reach the gut and contribute to the balance of our gut flora. Taking probiotic foods may help to restore the balance of the gut flora. The scientific evidence for the health benefits of probiotics is still building and more research is needed, but potentially they may include the following:-
They help the body's defence system by inhibiting the growth of harmful bacteria. A key benefit of this is reducing the risk of diarrhoea, especially 'travellers diarrhoea' and antibiotic-associated diarrhoea They may also help to improve digestion and possibly irritable bowel syndrome (IBS), help symptoms associated with lactose intolerance, and help improve the quality of life of people with inflammatory bowel disease. Examples of probiotics are yogurt or drinks containing lactobacilli or bifidus bacteria. Dietary supplements containing probiotic acidophilus (such as L. acidophilus or L.plantarum) are available.

Glycaemic Eating and ME/CFS

Glycaemic eating can help ME/CFS and can also help Candida issues. Dr. Swinbourne (now retired) is a fellow=sufferer, and she used this technique to help her patients. See Pathways 1, page 11.

The Glycaemic Index (GI) is simply a ranking of carbohydrate foods based on the rate at which they raise blood glucose levels. Each food is given a number or value. Foods that break down quickly will raise blood glucose quickly, and are given high GI values. Foods that break down slowly will raise blood glucose slowly, and are given low GI values. There is good scientific evidence that GI influences blood glucose levels. Slow, steady rises and falls in glucose may in addition help you feel full for longer. GI can play a role in weight management by helping to control appetite and insulin levels but it is not a “magic bullet” for weight loss. For GI to be effective in a slimming plan, it must be part of a calorie-controlled diet.

Most low GI foods (e.g. wholegrains, pasta, fruit, beans and lentils, and vegetables) are generally inherently healthy. Basing a diet plan on low GI foods of this kind can help you keep to healthy eating guidelines. Foods with a high GI are not necessarily "unhealthy" foods. Compare watermelon (a high GI food) with chocolate pudding (a low GI food). The way a food is cooked or processed can affect the GI. When you mix foods together, the GI changes. So, a high GI food (like a jacket potato) when mixed with a low GI food (like baked beans) becomes a medium GI meal. It makes good nutritional sense to add a salad or vegetables to meals, this also helps to lower the overall GI. Carbohydrate-free foods like meat and cheese are considered to have a zero GI. However, you should choose the leaner cuts of meat and lower fat dairy foods for a healthy diet. NB: GI is not supposed to be used in isolation. So, how can we use GI?
.
The greatest research is in the area of diabetes. The European Association for the Study of Diabetes, the Canadian Diabetes Association and the Australian Dietetic Association recommend high fibre, low GI foods as a means of improving blood glucose and weight control. GI can be of benefit in weight management when combined with a reduced calorie intake and regular physical activity. .Some low GI foods, such as those high in soluble fibre (e.g. beans and lentils) can help reduce blood cholesterol as part of a heart-healthy diet.

Low GI foods, such as pasta, are great for carbohydrate-loading before a sports event and high GI foods, like a glucose drink, provide fast release carbohydrate, quickly replacing glucose in the blood stream after an event. A low GI diet, along with lifestyle changes, may also benefit those with Metabolic Syndrome X (a condition characterised by carbohydrate, sensitivity, obesity, high blood pressure and abnormal blood fats). A diet based mainly on low GI foods may improve insulin sensitivity. (Insulin is the hormone which helps control blood glucose).

Healthy Low GI Foods

Pasta (choose tomato-based sauces)
Grainy breads (e.g. soya and linseed, granary)
Bran-based breakfast cereals
Porridge and reduced-sugar muesli
Sweet potatoes and new boiled potatoes in their skins
Nuts (limit to a small handful - 1 oz - a day)
Fruits
Vegetables (raw or lightly cooked)
Salad (choose low-fat dressings)
Basmati rice

High GI Foods to Reduce

Pies
Sweet pastries, doughnuts etc.
Croissants
Sugar-rich drinks
Shortbread
Try to eat fewer foods containing added sugar, such as sweets, cakes and biscuits, and drink fewer sugary drinks
Sugar is sucrose, glucose, fructose, maltose, hydrolysed starch and invert sugar, corn syrup and honey

Clouds Counselling Service

The Counselling contact-line number is 07962 907053.
Please leave your name and telephone number then Sally will ring back.

Food Allergies and or Intolerances

One in five people believe themselves to be intolerant (or 'allergic') to a food. In fact, less than 1% of the adult population has a true food allergy. However ME/CFS patients have more than their share of the problems. With more people self-diagnosing a food allergy, there is a risk of unnecessarily cutting out important foods from the diet and risking nutrient deficiencies.

Food intolerance is a term used to describe a whole range of adverse reactions to food, including allergies, enzyme deficiencies and pharmacological effects. It is thought that just 1-2% of adults and no more than 5-8% of children are affected by adverse reactions to food.
A true food allergy is an immediate and sometimes severe reaction by the body to a protein found in a particular food, for example nuts. The allergic response produces lots of IgE antibodies and this can make you feel ill immediately after eating the food.

The only reliable way to test for a true allergy is an IgE blood test, a skin prick test or a patch test. These tests should only ever be performed by trained medics in a specialist allergy clinic, because of the risk of severe reactions.
Blood tests measure the amount of IgE antibody you produce when you come into contact with an allergen (the food to which you are allergic).
Skin prick tests work by pricking the skin with a minute quantity of suspect allergens.
Patch tests are similar to skin prick tests, except the suspected allergens are applied to the skin, usually the back, using patches. After 48 hours any problem foods will show a red mark on the skin such as a small, red, swollen spot or weal on the skin which changes over time.

What to avoid. The following have no place in the diagnosis of true allergies.

Applied Kinesiology (measures muscle strength, and your resistance to foods).
The Auricular Cardiac Reflex method (tells you about your allergies by monitoring your pulse when suspect foods are offered to you).
Hair samples (some centres offer a diagnosis by looking at your hair samples, others will place drops of suspect foods under your tongue and monitor how you respond).
Vega Testing (where your magnetic field “gives away the secrets” of your allergies).

The bottom line is that food allergy and intolerance are both complicated to diagnose and are not as common as some would have us believe. They need a proper medical diagnosis and advice from a registered dietitian for safe and effective management. They also need to be regularly reviewed as allergies and intolerances to foods may change.

How to spot bad dietary advice

Stay away from diets that: Promise a quick fix; recommend magical fat-burning effects of foods (eg grapefruit); promote the avoidance or severe limitation of a whole food group, such as carbohydrate foods or dairy foods (and suggest large doses of vitamin and mineral supplements as a replacement); promote eating mainly one type of food (eg cabbage soup or eggs); suggest easy, rapid weight loss (more than 2lbs a week); recommend eating foods only in particular combinations; make claims that sound ‘too good to be true’ nb and focus only on your appearance rather than on health benefits. Don't be fooled by the fact that many beautiful celebrities are following some of these weird and bizarre regimens. They are blessed with 'beauty' genes, and usually have armies of trainers, chefs and stylists rather than nutrition qualifications. You should also be wary of unqualified practitioners who may be offering unproven techniques for diagnosis and treatment of nutritional problems. Be very sceptical of the following: Iridology, Kinesiology, Craniosacral therapy, Hair mineral analysis, Face reading, Tongue reading, Colonic irrigation, and Magnetic therapy

Seek the advice of a your doctor or Registered Dietitian (RD). Registered Dietitians have recognised qualifications and will be able to give you safe, unbiased, evidence-based advice.

The Sheffield ME/CFS Clinic

As the recent Sheffield Conference held in October the following question was asked.
Question: What are the criteria for referral to the multi-disciplinary team and what tests have to be done beforehand?

Anne Nichol (Occupational Therapist and Clinical Services Coordinator, South Yorkshire and North Derbyshire CFS/ME Service) replied for the Sheffield Clinic: In the early days of the clinic, referrals to the team could be made only by the Department of Infectious Diseases at the Hallamshire Hospital. There is now a GP on our team who has a special interest in ME/CFS and the process has changed so that referrals can be made directly by the patient's own GP to make access to the service easier. We have established the criteria for which GPs may refer patients which includes excluding other potential diagnoses prior to referral to the service. The symptoms would need to have been present for a number of months in the case of adults, and 3 months in the case of children. We do not specify the 6 month period which previously was in use for considering a diagnosis of ME/CFS as interventions need to be implemented at an earlier stage. The GP has to supply summary information about the patient's experience and their medical history, as well as the results of the following blood tests:

Tests	Checks for
Full blood count and film	Anaemia and other blood disorders
ESR/CRP	Levels of inflammation in the blood
Urea and electrolytes	Body salts level, checks kidney function
Creatine kinase	Muscle damage
Serum calcium and phosphate	Calcium and bone-related issues
Liver function tests	Liver disease/status
Thyroid function	Abnormal thyroid issues
Urinalysis for protein blood and sugar	Diabetes and kidney damage
Serum glucose	Diabetes and other endocrine disorders
Coeliac serology	Sensitivity to gluten in wheat flour

These criteria have been devised by the team and sent out to all GPs in the region, and published in the local Medical Council newsletter. They may be further developed when they have been used in practice. Eventually we may reach a stage when referrals may come from a wider source, for instance consultants, but at this time the only route into the clinic is through your G.P.

Richard Grunewald (Consultant Neurologist, Royal Hallamshire Hospital, Sheffield) replied: I see a lot of patients with a lot of unusual symptoms, which may not necessarily appear in the criteria. Individuals are variable, and as the disease evolves the symptoms change. ME/CFS patients have many diverse symptoms, not necessarily all related. The more doctors recognise the variety, the more chance of getting to the right services sooner. The crucial thing is getting people into treatment early.

Question: What single piece of advice would you give to someone who is newly diagnosed?
Anne Nichol: When we first see people at the clinic, they have usually been seen by numbers of doctors and been sent 'all round the houses' and often feel they have not received any real help. They have also in many cases had to justify their condition to colleagues, family and friends. The most helpful thing that people have fed back to the service is that they feel listened to and believed. There are two key things I would want to pass on to someone who is newly diagnosed: although there is currently no cure for ME/CFS—improvement is possible, and to realise that you are not on your own—there are others with this illness, who DO understand what you are going through and we can put you in touch with them.

Meeting Review 02/03/07: Margaret Armstrong and Personal Training

Following a suggestion based on the experience, of two of our members Hazel and Michelle, we invited Margaret to address the group meeting. We heard of how Margaret, a successful business woman, suffered a stroke and how a 'black hole' appeared in her life as a result. She found personal training helped her became rehabilitated. She realised that through her experience she could help others in a similar positions. Now she a well known Professional Personal Trainer running classes throughout the area. Personal training is an approach to life. It is aimed at making the best of the positive attributes one has, and minimising the effect of the negative. As is well known, stroke is vascular catastrophe, and unless steps are taken to prevent a recurrence, the risk is high it will occur again. She explained that with personal training, she had changed her diet and lifestyle to minimise this risk. She explained for example how she avoids white sugar and trans fats. She still has frequent medical checkups of blood pressure and cholesterol to ensure everything is just fine. We received the following email :

Hi Mike
Great to meet you and some of your ladies today. I have attached a flyer which I use for my Health and Wellbeing Talks around the country and you can take some information from it for your newsletter, as well as the information you already have on the leaflets.

'Isn't it interesting how often science fiction becomes scientific fact? We used to think that man would never walk on the moon or sail beneath the ocean. Science even used to argue that the earth was flat and that the sun and galaxies rotated around it. Nowadays, most of us laugh at such ideas.

Knowing how frequently "science" has been proven wrong, why do so many of us still find it hard to accept the mind-body wellness connection? The idea that our minds have an amazing power over our health appears to defy much of what science has taught us. There was time when I would have believed that such "science fiction" could never become "scientific fact". However, research is again showing us that drugs may not be answer to everything, that other alternatives, such as energy medicine, therapies, and importantly nutrition has a major part to play in recovery.

Instead of thinking "illness", which is part of our conditioning, how about thinking "wellness", "prevention". This 7 week Health and Wellbeing course is designed to help you look at "wellness" not "illness", it will help you look at life through a new pair of glasses. It will signpost you to new research and discoveries which will take years to filter down the "illness industry" through conventional channels. If you are looking for a light at the end of the tunnel, this course if for you. It is educational, inspirational, and its about giving you back the power to enhance your quality of life. All the best. Margaret .

A Journey

I feel I've come a million miles
But still feel I can touch,
The woman who I used to be,
Who thought she knew so much.

I feel that I'm connected
Growing into who I am,
Peeling back the plastic masks
I've worn since time began

I feel I'm making progress
I've never felt this warm,
And calm and peaceful,
joyful Renewing life reborn.

The lessons I am learning
I know will serve me well,
For I know I am accepting
Of all within myself.

Alicia L, 'Soul Inspiration'
workshop participant, Oct 06

I've since spoke to Margaret with a view to putting on a course at the Redmond Centre.
The earliest date is several months time. Please let us know if you wish to attend. *Mike*

Meeting Review 02/03/07: Ken Hall—Employment Support Worker, SYCIL.

Following big brother bullying tactics used by one of the DWP staff on one of our members and having unexpectedly received a number of enquiries on the helpline about ME/CFS and employment issues over the Christmas period, I decided to hold a meeting on employment issues. There have been back-to-work schemes like therapeutic work which have been unsatisfactory. The old Disabled Working Allowance is no longer available. It's replacement is the Pathways to Work programme.

I decided to invite Ken Hall an Employment Support Worker from SYCIL to address the meeting and to look at the options available. Ken told us how he became unable to work in his job in heavy engineering because of health issues, and how he had worked as a volunteer for SYCIL, eventually becoming employed by them. Issues discussed were volunteering, working with ME/CFS and Incapacity Benefit. A number of members raised about questions DWP issues. Ken also told us about SYCIL and the services it offers. I've included an extract based on a question and answer session from the recent Sheffield M.E. Group Conference Report 'M.E Question Time' held on Saturday 14 October 2006. Also, information which SYCIL have provided follows on the next page.
Mike. (SYCIL = South Yorkshire Centre for Inclusive Living)

The Job Centre I attend is working with the NHS to offer claimants a Condition Management Programme. I have found this very helpful. Is this going to be normal for all claimants in the future?

***Marcus Windle**: It's good to hear that your experience has been positive. There has only been one piece of research conducted into the Condition Management Programmes (CMPs), and this has been produced by the DWP (Department of Work and Pensions). It specifically mentioned M.E as an illness that hadn't been well addressed by the first few CMPs they researched. Maybe a lesson was learned and it's working better now. It is part of the Pathways to Work programme which has been piloted across about one third of the UK. Yes, it will soon be normal in all the regions and is planned for Sheffield in December. However the CMP part of Pathways to Work is expensive (it costs £1,500 per claimant) and it will not be offered to all claimants.*

***Alan Blair**: Derbyshire was one of the early pilots for Pathways to Work and the CMPs. Initially, it was devised for two main groups, which were mental health and physical health. The physical health element mainly addressed chronic pain, particularly back pain. The CMPs have now expanded and have a larger remit, including ME/CFS. People receive a varying combination of advice, information and therapy, as required, from Psychologists, Physiotherapists and Occupational Therapists. The model used varies across the country, and it's not possible to say which model might be used in Sheffield. It is not officially funded beyond 2008 but will most probably continue during the life of this parliament. The CMPs are going to be sensitive to political change. The research has shown that, overall, the programme 'pays for itself' (i.e. has been successful in helping people return to work).*

***Anne Nichol**: Lots of people who work on the CMPs have been in contact with the clinic and some have attended our recent training programme. There seems to have been genuine interest in learning about ME/CFS and enabling people to self-manage their condition.*

Which element of the programme is offered to people with M.E?

***Alan Blair**: Either or both elements can be offered. Someone with ME/CFS would have the opportunity to meet with the therapists and jointly decide what is appropriate.*

But what about conditionality – people's benefits being paid only on condition that they undertake the programme offered?

Marcus Windle*: So far there have not been any sanctions or compulsion involved because the need has not arisen. Pathways to Work has been around for a number of years and is entirely voluntary. It has given a pretty good level of satisfaction. It gives people a great chance to progress and maybe to save a job which they were on the verge of losing. I am aware of the contents of the recent government green paper and the Welfare Reform Bill (not yet passed by parliament). I am aware of the concerns and I would not support any form of compulsion or sanctions.*

South **Y**orkshire **C**entre for **I**nclusive **L**iving (SYCIL)

MOVING ON PROJECT, PATHWAYS TO WORK

Since its inception SYCIL has made a significant contribution to health and social care delivery in Doncaster. As a disability/user led organisation SYCIL offers specialist expertise, help and support to all disabled people in the Doncaster borough.

The Moving On Project is designed to meet the individual needs of people trying to obtain a job after a long period of unemployment or inactivity. The aim of the project is to put incapacity claimants on a level playing field with other unemployed people. The project is available to anyone who has been receiving sickness-related benefits for at least six months prior to April 1st 2006

Working as a Centre for Inclusive Living SYCIL has up to date knowledge and understanding of many of the barriers faced by people re-entering employment.

The Moving On Project provides support to those who wish to move on to training and/or employment, this will be achieved by providing support both on an individual and group basis in the following areas:

- Individual assessment of need
- Confidence Building & Assertiveness
- Coaching
- IT Training
- Job Search techniques including Application and Interview Support
- Volunteering opportunities

Whilst the Moving On project and the Pathways to Work scheme run concurrently, anyone participating in the Moving On project will only be placed on Pathways to Work when they feel the time is right. Pathways to Work provides financial help for incapacity claimants who are about to start work.

For further information please contact:
Ken Hall – Employment Support Worker*, SYCIL, Heavens Walk, Doncaster DN4 5HZ,*
tel: 01302 769219 e-mail: ken.h@sycil.org.uk

Blue Badge Enforcement

From autumn last year, police, traffic wardens, local authority parking attendants and civil enforcement officers will be able to inspect Blue Badges as part of their other parking enforcement functions. Whenever a Blue Badge is displayed on a motor vehicle, such officials will have the power to demand to see the badge for inspection purposes. It will be an offence if a person refuses, without reasonable excuse, to produce a badge for inspection—punishable on conviction by a fine of up to £1,000. This will have the effect of discouraging abuse of the Blue Badge Scheme. But beware though, some Blue badge holders have been fined in Doncaster for showing the wrong side – *Mike*

ME/CFS Drugwatch

Withdrawal of Co-proxamol

Following evidence that co-proxamol (a analgesic or painkiller containing paracetamol and and dextropropoxyphene is no better than Paracetamol alone, the CSM advised that co-proximal should be withdrawn from the market on the grounds that the benefits did not outweigh the risks. Co-proxamol is implicated in 300-400 deaths from overdose a year and in almost one fifth of drug-related suicides. Co-proxamol was to be withdrawn over an extended period of time to allow long term users an opportunity to move to suitable alternatives; the withdrawal will be phased over a period of up to 36 months. Some manufacturers have already withdrawn co-proxamol and a few will phase the withdrawal until the end of 2007. The agency accepts that “there is a small group of patients who are likely to find it very difficult to change; when alternatives appear not to be effective or suitable. For these patients, continued provision of co-proxamol through normal prescribing may continue until the cancellation of the licences at the end of 2007. After this time there is a provision for the supply of unlicensed co-proxamol, on the responsibility of the prescriber.” It adds that the public health gain from the withdrawal of this drug is already becoming apparent. For more information see Pathways No 3, Page 6. www.leger.me.uk

Azithromycin for ME/CFS.

I have watched a number of people take this direction of treatment, and twelve months later they are no better, and skint! Some private doctors are advocating Azithromycin for treatment of Lyme disease-induced ME/CFS, which they believe is a persistent Borrellia infection. The justification for this treatment is usually the results of private tests (usually blood samples) sent to the USA. Several NHS labs and NHS clinics have checked out these tests and strongly dispute the results. The BNF (NHS drug bible) makes recommendation that Lyme disease should generally be treated by those experienced in its management. Doxycycline is the antibacterial of choice for early Lyme disease. Amoxicillin [unlicensed indication], cefuroxime, axetil, or azithromycin [unlicensed indication] are alternatives if doxycycline is contra-indicated. Because of this some G.P.s are willing to prescribe it, but not at NHS expense; some patients end up paying.

Azithromycin is of the same family of antibiotics as erythromycin and has similar antibiotic activity. A similar course prescribed privately would cost about £32. This option would be more palatable to your G.P. and he may even be willing to prescribe it in the NHS as opposed to the £120 cost of Azithromycin. Penicillin family (amoxicillin) type drugs work just as well for Lyme and are cheaper, but sensitivity (allergy) may be a problem. In these cases erythromycin is prescribed. Azithromycin would only be justified as a 2nd line or 3rd line strategy, if the first had failed.

Azithromycin was designed for the American market, where profits are to be extracted at the expense of US Insurance Companies like Blue Cross. Antibiotics do not work for ME/CFS, because the illness is some sort of ‘damage’ left after the initial cause has long vanished. Any perceived improvement may be due to side effects of the drug or placebo effect. If it results in a ‘cure’ then the original diagnosis was wrong.

Inappropriate Secretion of Antidiuretic Hormone (ADH)

Some antipsychotic drugs and antidepressants cause excessive ADH secretion. This usually results in water fluid retention and sodium depletion, a condition known as Hyponatraemia. This may give rise to false alarms when U&E lab tests are done or it may be serious as a consequence of other diseases. The Medicines and Healthcare products Regulatory Agency (MHRA) have given guidance on the issue. Of significance are tricylcic type drugs like amitriptyline and nortriptyline used in ME/CFS for pain control. The problem has been associated with all types of antidepressants; however, it has been reported more frequently with SSRIs (e.g. prozac, seroxat) than with other antidepressants. The MHRA has advised that hyponatraemia should be considered in all patients who develop drowsiness, confusion, or convulsions while taking an antidepressant.

Sleep Apnoea and ME/CFS

What is sleep apnoea?

Sleep apnoea is a serious disorder that causes breathing to stop repeatedly while sleeping. These breathing pauses or "apnoeas" usually last 10 to 30 seconds and can happen many times throughout the night. Untreated sleep apnoea can lead to serious health problems like hypertension, accidents, and premature death but it can be treated effectively. There is one school of thought that says this may be one possible cause of Sudden Infant Death Syndrome (cot death).

A CPAP. mask is held in place by a headgear and tubing goes from the mask to the CPAP. unit. The unit is plugged into an electrical outlet and provides a constant flow of air to the mask to keep the airways open.

The most common type of sleep apnoea is obstructive sleep apnoea, which happens when the upper airway gets blocked during sleep. This often happens when the soft tissue in the back of the throat collapses and closes during sleep. Relaxed throat muscles, a narrow airway, a large tongue, small lower jaw or extra fatty tissue in the throat can also block the airway. There are other rare types often related to brain dysfunction, typically the brainstem. Untreated sleep apnoea can cause serious health problems excessive daytime drowsiness, decreased intellectual functioning, memory loss, depression, hypertension and can lead to heart attacks and strokes.

Who gets sleep apnoea?

Men, women and children of all ages. One in five adults mild, one in fifteen moderate. 1-3% of children are affected to some degree. Higher risks apply to smokers, those who drink alcohol, are overweight (17½ in collar), have a large tongue, narrow throat, large adenoids and tonsils. As many as 1 in 100 men between the ages of 30 and 50 have the condition, a typical sufferer being overweight and a heavy snorer. Obese people who are excessively sleepy and are said to have Pickwickian syndrome.

Signs & Symptoms

Life events like an accident or poor performance at work many be symptomatic. Most people who suffer don't know they have it. They commonly seek help because of daytime drowsiness, or loud snoring followed by silent pauses in breathing noted by their bed partner. Morning headaches, irritability, mood changes, memory loss and falling asleep while driving. Very often the bed looks like a battlefield. Family members or bed partners often pick up on the problems first.

Treatment

For mild cases lifestyle changes and weight reduction may be all that is needed. Continuous Positive Airway Pressure (CPAP) devices, and dental devices may help. Surgical procedures may offer a permanent solution.

Relevance to ME/CFS

Sleep apnoea is a cause of fatigue, and is one of the group of health problems that can mimic ME/CFS and so must be excluded before a diagnosis can be given. Obviously if you think you have this problem the first port of call should be your G.P.

Battle

I battle with the nausea
and also with the pain
I strive to get some order
out of my muddled brain.

The constant chills and all the ills
I struggle with in vain
But the one I fight the hardest
is the battle to stay sane!!

Janer Andrews

M.E. charities demand an overhaul of the NICE Guidelines on M.E.

From 'Outreach' Winter 2007, the newsletter of the West London M.E. Group.

In an unprecedented move, all eight major M.E. charities have united to criticise the National Institute for Health and Clinical Excellence (NICE) and are calling for it to rewrite Its draft guidelines on the clinical assessment, treatment and management of M.E. The UK's leading M.E. charities want NICE to rewrite its draft guidelines as they are concerned that these guidelines will hinder rather than help doctors treating those with this chronic illness. They argue that the guidelines as they stand will lead to the misdiagnosis and mismanagement of this neurological condition.

"We have no argument with doctors and other health professionals being provided with comprehensive, evidence-based and balanced guidance about M.E.", said a spokesperson for the charities. "But these guidelines for M.E./Chronic Fatigue Syndrome—due to be published in April next year—don't do that. The guidelines' recommended 'treatments of first choice' could lead to inappropriate and damaging use of graded exercise therapy." Other key criticisms include:

- Research does not support NICE's 'one size fits all' approach, where cognitive behaviour therapy (CBT) and graded exercise therapy (GET) are seen as 'treatments of first choice' for everyone with M.E.
- A large majority of patients have reported that GET can damage not improve health. NICE has ignored this The guidelines' definition of the illness is so wide that it includes almost everyone with unexplained chronic fatigue, rather than M.E. itself.
- The guidelines do not acknowledge the urgent need for research into the underlying physical cause of ME.
- The guidelines provide limited advice for those with severe M.E., and fail to provide a 'portfolio' of techniques for symptom control required by individuals.

The spokesperson for the charities added: "The guidelines need rewriting, with greater involvement of health professionals who understand the complicated physical nature of the illness, as well as patient representatives—whose evidence so far has been sidelined." Three of the main national M.E. charities (the 25% ME Group for the Severely Affected, BRAME and the Young ME Sufferers Trust) who represent the two most vulnerable groups—children and the severely affected—have added further criticisms. Jane Colby, Chief Executive of The Young ME Sufferers Trust said: "My figures suggest that up to 8000 children could be damaged by the NICE guidance. We have seen terrible results where children are forced to school, forced to exercise and refused other support. Young people have ended up in wheelchairs or having to be fed by tube. One young man, who had not recovered from the treatment 11 years later, told me 'They must be stopped'. That is our aim." Simon Lawrence from the 25% ME Group, which represents the most severely affected said; "Patient experience of this serious neurological illness, which affects up to 250,000 people in the UK, has been all but ignored in favour of a psychological approach. The illness affects many body systems and their functions, and an estimated 60,000 develop M.E. so severely they become bed or house bound, with others needing to be tube fed." of Colby is co-author of the largest study of ME worldwide, which found that M.E. is the biggest cause of long term sickness absence from school. It is more disabling than many more well known illnesses. It is far more severe than 'chronic fatigue' but has become trapped under that label. Colby maintains that doctors do need guidance, but says that NICE's guidance is wrong for M.E.

The UK M.E. charities that have produced this statement are:
Action for M.E., The ME Association, The Young ME Sufferers Trust, The 25% Group representing the severely affected, Case History for Research into ME (CHROME), Blue Ribbon Awareness for ME (BRAME), The National ME Centre, The Association of Young People with ME (AYME)

P.S. We have heard that owing to the volume of comments received, the publication date of April 2007 will no longer be achievable. It will be now be 22nd August 2007. Keep up the good work folks!

The Gibson Report *From a press release dated 26th November 2006*

The Group on Scientific Research into Myalgic Encephalomyelitis (ME) today releases its Inquiry Report "Inquiry into the status of CFS/ME and research into causes and treatment". The report also known as the Gibson Inquiry has been ongoing for almost a year. The Group is an offshoot of the All Party Parliamentary Group on ME. Over the past year, it has received written submission of evidence from medical experts, scientists, patients and patient groups across the UK and internationally. The Inquiry also held 5 oral hearings details of which are on the website www.erythos.com/gibsonenquiry. The Group undertook this Inquiry after meeting with patient groups in 2005. CFS/ME is arguably one of the most contentious illnesses in medicine today. Even the name is a point of contention. Patient Groups refer to themselves as the 'ME Community' and consider CFS to be a term invented by psychiatrists who do not believe their condition exists. Meanwhile the situation in the UK is that due to a lack of research there are only symptomatic treatments available and indeed these have proved useful in some controlled trials.

The Gibson Committee.:

Dr Ian Gibson MP (Chair),
Dr Richard Taylor MP (Vice-Chair),
Ms Ann Cryer MP (Secretary),
Rt Hon Michael Meacher MP,
Dr Des Turner MP,
Mr David Taylor MP,
Lord Turnberg,
The Countess of Mar,
Baroness Cumberlege

M.E. is treated with Cognitive Behavioural Therapy (CBT), Pacing, where the patient paces their energy and Graded Exercise Therapy (GET). These treatments are useful to people with a number of long term debilitating illnesses but are usually prescribed as well as medical treatment not instead of it. The Gibson Inquiry argues that we must invest massively in research into biomedical models of this illness. It is still unclear whether CFS/ME is one illness with a spectrum of severity or whether it is two separate illnesses. The most severely affected are least helped by the existing symptomatic treatments. And indeed many of the most severely affected find GET massively worsens their condition. Researching the possibility of sub groups is essential so sufferers can get the best treatment.

One problem with investigating CFS/ME is that the 'Oxford Criteria', the guideline for selecting patients for research trials, is very vague and focuses on fatigue rather than the numerous other symptoms of CFS/ME. As such, the knowledge we do have of the illness may have been gleaned from people who did not genuinely have the condition. NICE has just finished consulting on their draft guidelines for treating CFS/ME. These guidelines have been widely criticised by patient groups and by the APPG on ME. Chair Des Turner described them in a meeting last week as 'not fit for man nor beast'.
Dr Ian Gibson MP of the Inquiry described them as 'useless'. ME patient groups have questioned the independence of reviewers in previous Inquiries and believe that the psychosocial school has received an unfair historical advantage in terms of funding for research.

The Inquiry calls on the government to rectify this historical bias toward a psychological model and commission a genuinely independent panel of medical experts consisting of virologists, immunologists, geneticists, biochemists etc who can asses the international and UK evidence objectively.
The inquiry also calls on the MRC to encourage research projects into a biomedical model. The government invested £8.5 million in treatment centres around the UK, these centres should also be used a for research programmes. The UK is supposed to be currently focusing efforts on science technology and innovation. However the UK is falling behind the rest of the world when it comes to CFS/ME and it is the patients in the UK who are paying the price. There is also a benefits issue. While the illness remains undefined and perceived by many as psychological, patients find it almost impossible to receive higher rate DLA despite in many cases being severely incapacitated, house bound and in need of 24 hour care.

Dr Ian Gibson MP said "At last there is an Inquiry which identifies the seriousness of CFS/ME. For too long the patient voice has been left out of the debate. I hope that our Inquiry will highlight the difficult issues surrounding this illness and the urgent need further research. There is a wealth of published and evidence-based research on this subject, some in the UK but mostly internationally. Canada and the US are leaving us way behind on this issue. We are a Group on ME and even in our group there have been conflicting opinions on the evidence. One thing is sure, we have a fantastic opportunity here with our Inquiry and the new NICE Guidelines to really begin to recognise this illness for what it is, to look for causes and new treatments and to really build consensus amongst doctors and patient groups".

North of Doncaster

Personal Comment about the World of ME by Trevor Wainwright from West Yorkshire.

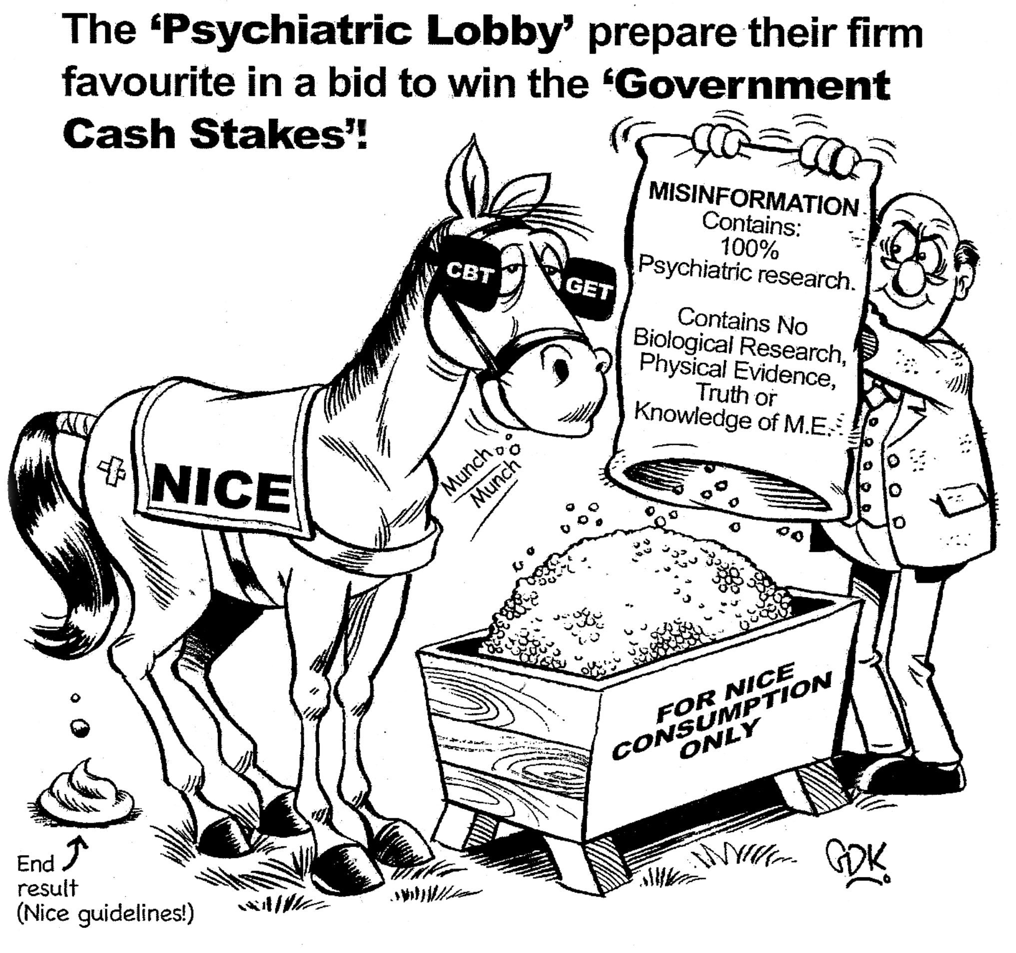
Well it seems I am to begin this issue's column with an amendment to last issue's column when I referred to Princess Michael of Kent as the Duchess of Kent, my apologies for this. Somehow I can't see t'owd Queen Liz 2 crying "treason, 'orf with his head". Which brings me to the subject of a real royal patron, Lady Elizabeth Anston, ME Sufferer, first cousin of the Queen, and not a bad lass really.

Toward the end of my fundraising through MERSC I was invited to a Champagne Reception at her house in London by TYMES Trust, me and others in recognition of the work we had done for TYMES, we the ordinary people. This came about when TYMES were having trouble honouring their rank and file and Lady Elizabeth agreed to hold the reception at her house in London. So, arriving, I was met by TYMES Trust staff and welcomed warmly as usual, but which one was Lady Anston? There were quite a few well dressed ladies but again the thought, which one? "Would you like a canapé?" a voice said, "Thanks love" I replied "You're very welcome" she said smiling. Yes the woman in ordinary clothes serving was Lady Anston, no airs or graces about her, just doing her job and doing it well. After the event I was able to thank her personally and was pleased that she asked what the two Blue Ribbons I was wearing represented, I was able to tell her that they represented two remarkable people's organisations, BRAME and MAME (Mothers Against ME) note ME not CFS.

Well now the Gibson Report is doing the rounds of the ME World, garnering various comments.
I have yet to finish my review of it but have sent my comments on certain aspects of it to Dr Gibson. It does seem to have a comedy aspect to it, when it refers to Simon Wessely (boo hiss), considered by many to be the leading expert on treating CFS/ME yet his treatment has not worked perhaps because they are psychologically based. Apparently Wessely gave up the research side of his work possibly due to extreme harassment he received from a very small fringe section of the ME community. There is great dispute over the findings and beliefs of Professor Simon Wessely. Many patient groups believe Wessely and his colleagues are responsible for maintaining the perception that ME is a psychosocial illness. Strange how he turned down an offer to address the Gibson Group at an oral hearing but instead sent two of his staff.

Well, if anyone wants details of the Gibson Group study, which makes interesting reading, it is available on: http://www.erythos.com/gibsonenquiry/news.html .

Lastly it looks like People Power in Action again as once more the People plan their events for ME Awareness Week with two planned People's events in London. Even now work is in motion to ensure these plans come to fruition, as to the support, well, we'll just have to wait and see. Our profiles as Patrons of the event are to be published on the People's Events Website along with other details of the events. More in the next issue. - *Trev*



Thanks to the 25% for such a good way to summarise the issues.