Price £ 3.75 (Free to members)

Pathways

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

Welcome to Pathways 48 (Summer 2016 Edition)

The River Irt leaves the turntable at Dalegarth Station ready to take a train back to Ravenglass.

You Write In

A selection of email received at the Leger ME office.

Mary Writes: Nobody gives me the time of day because nobody really understands it, including my GP. I am constantly having to defend myself to strangers, even family and friends who do not understand but I do not think they ever will without help.

Your experience is shared with many ME/CFS sufferers. It's usually because of a combination of denial and misunderstanding on the part of others. There is no magic wand I can wave to deal with it. I think firstly you yourself have to understand the problem.

Most people I know with ME can't function in a morning, and yet they are capable of better function in the afternoon. There are a few people opposite to that; better in a morning, but shattered for the rest of the day. Many people with ME suffer from morning stiffness, which typically lasts 2-3 hours. It's something similar to what happens with arthritis, except worse. It's caused by impaired HPA activation and it can be proven. There is a lab test that looks at salivary cortisol over 24 hours. The profile is usually skewed and on average 6 hours late. The test is not that expensive and is doesn't lead to a treatment, but it explains the observation. The theory goes that you have only have a fixed amount of energy during the day. There are peak periods where energy-use is expensive. Think about peak railway commuter fares. morning and evening. Its use is cheaper later in the day, think about cheap day tickets on the railways. There is something similar in overnight electricity tariffs (white meter) for storage heaters. So for example taking kids to school in a morning can drain someone's energy for the day, and is overcome if someone else takes the kids to school in a morning, whereas picking the kids up in the afternoon is nowhere near as energy-draining.

In ME/CFS, if the energy limit is exceeded (cf like running out of money) it's got to be paid back with massive interest. In early ME/CFS it starts almost immediately, whereas in later ME/CFS nothing may happen until the following day. This is called a rebound, and usually takes 2-3 days to recover the previous energy level. It is as though the excess activity depletes mitochondrial AMP, and it takes 2-3 days to recover the levels. Again there is a private lab test which costs about £500 to prove it, but there is really no treatment that is effective. Sometimes the lab test results are used as evidence in DWP benefits or legal disputes.

There is a book called Living with ME by Dr Charles Shepherd. Medical Director of the ME Association which comprehensively covers this. It's a paperback and you can get it from booksellers or Amazon. We have copies in the group library, but they are always in heavy demand. Here are the details if you would like to buy your own copy

Living with ME by Dr Charles Shepherd, Publisher: Random House UK; 3rd edition (February 1, 1999), ISBN-10: 0091816793 ISBN-13: 978-0091816797.

Tony Writes: I think you are wrong when you voted for to stay in at the recent referendum. I voted to leave. At the risk of sticking my chin out to be hit, I thought I would note down the reasons for my conclusion, after very careful thought, to vote Leave. At the start of the campaign, I was inclined towards Remain, partly out of loyalty to the Prime Minister but also because I felt that a decision to leave would create considerable uncertainty in the financial markets. Investors hate uncertainty and there is no doubt that for a period of years an additional risk premium would be required by investors in UK capital projects or equities. The arguments for Leave therefore needed to be strong indeed.
As the campaign progressed, I became increasingly irritated by the Remain campaign's carefully orchestrated parade of worthies preaching to the British public - everyone from Christine Lagarde to President Obama, from retired former US Treasury Secretaries to David Beckham. The Leave campaign was also guilty from time to time of treating the electorate like idiots (particularly by their insistence on the misleading £350m a week number) but to a lesser extent, I felt, than Remain.
My eventual conclusion was based on three factors:

Firstly, Immigration is out of control and needs to be managed more effectively. I had assumed that our immigration data was based on information gathered at passport and visa control, and was horrified to learn that the Government's official net immigration statistics are based on surveys carried out by

people with clipboards at airports and on ferries (where are they, by the way? I travelled extensively when I was working - distances equivalent to the moon and back several times according to British Airways - and I don't remember ever being interviewed). Net immigration on this basis was 333,000 in the year to Dec 2015; however, over the same period, 828,000 new National Insurance Number registrations were issued to adult overseas nationals, of which 630,000 were issued to EU citizens, suggesting that the official numbers are significantly under-estimated particularly when dependants are taken into account. It is hard enough to manage and finance the NHS in 2016 to meet ideals established in 1948 without the strain of unbudgeted EU immigrants entitled to free healthcare. The same goes, broadly speaking, for housing and education. I find the Prime Minister's claim that EU jobseekers who have not found work will be removed wholly unconvincing; the thought that a family of, for example, Romanians, might be forcibly uprooted from a council house after living in the UK for 2 years, taken to an airport with their belongings and expelled, seems inconceivable. It is not difficult to conclude that immigration may be more readily brought under control over the next several years without the requirement to allow free movement of labour within the EU.

Secondly, I feel that over time, the European Court of Justice has become increasingly influential in British law; it is also true that a significant proportion of the UK's legislation is derived from our membership of the EU, originating with the unelected European Commission. These developments have been insidious and persistent and were not contemplated when we joined the Common Market in the 1970s. There seem to me to be good arguments for believing that UK laws should be promulgated by our elected parliament, and finally judicially determined by the UK courts.

Thirdly, The drive towards ever-increasing integration of EU countries benefits most significantly the strongest nations within the EU and this is particularly true of the Common Currency project. When the Euro was launched in 1995, the process of reunification of East and West Germany was in its early years. East Germany had a large labour force including about 3 million unemployed in 1994, poor productivity and inadequate infrastructure. The German State invested significant amounts in bringing the infrastructure up-to-date, so what it now needed was demand for the output of its new manufacturing facilities. By the formation of the Eurozone, the relatively unproductive economies of Spain, Portugal and Greece were deprived of the only tool of economic management which had enabled them to remain competitive over the previous decades - currency devaluation. Over the next decade, manufacturing capacity in the weaker European economies shrank and Germany grew significantly, leading to 27% unemployment in Spain (over 50% for young people). Effectively, the formation of the Euro brought about the transfer of massive volumes of manufacturing capacity from the weaker economies to Germany; I find it very hard to believe that the German economic planners working on the formation of the Eurozone did not have exactly this objective in their sights.
We should not continue to connive in this abuse of weaker European nations by the strong. The name of Winston Churchill was invoked by David Cameron towards the end of the campaign. It is difficult to imagine that the great man would have been in favour of the UKs continued participation in a project whose effect has been to re-establish the domination of Europe by Germany.

Finally, David Cameron's downfall was in failing to achieve any significant reform in his renegotiation in February 2016. Having determined his course, to be methodologically consistent he had to go to Brussels determined to make clear that he intended to recommend Leave on the basis of the status quo; he then needed to achieve enough in his renegotiation in February to support his shift to a Remain recommendation. However, he singularly failed to achieve anything of any consequence. Experience of complex negotiations tells me that much is won by determination, graft, stamina and sheer hard work. Having heard John Major describe his team's efforts over the Maastricht negotiation in 1991, it is difficult to believe that the Cameron team committed anything like as much to their task.

I voted well before the main hustings started. My logic for voting for Remain was based on the fact Brexit would cause financial uncertainty, and overall there would be less money around. It's wealth that pays for the NHS, welfare payments and pensions, and this would mean many people within our community would be less well off. Many people I've spoken too since voting day who have voted for Leave did so on gut feeling rather than on any logical principle. It tended to be a vote against the status quo, and was a general dissatisfaction protest. Today, I note that the Chancellor has abandoned his target to restore government finances to a surplus by 2020 which would have meant further funding cuts under a financial system showing signs of stress.

The matter is now closed.

Letters from America *by Carolyn*

I am in frequent contact with Leger ME member, Sandy, from Cincinatti, Ohio, who regularly gets a copy of her local newspaper 'Suburban Life' and whilst reading it a few weeks ago noticed the following question and decided to reply. Here is her letter which the paper duly printed. Well done Sandy!

'SURBURBAN LIFE'
CH@TROOM

May 25th Question:-

What is your all-time favorite movie – the one that you will always watch if you come across it while channel surfing? Why do you like it?

_____

"84, Charing Cross Road," will always be my all-time favorite movie. It is from a simpler time when simple courtesies and kindnesses seemed to be spontaneous and appreciated.

A lovely friendship developed between two opposite personalities through letters and a love of books. I would be as excited as Helene Hanff was whenever she received one of her parcels from the book store at No.84, wrapped in brown paper and twine, that had travelled across the Atlantic on a ship.

I have a friend in the UK who sends me packages wrapped in brown paper and twine and it always makes me smile and think of Helene; and I always save the twine!

The goodness of the people working at No.84 sharing out a small parcel of foodstuffs from Helene that she had sent to show her appreciation for their book finding efforts and written communications was tender, generous, and typical of a people living during rationing. That gave me a feeling of lives that were very wholesome and worthwhile, meagre that they might have been.

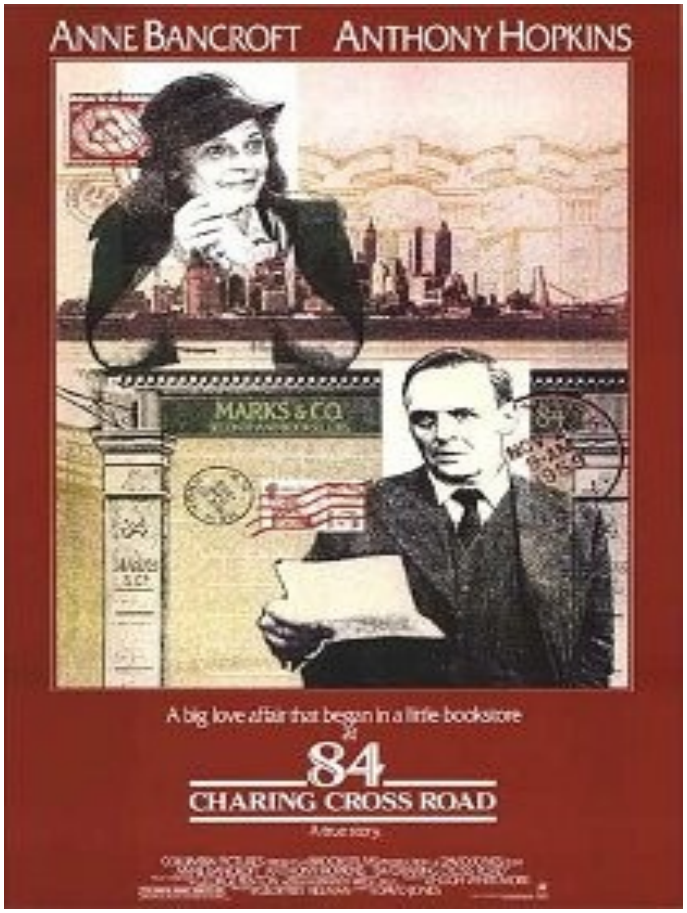
Sandy

We wonder if any of you readers have a favorite film and why you like it?

Could it happen here?

Spotted on Facebook and what a lovely idea, but sadly this would be unlikely to happen over here with all our health and safety…

Orange juice, squirts in eye! Choke hazard! Banana skin, slip hazard!



84 Charing Cross Road is a 1987 British-American drama film directed by David Jones.
The screenplay by Hugh Whitemore is based on a play by James Roose-Evans, which itself was an adaptation of the 1970 epistolary memoir of the same name by Helene Hanff, a compilation of letters between herself and Frank Doel dating from 1949 to 1968. The play has only two characters, but the dramatis personae for the film were expanded to include Hanff's Manhattan friends, the bookshop staff, and Doel's wife Nora

A Message from The Doncaster Domestic Abuse Service

In a healthy relationship each partner respects the wishes and feelings of the other, does not want to impose their will on the other person, and each partner feels secure and cared for. When abusive behaviour first starts, it can seem like caring, loving behaviour, just perhaps a little over the top. But jealousy, possessiveness controlling what you do or what you wear for instance, can be a sign of abusive behaviour developing. Domestic abuse can cause serious harm to both adults and children. The Service works to protect and support victims of domestic abuse and their children, challenge abusive behaviour and support people to change their behaviour. They also want to educate all ages about domestic and relationship abuse so that it can be recognised early, and avoid its becoming very serious.

Domestic abuse includes any kind of abuse; verbal, emotional, physical, sexual, financial by members of an intimate relationship aged 16 or over, or family members. It can also mean abuse by a former partner. You don't have to be living together, or ever have lived together; you might just be going out together. It can be hard to recognise abusive behaviour, whether you are doing it, or on the receiving end of it. Have a look at the checklists to the right, and see how healthy your relationship is.

The Doncaster Domestic Abuse Service is a partnership made up of services such as the Council, Police, Doncaster Children's Services Trust, NHS, and voluntary sector services that are commissioned to deliver some of the services. They provide a range of services for anyone affected by domestic abuse, and also for professionals working with families. Whether you are experiencing domestic abuse yourself, concerned about a relative or friend, or want help to change your own behaviour, you will find information and details of services that can help.

If you are suffering domestic abuse, or know someone who is, please tell someone, call our helpline (see below). If you are in danger right now, call 999 immediately. The advisors are there to listen and help to decide what to do. On our website you can watch a video made by some people we've supported:

Contact details:

Helpline: 0800 4701 505, open Monday to Friday 9am -10.30 pm. There is a confidential advisor available.

Website
http://www.doncasterdomesticabuse.co.uk/

This website contains further useful advice and information.

What is domestic abuse?

Any abuse that happens in a family or personal relationship.

- It's never ok and you don't have to put up with it.
- It's never your fault and you are not alone.
- Children are badly affected by living with and witnessing domestic abuse and young people can be vulnerable to abuse in their own relationships.
- It's a crime.

Are you at risk?

If you answered 'YES' to any of these questions, tell someone or take action.

1) Do you feel nervous around your partner?
2) Do you have to be careful to control your behaviour to avoid their anger?
3) Are you scared of disagreeing with them?
4) Do they wrongly accuse you of seeing or flirting with other people?
5) Do they say that if you changed they wouldn't abuse you?
6) Do they prevent you from doing things you want to do?
7) Do they make you feel like you are wrong, stupid, crazy, or inadequate?
8) Do you feel that nothing you do is ever good enough?
9) Do they say that they will hurt themselves if you break up with them?
10) Do they insist you have sex even when you don't want to?
11) Do they control your finances?

NIHCE guidance for ME/CFS CG53: The Disability scale

The National Institute for Health and Care Excellence (NIHCE) provides national guidance and advice to improve health and social care. In August 2007 the guidance on Chronic fatigue syndrome/Myalgic encephalomyelitis (CG53) was published. Day one, it was a disappointment focusing on Cognitive Behavioural Therapy and Graded Exercise. ME/CFS is not the only victim of the NIHCE guidelines. Most notorious perhaps are refusal or rationing of new treatments for life threatening conditions. Some doctors I know have coined the phrase '*National Institute of Clinical Economics'.*

There have been a number of tried and tested treatments in the private sector and abroad which were totally ignored. Action for ME and the ME Association have disagreed with many of these guidelines. From the Leger ME point of view, the only benefit has been official recognition of the condition and an official severity scale for the UK

The NIHCE Degree of Severity Scale

The degree to which CFS/ME affects a person's functioning and daily life is listed as a three stage grading system by NIHCE

Mild

People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.

Moderate

People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

Severe.

People with severe CFS/ME are unable to perform any activity for themselves, or can carry out minimal daily tasks only (such as face washing and cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

The system follows standard clinical practice for many other conditions, however for leger ME purposes this is insufficient. We tend to use an addition item or 'Very Severe' simply because NIHCE does not recognise complications.

Very Severe.

People with severe CFS/ME are the same as moderate or severe cases, but the ME/CFS has additional complications such as irritable bowel syndrome, gut fermentation, asthma and diabetes. Here the clinical picture is a hybrid of the two or more additional conditions present.

The main problem with the NIHCE system is that it is oversimplified. Our scale of choice is a modified Bell scale used by Dr. Myhill's practice, which is a percentage scale. Research has shown and this, in many cases, forms a linear relationship with the Acumen mitochondrial function test.

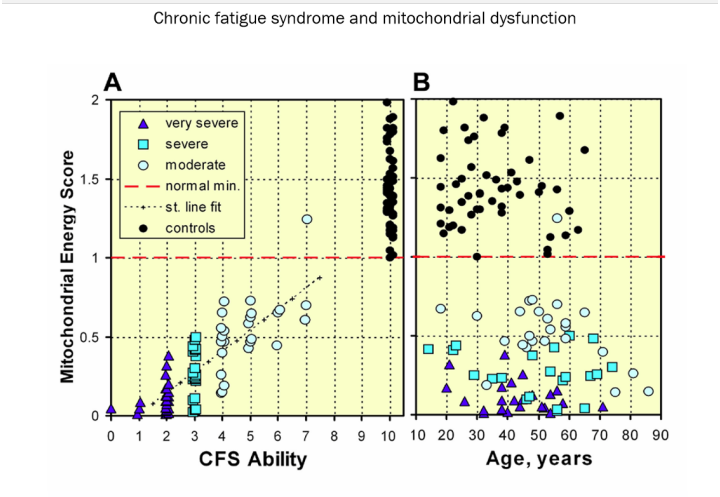


Figure 4. The Mitochondrial Energy Score. A. The Energy Score plotted against CFS Ability with a point for each patient. A point for each control is plotted at CFS Ability = 10. The horizontal dashed line at Energy Score = 1.00 is our normalisation at the minimum Energy Score for controls. Also shown is the best straight line fit to the patient data. B. The Energy Score plotted vs. Age of patients and controls.

The NIHCE 'Do Not Do' list

It is now some nine years on from the original publication of NIHCE's GC53. There has been a reframing in the form of DO NOT DO guidelines. From our point of view, some are well thought out, some are just junk, and some are questionable.

Do Not Do	Rating	Background
Tests for serum ferritin in adults should not be carried out unless a full blood count and other haematological indices suggest iron deficiency	Questionable	Iron deficiency can cause fatigue. If is a problems with a significant number of members possibly due to dietary restrictions.
Tests for vitamin B12 deficiency should not be carried out unless a full blood count and mean cell volume show a macrocytosis.	Questionable	It is known in the USA and in private medicine that B12 injections reduce oxidative cell damage and can help ME/CFS management irrespective of actual B12 levels.
Tests for folate levels should not be carried out unless a full blood count and mean cell volume show a macrocytosis.	Questionable	Reduced levels of folate may indicate general vitamin deficiency
The head-up tilt test should not be done routinely to aid diagnosis.	Credible	Not diagnostic of ME/CFS, but carried out for a POTS diagnosis, an ME/CFS complication
Auditory brainstem responses should not be done routinely to aid diagnosis.	Credible	Hyperacusis is a problem that affects many people with ME/CFS
Electro-dermal conductivity should not be done routinely to aid diagnosis.	Credible	This refers to the Vega type test carried out by some alternative practitioners. It is a con.
Serological testing should not be carried out unless the history is indicative of an infection.	Questionable	Many people with ME/CFS have subclinical infections—most commonly gut dysbiosis
Monoamine oxidase inhibitors should not be used for the treatment of ME/CFS.	Credible	MAOI as used to treat severe depression but of no value in ME/CFS
Glucocorticoids (such as hydrocortisone) should not be used for the treatment of ME/CFS.	Credible	There is no general consensus about hydrocortisone in ME/CFS. There is a functional depletion. Clinical trials show no benefit.
.Mineralocorticoids (such as fludrocortisone) should not be used for the treatment of ME/CFS.	Credible	Same as above
Methylphenidate should not be used for the treatment of ME/CFS.	Credible	Methylphenidate is a stimulant and has been found to have no value in ME/CFS management.
Thyroxine should not be used for the treatment of ME/CFS.	Questionable	Some people have thyroid resistance and/or a T3 conversion problem. T4 and T3 can sometimes help, but it needs an open minded specialist. Thyroid hormone given without medical supervision can cause heart arrhythmias.
Antiviral agents should not be used for the treatment of ME/CFS.	Credible	ME/CFS in some cases is the damage left after the virus has long since disappeared from the body.
Advice to undertake unsupervised, or unstructured, vigorous exercise (such as simply go to the gym or exercise more) should not be offered to people with ME/CFS because this may worsen symptoms.	Credible	This could cause worsening of ME/CFS and heart damage.
Specialist management programmes delivered by practitioners with no experience in the condition should not be offered to people with ME/CFS.	Credible	This could cause worsening of ME/CFS and heart damage.
Strategies for managing ME/CFS should not include prolonged or complete rest or extended periods of daytime rest in response to a slight increase in symptoms.	Junk	If someone needs daytime rest they need to take it. (This mostly happens during a relapse, payback or rebound period.)
Strategies for managing ME/CFS should not include an imposed rigid schedule of activity and rest.	Credible	This could cause worsening of ME/CFS and heart damage.
There is insufficient evidence for the use of supplements such as vitamin B12, vitamin C, co enzyme Q10, magnesium, NADH (nicotinamide adenine dinucleotide) or multivitamins and minerals for people with ME/CFS, and therefore they should not be prescribed for treating the symptoms of the condition. However, some people with ME/CFS have reported finding these helpful as a part of a self-management strategy for their symptoms.	Junk	This is just an opt out by NICHE to avoid vitamin supplements being supplied on NHS prescriptions. Many people with ME/CFS have definite vitamin deficiencies, possibly due to poor diet or lifestyle. Additive-free supplements are preferable.
There is insufficient evidence that complementary therapies are effective treatments for ME/CFS and therefore their use is not recommended.	Junk	Some people with CFS/ME choose to use some of these therapies for symptom control, and find them helpful.

Welfare Rights and State Benefits Matters

with thanks to 'Benefits and Work'

Benefits and Work
Guides you can trust

Consequences of 'Brexit'

There has been only one story in town since the last newsletter, the referendum and its consequences for the UK and the major political parties. We now know that the vote was for leave, but we know very little else. We do know that the agreement David Cameron negotiated in February for an emergency brake on in-work benefits for EU migrant workers will no longer happen, nor will the cuts to child benefit which would have reduced payments where the child lives in another country. In addition, sterling suffered a heavy fall in value, especially against the dollar, which may mean price rises for many basic commodities including food and fuel.

Aside from that, here at Benefits and Work, we are as much in the dark as everyone else. Will IDS return to the front bench when a new leader of the Conservative party is elected? And if so, will he want his old job back at the DWP? If sterling continues to decline and businesses cut back on hiring, will this lead to further inflation, a loss of tax revenue and calls for more cuts to benefits in a new wave of post-referendum austerity? Or will things calm down very quickly, with sterling continuing to bounce back and everything carrying on much the same as it did before last week's momentous result? Could things even improve, with politicians deciding that there will be more cash available to spend on claimants once we don't have to pay out for EU membership? Your guess is very definitely as good as ours.

PIP award Rates

The percentage of DLA to PIP claimants who get any award at all of PIP has fallen from a high of 80% in March 2014 to 70% in April 2016. That is almost one in three people who are losing out entirely, with no explanation as to why decisions are becoming harsher.
Meanwhile, the award rate for fresh claims for PIP has plunged even more dramatically. In March 2014 62% of new claimants got an award of PIP, this had fallen to just 42% by April 2016. Again, there is no explanation of why so few awards are being made. The mandatory reconsideration success rate for DLA to PIP transfers has also plummeted. In April 2015, the success rate was 42% but by April 2016 only 19.5% of mandatory reconsiderations for DLA to PIP decisions were successful. By contrast, mandatory reconsideration success rates for fresh PIP claims have stayed relatively stable, though dismally low, rising from 16.6% in April 2015 to 17.2% in April 2016.
With PIP appeal success rates currently standing at 63% and rising, as we reported in the last newsletter, the lesson is clear: mandatory reconsideration is largely just an obstacle to try to wear claimants down before they can appeal.

Whatever happens, Pathways will keep you updated

Action on the PIP 20-metre rule *From the Spartacus team*

Have you lost your higher rate mobility in a transfer from DLA to PIP? Lost your Motability vehicle? Do you think your mobility needs were unfairly assessed in a PIP assessment? Thanks to a recent House of Lords motion by Baroness Thomas of Winchester, there's a chance to make the Government rethink the notorious "20 metre" rule for qualifying for the Enhanced Rate Mobility component of Personal Independence Payments (PIP). We need case studies of people affected by this 20m rule for Department of Health officials to examine its fairness and its impact on people's lives. Please note, you must be willing to disclose your National Insurance number, so that details of your case can be looked into. The 20m rule, not included in the original consultation on PIP, restricts eligibility for the mobility component for people with severe walking difficulties from the previous 50m benchmark used in DLA down to 20m. There is no evidence that people who can walk more than 20m but less than 50m face lower costs for mobility and transport than those who cannot walk 20m. This aspect of PIP means disabled people who would have qualified for the Higher Rate mobility component under DLA lose £33.25 per week or access to their Motability vehicle. Please write to Baroness Thomas, with details of your case and your NI number if you can help, at thomascm@parliament.uk

Recipe Corner *by Carolyn*

Here are two summer recipes taken from the Doncaster and Bassetlaw Hospitals' leaflets.

Mince Kebabs

This recipe serves four people.

Method:

- Using a non-stick pan, gently dry fry the mince in 30-45ml (2-3 tablespoons) of water until browned. Drain off any excess fat.
- Add the chopped onion and garlic and cook until softened.
- Add 30ml (2 tablespoons) of tomato puree and stir in the ratatouille.
- Cook for a further 10-15 minutes or until cooked through.
- Lightly grill the pitta-bread, slice in half and fill with the mince mixture.
- Serve with rice or couscous and a crisp green salad.

Ingredients

450g (1lb) Lean mince
1 Onion, peeled and finely sliced
2 Cloves of Garlic, crushed
30ml (2 tablespoons) Tomato puree
400g (1 large) tin of ratatouille
4 Pitta-breads

Crustless Quiche

For this one you will need oven-proof flan dish.

Method:

- Prepare whatever vegetables take your fancy, we've used the ones stated just as a suggestion. You can dry-fry them until soft or, leave them raw for extra crunch.
- Mix together the 3 eggs, the 150g fat-free natural cottage cheese and some chopped parsley.
- Lay the chopped vegetables out in an oven-proof flan dish then pour the cottage cheese mixture over.
- Pop into the oven at 190°C/170°Fan/Gas 5, for around 30 minutes, or until the quiche is set and golden brown.

Ingredients

Peppers, diced
Onions, chopped
Courgettes, diced
Baby sweetcorn, sliced
Mushrooms, chopped
Cherry tomatoes, sliced
3 eggs
150g fat free natural cottage cheese
Some chopped parsley

Foods Allergy and Intolerance Testing

with thanks to the British Dietetic Association.

On the following pages we've reproduced factsheets by the BDA. Quite frequently I come across people, who have had private tests at considerable costs. The main issues are that many of them are 'junk' tests. The BDA quite diplomatically used the phrase 'the results of the tests are no better than chance'. People who have food allergies usually work it out for themselves. There is a simple way.to find out. If you suspect a food is a problem, just leave the offending food out of your diet for a while, and then try it again. If you get a reaction then you have an answer. With ME/CFS skin RAST tests and Ige tests are usually unreliable because the sensitivity seems to vary and drift. Apart from avoidance, there is one desensitisation technique with works quite well and that is EPD. Locally this is available privately through Dr. Roper's Clinic in Sheffield. I am not aware of any local NHS facilities.

BDA The Association of UK Dietitians

Food Fact Sheet

Food Allergy and Intolerance Testing

The use of complementary and alternative medicine to diagnose food allergy and intolerance is growing fast. There are many types of 'tests' available on the high street and on the internet and it is difficult to know what is reliable and scientifically sound. This fact sheet looks at various tests available and discusses the scientific background or 'evidence' behind them.

Conventional Allergy Testing

These tests are evidence-based and performed by registered health professionals:

Skin prick test

A small amount of diluted allergen (suspected protein that person is allergic to) is placed on the skin and the skin is then pricked. If a small swollen lump or 'weal' appears, in conjunction with a detailed clinical history, an IgE mediated food allergy may be diagnosed. This test is only performed under medical supervision.

Blood tests

A specific IgE test, formally known as Radio Allergo Sorbent Test (RAST) is carried out by measuring the amount of IgE antibodies to a suspect food in the blood. The results are interpreted with a detailed clinical history to give a diagnosis of IgE mediated food allergy. This blood test can be organised by your GP or hospital clinician. There are commercial companies who offer a similar blood test called MAST (Multi-Allergen Screening Test). However, as they do not have your detailed clinical history, it is difficult for

> "Alternative allergy testing should be avoided as it has no scientific basis."

Common words

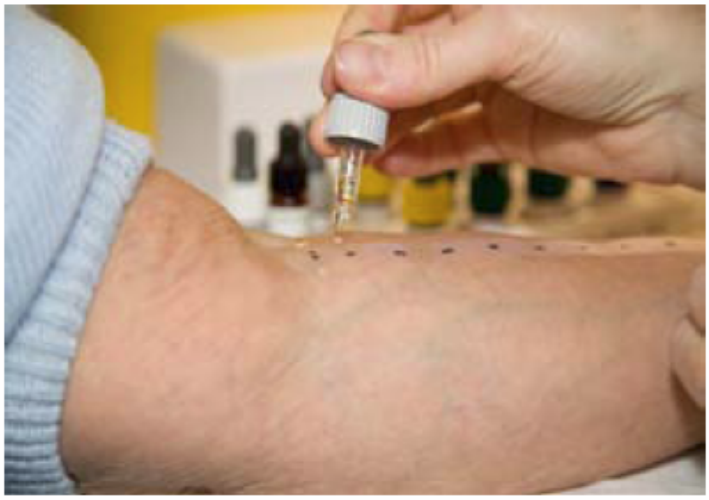
Medical terms for food allergy and intolerance can be confusing, so here is a list of their descriptions:

Food hypersensitivity
Covers all bad reactions to food.

IgE mediated food allergy
The reaction is immediate and can be severe. This reaction involves IgE antibodies which are produced by your immune system.

Non-IgE mediated food allergy
The reaction is delayed or 'slow onset'. The immune system is involved but not IgE antibodies.

Non-allergic food ypersensitivity
The immune system is not involved.



commercial companies give an accurate diagnosis.

Food challenges

Very small amounts of the suspect food are given orally (in the mouth) and symptoms are observed. The food may be given openly or 'blinded' (when people are unaware which food they are eating). Again, this should only be performed under medical supervision where medical facilities and resuscitation equipment are available.

Food exclusion and reintroduction

The suspected food or foods are excluded for a period of time and symptoms observed and recorded. If symptoms improve then the suspect food is reintroduced. If symptoms return then this would indicate that there is a problem with that particular food.

This can be very time consuming and is best carried out under the supervision of a registered dietitian, especially if children are involved. It is important to ensure a well balanced nutritional intake during the test period and in the design of a diet where major food groups are excluded (e.g. dairy or wheat).

Alternative allergy tests

There are also many commercially available tests that claim they can diagnose food hypersensitivity. These should be avoided as they have no scientific basis:

IgG blood test

This blood test looks at IgG antibodies present in the blood. It's claimed that an increase in IgG to a certain food indicates an intolerance to that food. At present there is no convincing evidence to support this test, and it's not recommended as a diagnostic tool.

Kinesiology

This is based on the idea that certain foods cause an energy imbalance in the body which is detected by testing the response of the muscle. The client holds the suspect food which is in a glass vial and the therapist tests the muscle response. The result can lead to many foods being eliminated from the diet however research studies show that this test is no better than chance.

Hair analysis

A small lock of hair is sent off to a laboratory and the energy fields in the hair are scanned. The results are compared to other established data to identify a food hypersensitivity. Although this is used in testing for recreational drug use as well as lead and mercury poisoning, its use in allergy testing is unproven and has no scientific basis.

Leucocytotoxic or Cytotoxic test

This is a blood test where the white blood cells are mixed with the suspect food and if they swell this would indicate a problem with that food. There is no rational scientific basis for this test.

Pulse test

The pulse is taken before eating the suspect food and then 15 minutes afterwards. An increase of ten beats per minute would indicate food intolerance. Research shows there is no connection between the increased pulse and food intolerance.

Electrodermal (Vega) test

This test measures the electromagnetic conductivity in the body. An offending food will show a dip in the electromagnetic conductivity. Research studies show that this test is no better than chance.

These alternative allergy tests may suggest long lists of foods to be excluded from the diet unnecessarily. Excluding a major food group e.g. wheat or milk, or a combination of different foods, creates many practical difficulties. Without good nutritional advice, a restricted diet can lead to severe nutritional deficiencies leadin to malnutrition.

Summary

If a food allergy is suspected, you should seek medical advice and discuss the use of evidence-based conventional allergy testing. Alternative allergy testing should be avoided as there is no scientific basis.

Dietitians can give you the correct nutritional advice and ensure a well-balanced nutritional intake which will be tasty, varied and culturally acceptable.

Children should not follow a restricted diet unless supervised by a dietitian as they require a well-balanced diet to ensure adequate growth and development.

Further information: Food Fact Sheets on other topics including *Food Allergy and Intolerance* are avaiable at www.bda.uk.com/foodfacts

The Myhill Files : Oxford CFS/ME Conference 5th March 2016

Here is an abridged transcription of a presentation given by Dr. Myhill to the Oxford CFS/ME Conference 5 March 2016 on the Treatment of CFS/ME. The full transcription and further information are available from:
Dr. Sarah Myhill MB BS Upper Weston Llangunllo Knighton Powys LD7 1SL www.doctormyhill.co.uk
Telephone: 01547 550 331

"The tools of the trade: As there are not enough therapists for patients, the only job is to give you the Rules of the Game and the Tools of the trade. Only one person can get you well and that is you. As I get older, and perhaps wiser, I find that the very basic things done very well, get you a long way!"

Introduction: The tools of the trade divide quite neatly into two sections: first, those we should all be doing all the time, in order to reduce the possibility of ill health arising in the first place and then, secondly, the "bolt on" extras which should be employed where a specific condition has been identified.

The Basic Package - what we should all be doing all the time:

I: Stone-age diet
II: Multivitamins, Minerals, Essential fatty acids
III: Sleep
IV: Pacing activity
V: Sunshine and light
VI: Reduce the chemical burden
VII: Wellbeing
VIII: Avoid infections and treat aggressively

The Bolt on Extras - the therapeutic tools of the trade. 'We do not have all the tools to treat all the problems, but the body is fabulous at healing itself. We only have to get the package 51% right and the body will do the rest. Only 49% right and one is on the slippery downhill slope. Many tools multitask

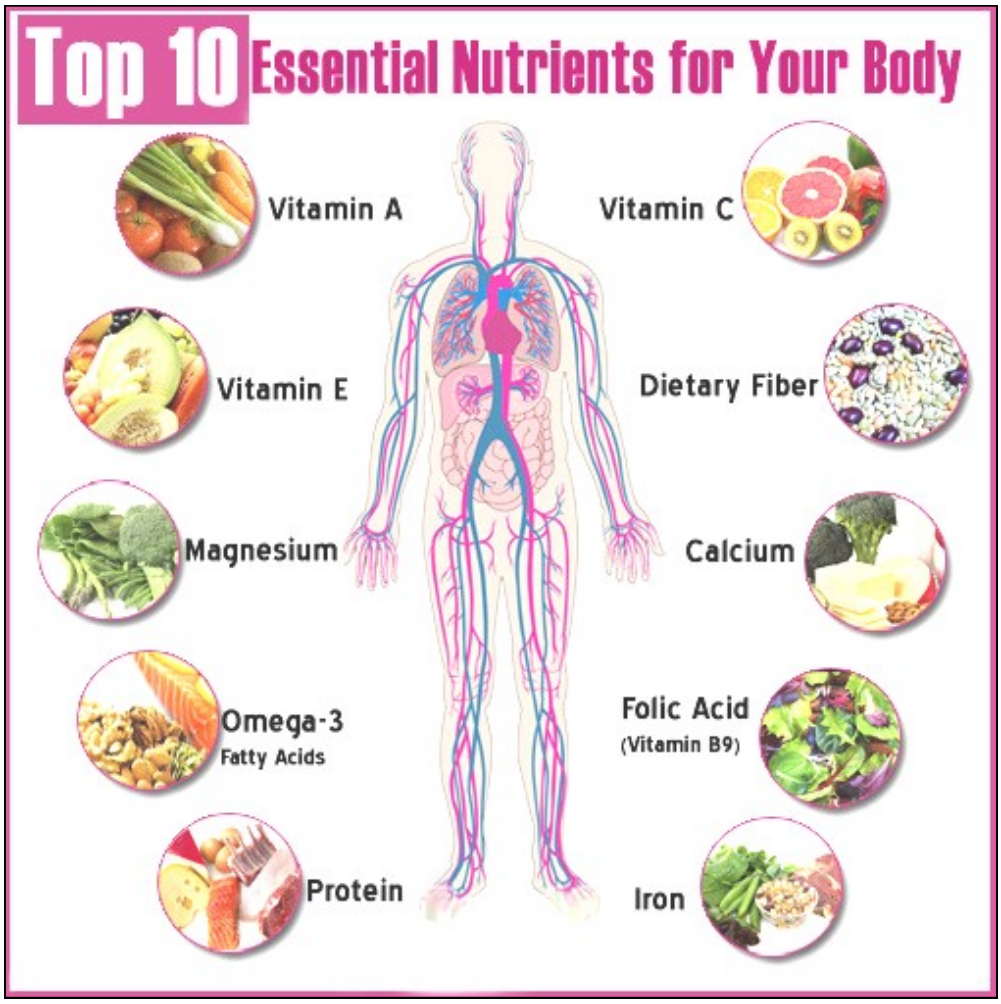
1 -- The Stone-Age Diet

Changing one's diet is the most difficult but perhaps the most important thing one needs to do for good health. Any one eating a Modern Western diet high in sugar and refined carbohydrates can expect to become fat, feel fatigued and/or die prematurely from heart disease, cancer and/or dementia.

People initially complain that the stone-age diet boring. Actually it is far more varied in composition, texture and flavour than any Modern Western diet which actually relies on remarkably few foods. What gets in the way is addiction—people subconsciously recognize the addictive high they get from high carbohydrate diets and mistake the absence of this for boredom. The convenience of Modern Western diets is also a major factor. There's no one-size-fits-all stone-age diet, but general principles that need to be honed to individual needs. The basic diet is as below, but changes may need to be made if there are allergies to foods and/or problems with the fermenting gut. The starting point for all healthy people observes all the above rules. However, for patients who come to see me with some ill-health problem the diet may have to be further honed according to other factors.

The common starting-point use would be for otherwise healthy people with no symptoms and no disease:

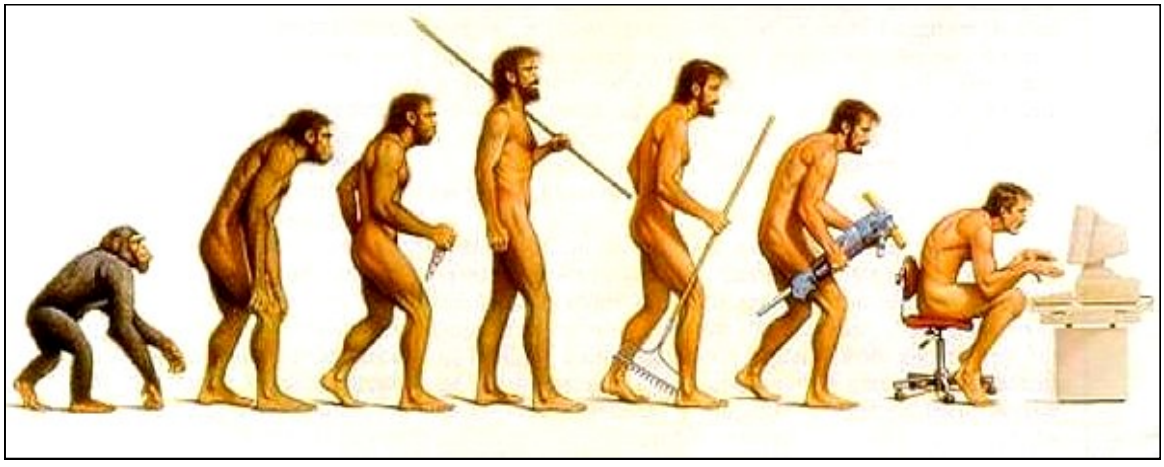
- No added sugar or refined carbohydrates. The occasional carbohydrate feast will not upset a healthy gut.
- No dairy products, except butter. It is milk protein which contains growth promoters and may be carcinogenic.
- Initially avoid addictions such as alcohol and caffeine. Then use judiciously.
- No fruit juices which are rich in addictive sugars especially fructose. High sugar fruits should be avoided. Berries are usually fine; however even strawberries are being so cultivated they are becoming too sweet.
- Eat fermented foods such as Kefir and sauerkraut.
- Avoid chemical additives. Eat as organic as possible. Eat foods in season, locally-grown for freshness.



2 -- Multivitamins, minerals, & essential fatty acids

Westerners all need to take micronutrients for life for the reasons given previously. My standard packages:
Multivitamins - containing at least 25mg of B1, B2, B3, BS, B6 vitamins, 1mg of folic acid, 1mg of B12, vitamin A 2,000u, vitamin E 50mg and vitamin K 0.2mg.

Minerals: - the following doses of elemental weight are per 2 stone of body weight (12.5 Kgs) - Calcium 60 mg, magnesium 70 mg, potassium 40 mg, zinc 6 mgs, iron 3 mg, boron 2 mg, iodine 0.3 mg, copper 0.2 mg, manganese 0.2 mgs, molybdenum 40 mcg, selenium 40 mcg, chromium 40mg. These doses should be taken up to a maximum dose for a 10 stone (62.Skg) person, i.e. up to five times the amounts listed above. Use one gram of powder per litre of water - this can also be used to make hot drinks. do not include sodium chloride (salt) because this is contained in so many foods. If absent then sea salt should be used, approx. one gram per 2 stone of body weight per day.



Vitamin D - at least 2,000u daily but up to 10,000u daily
Hemp oil - one dessertspoonful, together with 2 capsules of fish oil.

Vitamin C at least 2 grams, possibly up to 10 grams at night.
These doses assume that nothing comes from the diet - as the stone-age diet is adopted and sun-bathing possible, these doses can be reduced.

3 -- Sleep

One cannot create energy and function without dong some damage. Most creatures, right down to bacteria, require rest when systems are shut down to allow healing and repair. We call this sleep. Without a good night's sleep on a regular bass all other interventions are to no avail.

4 Pacing activity and Exercise

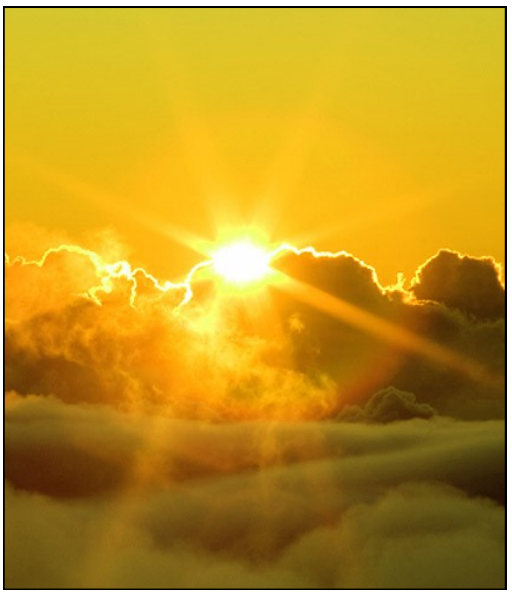
This must be right sort to get benefit. Humans, along with all other mammals, evolved living physically active lives. This usually meant long hours of sustained activity, but there would be occasions when maximal energy-output was needed, for example, to fight an enemy or bring down a prey. internal metabolism is fully geared to physical activity and without this we cannot be fully well.

One needs exercise as one needs food and water: in just the right amount. Too much risks injury and muscle damage; too little and we degenerate. To maintain optimal fitness, we need steady sustained exercise combined with outbursts of extreme energy. Just as with food, the type of exercise and the amount is critical. After research and practical application, Dr. Doug McGuff and John Little, produced their book "Body by Science - a research-based programme for strength training, body building and complete fitness in 12 minutes a week". Thanks to their work, we can now see how to exercise most efficiently. We do not want to do so much that we wear out our body (this is what happens with so many athletes - most runners are carrying injures!) but when we do exercise it must be effective to improve cardiovascular fitness. What is so interesting about McGuff and Little's approach s how well this correlates with what we already know about mitochondria, blood sugar control and fats.

This approach makes perfect evolutionary sense. I do not see badgers and foxes trotting round my hill every morning to get fit! Most of the time wild animals are in hiding or feeding quietly. Once a week there will be a predator-prey interaction - the predator must run for his life to get his breakfast, the prey must run for his life to avoid being breakfast! In so doing both parties will achieve maximal lactic acid burn. This is all that is required to get fit and stay fit.

5 -- Sunshine and light

We make vitamin D from UV light—Western cultures have become almost phobic about any exposure of unprotected skin to sunshine. Indeed, the US Environmental Protection Agency advised that ultraviolet light, and therefore sunlight, is so dangerous that we should "protect ourselves against ultraviolet light whenever we can see our shadow". That advice is just nuts!



The best source of vitamin Ds sunshine - not so much that the skin burns, but enough to tan. One hour of whole body exposure to Mediterranean sunshine can produce 10,000 to 20,000 u of vitamin D. We need at least 2,000u daily and probably more for optimal health. No studies have shown any toxicity in doses up to 10,000u daily. I use high dose vitamin D routinely n the treatment of multiple sclerosis, any condition associated with inflammation (allergy, infection, autoimmunity), osteoporosis and arthritis. My ME/CFS patents are nearly always deficient. Note that the normal blood levels for NHS labs are set very low at 30-60ng/ml. I like to see levels at 75-200ng/ml.

Whilst sunshine exposure is a risk for basal and squamous cell cancer, these are relatively benign, easily treated and rarely kill. At the first sign of sun damage to skin I recommend Curaderm, extract of eggplant. It is highly effective in treating solar keratosis, early basal cell carcinoma (rodent ulcers) and early squamous cell carcinomas. If there's no sign of remission after 8 weeks of use, then consultant opinion is necessary. There's increasing evidence that sunshine is not a risk factor for the aggressive melanoma. If it were then this tumour would have the same distribution as other skin tumours. It does not. Do not use sun tan lotions. There's evidence to suggest that they increase cancer risk directly or, because they give a false sense of security, then they increase cancer risk indirectly through complacency. Once there's a risk of burning, head for the shade or cover up.

To make us happy- absence of full spectrum light results in SAD (Seasonal Affective Disorder). This is no fun but evolutionarily desirable - it helps us conserve energy through long cold winters because we do not want to do things - boring, but with survival advantage. Sunshine is addictive - indeed one measure of addiction is how much money we are prepared to spend on such. Holidays in hot climates are expensive but still highly desirable!

To receive heat in the form of far infra-red - such free heat means we do not have to generate so much heat from our own mitochondria. This too has survival benefits as an energy-conservation method. Indeed, the mitochondria of native Africans run slower than Caucasians and much slower than Inuit Indian Eskimos. The latter have a high metabolic rate and are excellent at fat burning, which is essential to deal with the cold. They need abundant food to fuel this demand. By contrast native Africans run their mitochondria slow, and this makes them much more susceptible to metabolic syndrome and all its complications. They are metabolically highly efficient.

We use this form of heat in FIR saunas to detoxify chemicals. However, I suspect this is just one of many possible benefits of FIR about which we have much more to learn. The heat from muscular activity radiates as infrared. This warming reduces friction in connective tissue to reduce stiffness.

6 -- Reduce the chemical burden

We live n an increasingly polluted world containing an increasing number of toxic chemicals which are toxic to our genes, to our brains, to our internal metabolism and to our immune system. These "nasty" toxic chemicals contribute to our ever increasing incidence of cancer and birth defects, our declining fertility due to lifetime exposure and they also make us more susceptible to chronic fatigue syndrome.

It is impossible to completely avoid every "nasty" chemical. I have yet to do a fat biopsy or measure toxic metals in urine following DMSA challenge and find a normal result. We live in equilibrium with our environment and the best we can do is keep the total toxic load as low as reasonably possible, anything which can be done to reduce the toxic chemical load will be helpful n allowing our bodes to recover.

Dr. Paula Baillie Hamlton in her book "The Detox Diet" explains how chemicals in foods and the are interfere with internal metabolism to make us fat and lethargic - indeed she points out that farm animals are deliberately fed hormones, antibiotics and pesticides to make them fat and lethargic, and therefore they do not have to eat so much in order to put on weight (cheap meat!). Effectively we are treating our farm animals to produce a metabolic syndrome. Many chemicals are persistent and concentrate up through the food chain - it's very likely that if Westernised humans were a farm animal they would be declared too toxic to eat.

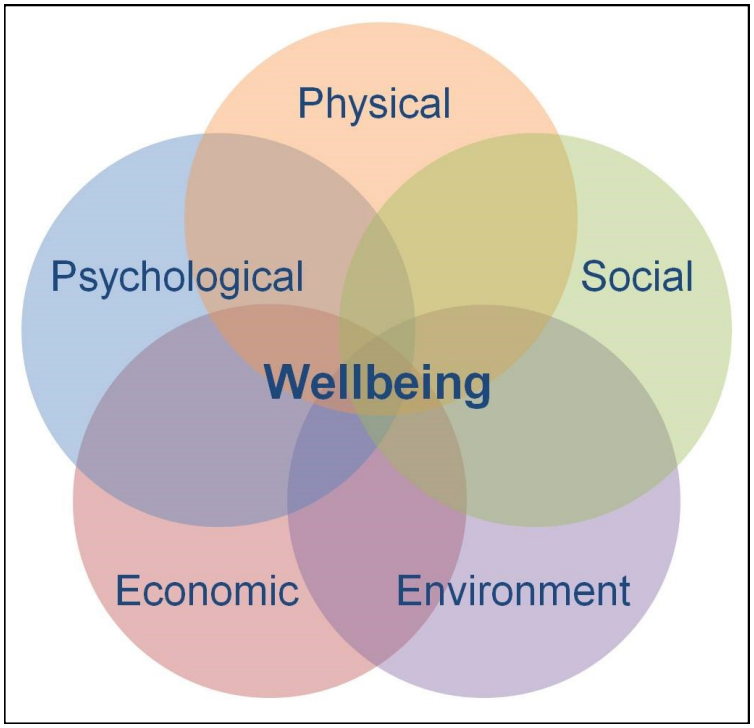
Reduce your chemical exposure: in foods , water, air, cosmetics, garden and agricultural chemicals, social and prescription drugs and outdoor air pollution.

I believe the late Dr. Dick van Steenis did more for the health of the nation than any other doctor through his campaigning work against polluting industry.

Good nutrition is highly protective against toxic stress - this is further reason to take nutritional supplements. One example of this came out of the research into thalidomide. This drug prescribed to women in pregnancy as a "pregnancy-safe hypnotic" caused serious birth defects if the women took it during early pregnancy. But not all babies were affected. This drug was tested in rats - no offspring were abnormal. This was a mystery to researchers, until someone had the bright idea of putting the rats onto nutritionally depleted diets. Then the baby rats developed the foetal abnormality of phocomelia ("flipper limbs"). It was a combination of toxic stress (the drug) and nutritional deficiency which caused the problem to become apparent.

7-- Wellbeing

It is beyond the scope of this book to discuss the psychological and spiritual imperatives that we must fulfil for optimal physical and psychological health and I am no expert. I am deeply grateful for a loving carefree childhood with a Mum who was a brilliant cook. This love flowed further to my two gorgeous daughters Ruth and Claire, but as they became more independent my affections embraced my pets - horses and more recently my lovely puppy Nancy. Pets are far more emotionally intelligent and sensitive than humans! I think it is essential for anyone living alone, or in an emotionally lacking relationship, to have a loving pet.



My horizons are constantly changing. When my girls were little, my hobby was watching them have fun. Most recently I want my house, which is too big for one, to become the Marigold Hotel for horse and dog lovers! Humans evolved to live in tribes, certainly not to live alone and probably not just within a single family. A complex social life is vital to good mental health.

Simply identifying the above needs is often helpful to patients. Knowing what they need, they then come up with innovative solutions.

8 -- Avoid infections

Acute infections clearly cause short term misery, but I am more concerned by their potential to switch on ME/CFS, allergies, auto-immunity and cancer. Even arterial disease may have an infectious component - it is clearly driven by inflammation. Many cancers we know are infection driven such as cervical cancer {Human Papilloma Virus, HPV}, stomach cancer {Helicobacter pylori}, Kaposi's sarcoma {HIV infection}, Burkitt's lymphoma {Epstein Barr Virus}, hepatoma {hepatitis B}, lung cancer {tuberculosis}, and so on. We also know many cases of auto-immunity are infection-driven. I suspect that the upper fermenting gut will eventually prove to be the major risk factor for oesophageal, stomach and colon cancer. Avoiding infection is an important part of long term good health. Here are ways to avoid infection:-

- Keep warm—cold kills. When the Mistral wind blows in France, death rates increase. I Drink clean water and eat clean food.
- Care with sexual partners. Passionate love is a form of insanity that makes us do insane things and take insane risks!

- Avoid insect bites with the potential for blood to blood transmission of pathogens. We are seeing epidemics of Lyme's disease from biting insects.
- Treat breaches of the skin thoroughly- keep clean and wrap up. All animal bites get infected! I have seen infections of heart valves and inter-vertebral discs arising from such.
- Eat a low-carb diet and especially avoid sugar and fruit sugar- these are the substrates that microbes love to ferment. New cases of diabetes may be picked up because of recurrent thrush, fungal toenails or staphylococcal skin infections.
- Dental hygiene - the commonest chronic infection is streptococcus mutans which causes dental decay with gum disease resulting downstream. Dental decay is a marker symptom of many other diseases including the clinical picture of metabolic syndrome and of course upper fermenting gut! Avoid sugar, brush teeth regularly and perhaps use herbal antiseptic mouthwashes such as neem.

- Identify and treat hypochlorhydria - an acid stomach is a major line of defence against infection. Microbes that are inhaled stick to the mucous lining the airways and are coughed up and swallowed - so most end up in the stomach. This should be an acid bath to sterilise the upper gut. This is particularly important where there is hypochlorhydria. Hypochlorhydrics are at increased risk of food poisoning and recurrent infections.
- Do not graze - this never allows the stomach time to become fully acidic between meals.
- Take probiotics regularly- these are of proven benefit in, for example, avoiding travelers' diarrhea.
- L Vitamin C - this is toxic to bacteria, viruses and fungi (and, incidentally, cancer cells). It is harmless to normal cells. It is a fabulous defence against infection. Taken by mouth it is poorly absorbed, but that helps protect against infection via the gut.
- I advocate taking a dose of vitamin C last thing at night on an empty stomach. The idea is to reduce microbial numbers in the upper gut by killing the millions of microbes in the upper gut (those fermenting or ingested) but not sufficient to kill the billions of microbes in the lower gut. Too much vitamin C will do the latter and result in diarrhea.

Do not be obsessed with hygiene and chemical disinfectants —these may be counter-productive. You can never sterilize a surface, microbes will always be present. The immune system needs normal exposure to everyday microbes for correct programming. Mothers are usually fastidious with first born babies, less so with the rest - first born children are more likely to suffer from allergy.

"A child who is protected from all controversial ideas is as vulnerable as a child who is protected from every germ. The infection, when it comes- and it will come- may overwhelm the system, be it the immune system or the belief system." Jane Smiley 1949-

Symptoms of acute infection should not be suppressed with drugs. Symptoms arise to make us do the things we need to reduce numbers of microbes (cough, wheeze, sneeze etc), or rest to conserve energy and resources for fighting infection efficiently. Only too often my ME/CFS patients tell me they had an infection and continued to work by dint of taking paracetamol, caffeine, antihistamine and pseudoephedrine, then turn to addictions to cope with the stress so allowing their virus to get topside. This is short term gain, long term pain.

The Bolt on Extras

You'll have to got to Dr. Myhills website to see these …..

Out and About with ME in Cumbria: La'al Ratty

Meet La'al Ratty, the Ravenglass & Eskdale Railway and watervole station master and logo for the Kids

The Lake District is a popular well known recreational area for outdoor activities like hill climbing walking, water activities and camping. These are fine for normal healthy people, but if you have ME/CFS these are of no interest. What is less well know there are a number of attractions with more sedate activities including boat trips on the lakes, museums and entertainment. There are also three preserved railways well worth a visit. For us the most popular is La'al Ratty, which for us no visit to Cumbria is complete without visiting.

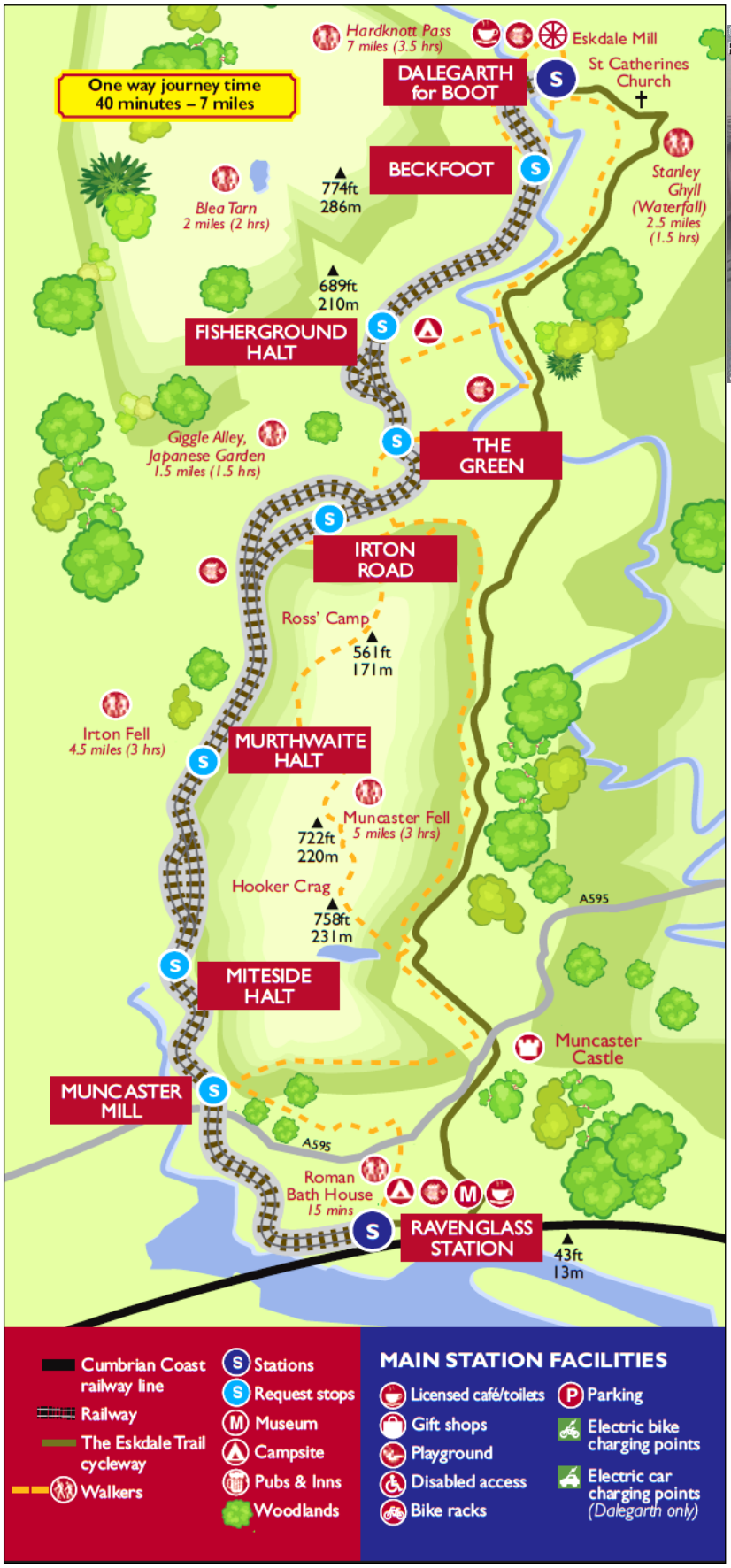
The Ravenglass & Eskdale Railway is one of the oldest and longest narrow gauge railways in England, known affectionately as La'al Ratty meaning "*little railway "in* old the Cumbrian dialect. It was 100 years ago in April 1913 that the original 3ft line closed and in 1915 the new 15 inch La'al Ratty was born. Passengers can choose between open and covered seating, with some saloon coaches being fitted with heaters for the winter months. Disabled passengers and cycles can also be conveyed by the trains, but prior notice is required. The locomotives are ⅓ scale models of mainline locomotives and are air-braked at 50 psi. There are over a hundred regular volunteers that help with the running of the railways, which include guarding the trains, carriage shunting and selling tickets at the major intermediate stations along the route.

The heritage steam engines transport passengers from Ravenglass, the only coastal village in the Lake District National Park which was of huge significance in Roman times, being a significant last defence point of the infamous Hadrian's Wall, to Dalegarth for Boot some 210ft above sea level. The journey itself was one of Wainwright's favourites crossing through seven miles of spectacular scenery within sight of England's highest mountains, the Scafell Range. The journey takes about 40 minutes up the line from the protected nature reserves of the Ravenglass Estuary through the ancient woodlands and fells of the Eskdale Valley.

Our Journey

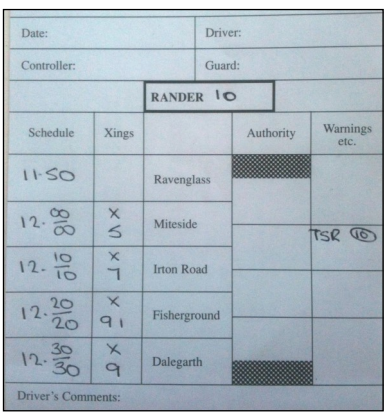
Our most recent visit took place in early April. We headed for Ravenglass railway station which is the main terminus of the line. We started off from Keswick following the A66. We then turned on to the A595. You can tell when you need to turn off because you go over a railway bridge with narrow track as Muncaster Mill. Following on for a short distance, Ravenglass is a right turn. Following the road, the Ratty station is a left hand turn just under the first railway bridge. We collected our tickets from the gift shop, which doubles up as a booking office. We then proceeded to the platform.

Ravenglass houses two locomotive sheds, on the southern side of the track, and a carriage shed on the northern side. There is a carriage & wagon workshop beyond Platform 1, opposite the signal box. The Turntable Café is situated on Platform 1. The car park has spaces for 100 cars, as well as coaches. There are only two disabled bays next to the booking office. The is no free disabled parking, everyone has to pay. There are two charge scales—£1 for less than an hour and £3.50 over that. For railway enthusiasts, there are holiday accommodation facilities for weekly use, which consist of the Pullman camping coaches 135 Elmira and 137 Maid of Kent, and a holiday bungalow, the Hilton Cottage.



Ravenglass station is the headquarters of the railway company and houses the railway museum, managerial offices and rolling stock maintenance facilities. There is a turntable at the western extremity of the station's platforms, which doubles as the datum for mileage markers on the line.
The movements around the station are controlled by semaphore signals operated from a signal box at the end of the platform. No semaphore signals are used outside Ravenglass station. However, the railway uses the Radio Control Train Order Signalling System outside Ravenglass station, where the line is single track with passing loops at Miteside, Irton Road and Fisherground. Trains operate by radio VHF radio communication between drivers and at Ravenglass signal box. At passing loops and the terminus station, drivers contact the controller, using "RANDER" reporting numbers (even numbers for up trains, and odd for down), to indicate that the train is within the loop and is clear of the preceding single track. To leave the loop, the driver contacts control to gain authorisation to enter the next single track section. Points at passing loops are weighted with direction indicators, meaning that no human intervention is required and the points reset themselves automatically after the passage of a train when entering the points from a trailing direction when the points are set for the other rail line. When going over points, the train slows down and or stops as required.

When leaving a passing loop the train moves slowly. The guard at the end of the train checks to see that the back of the train has cleared the points. He then raises his hand to signal to the driver that the points have been passed safely, and the train builds up speed.


Date: Driver:
Controller: Guard:
RANDER 10

Schedule	Xings		Authority	Warnings etc.
11.50		Ravenglass		
12.00	X 5	Miteside		
12.10	X 7	Irton Road		TSR 10
12.20	X 91	Fisherground		
12.30	X 9	Dalegarth		

Driver's Comments:

Right -A RANDER board, issued to a train's driver and guard by the duty controller. Elements of the operation were used by British Rail to cut costs on remote lines. What became known as Radio Electronic Token Block signalling shared features with the Ratty, such as centralised control, automatic points at loops, and on-train equipment rather than fixed equipment at remote locations.

On peak days in the summer months, two trains depart each end of the line per hour. Capacity on the railway allows for a service run at 20 minute intervals.

Muncaster Mill is 1 mile or 1.6 kilometres from Ravenglass, adjacent to an historic corn mill (sadly a private house and no longer open to the public). It is an unmanned station and was formerly known simply as Muncaster. It is accessible from the A595.

Miteside Halt is 1¾miles (2.8km) from Ravenglass. It is accessible only from a footpath that passes along Miterdale, at the foot of Muncaster Fell. The station shelter is the wooden hull of an old boat, the third such structure at the Halt.

Murthwaite Halt is 2¾ miles (4.4km) from Ravenglass and is also only accessible from a footpath.

Irton Road is 4¼ miles (6.8km) from Ravenglass, approximately halfway along the line. It was formerly known as Hollowstones, after the adjacent farm. There is a passing loop within the station and, consequently, two platforms. It has three sidings which branch off from the "up" loop - two of which run into a small shed, and the third of which is used for ballast and log traffic. There is a station building, which dates from 1875.

Eskdale Green, is 4¾ miles (7.6km) from Ravenglass. It was formerly known as King of Prussia after a local pub, then Eskdale Green, and since has changed between Eskdale Green and The Green several times. It has recently received a new picnic area.

Fisherground is accessible via a public footpath, adjacent to Fisherground campsite. It is 5½ miles (8.9km) from Ravenglass, just east of Fisherground loop.

Beckfoot is 6½miles (10.5km) from Ravenglass. Setting down is permitted only from trains travelling from Ravenglass, and picking up is permitted only on trains to Ravenglass.

Dalegarth (for Boot) is a few yards short of 7 miles or 11.3 kilometres from Ravenglass and is the eastern terminus of the railway. It was formerly known as Eskdale (Dalegarth). There are two platforms and a turntable. The facilities at this station include Fellbites Café and the Scafell Gift Shop. A water supply to platform 1 allows topping up of the steam locomotive's tenders. At the back of the café is a basement where you can enjoy cooked food, and take in your dog. Here the locomotives are turned ready for the return trip. Just before we reached Ravenglass Station we spotted a brown hare.

Verdict: Well worth a visit—but if you are a wheelchair user contact the railway before you set off.

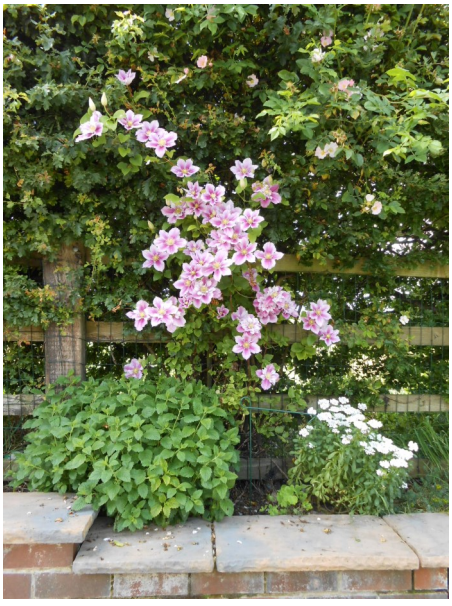
Summer Garden Watch *by Carolyn*

I am not too sure where 'Summer' has got to this year as the garden gets ravaged by persistent heavy rain and I don't often have anything to blow my own trumpet about, so I am pleased to report one very big success in having successfully reared the frogspawn a member kindly gave for our new small Wildlife pond. It felt like a big responsibility looking after them all the way through and it is good to report that we now have many gorgeous little brown frogs in the garden. The one just climbing out of the net had to be hastily rescued from underneath the lawn mower as thankfully, Mike had spotted him. This caused a search of the long grass and four more were found and returned to the safety of their pond whilst the mowing job got finished!

I wish the pot of summer bulbs 'Acidanthera' and' Babiana' was the same success story but so far, yes, the bulbs have all come through and much green is growing but, so far, no flowers. It should soon be looking like this:

But at present is looking like this:

If we can only get some sunshine I feel sure it will flower in time but it certainly is disappointingly slow at the moment.

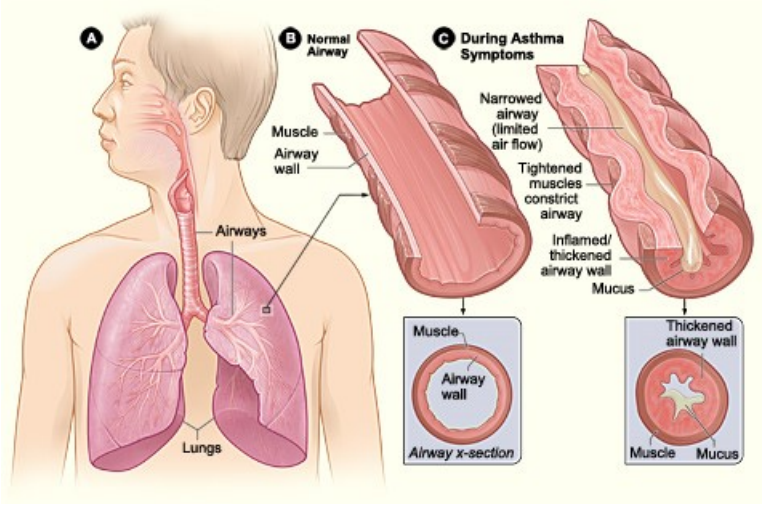


On a much happier note , the two Maples I planted in pots beside the front door are growing very well but then they absolutely love this warm and rainy weather! Later on, the deep red leaves will take on tones of green and gold. I am wondering about planting some small plants in with them to give some Spring colour – perhaps violas grown from a packet of seed might be a good idea.

This is a good year for Clematis and here is an especially pretty one that does well growing up the hedge in the back garden:

Back in Autumn, happy gardening, whatever the weather. Carolyn.

Asthma in ME/CFS Update



Around 40% of Leger ME members I see are asthmatic to some degree. Asthma is an abnormal reaction to some environmental stressor which causes lung/airways inflammation. In an asthmatic the airflow is normal except when and asthmatic attack is triggered. The constriction of the airway makes a victim breathless and there are knock-on effects which can be fatal if not treated. Asthma, like ME/CFS, is an abnormal reaction to some sort of stress but rather than fatigue and pain there is short ness of breath. Most MEs have seasonal asthma where they are only affected in the summer months, but some are affected all year round. Asthma is different to Chronic Obstructive Pulmonary Disease because the Airways obstruction is reversible. The Major cause of COPD is smoking. The airways themselves have smooth muscle which responds to adrenalin and acetylcholine produced by various systems in the body. Adrenalin stimulates the airways to dilate (open up) and acetylcholine to close up. One particular problem with ME's is the impaired activation of the HPA axis and adrenal system which may make them more susceptible to an asthma attack.

Asthma Attack Relief. Historically the first treatment for asthma was a plant called Ephedra, which was well known to herbalists and used in Arabic and Chinese medicinal practice. The active ingredient is an alkaloid called Ephedrine. – which in the early days of medicines was a kingpin of asthma attack control. Although ephedrine works quite well, it causes a general stimulation of body systems with dangerous increases in heart rate and blood pressure which caused the death of many patients. With the development of the pharmaceutical industry came along salbutamol (Ventolin) which worked likes ephedrine, but has a safer and cleaner side effect profile. Salbutamol is used to today in 'rescue' inhalers. The main problems with salbutamol is that it is short acting requiring repeated doses during the day. It known as an SABA (short acting beta agonist). More recent developments have seen longer acting versions of salbutamol like formoterol. These are known as LABAs (long acting beta agonists) and are usually administered twice a day. In recent years a once a day LABA has been trialled.

Epherdra plants.

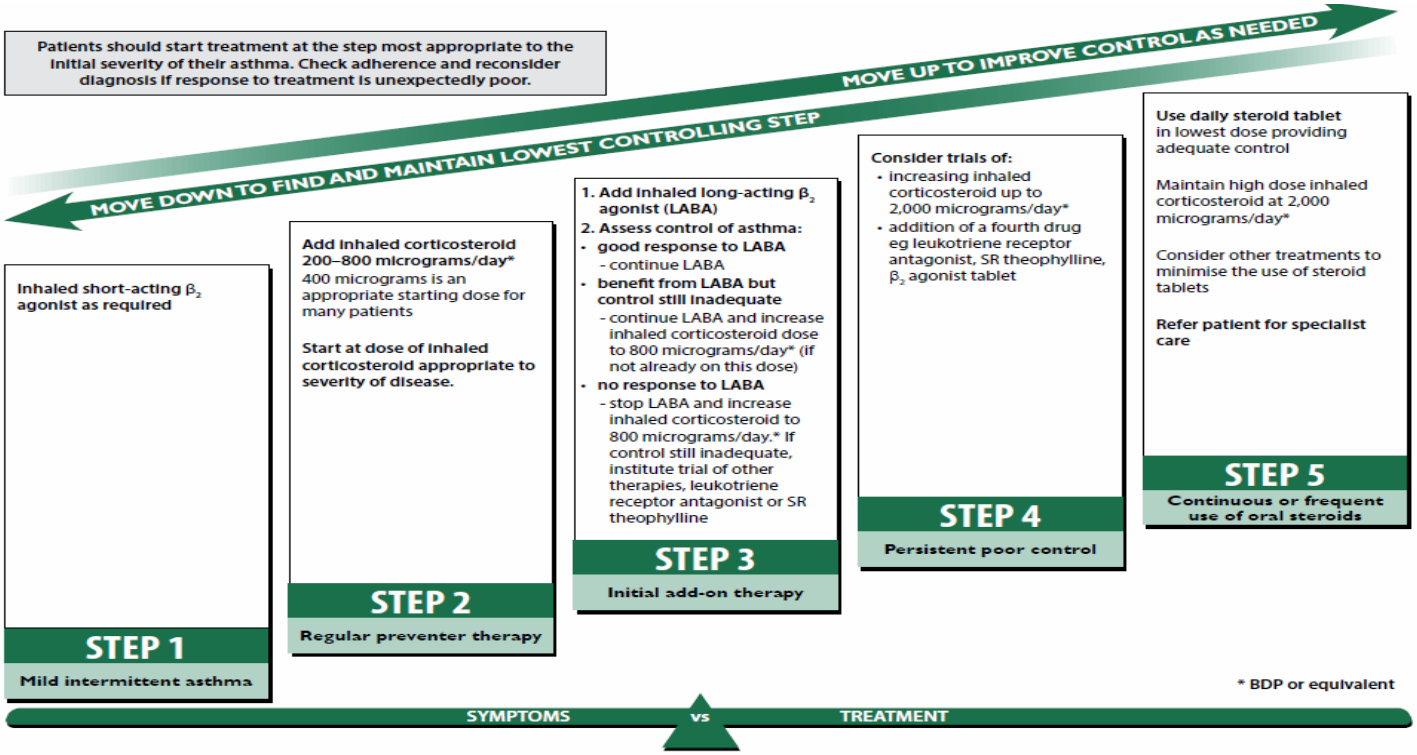
A second strategy has also been used. Acetylcholine works opposite the adrenalin. Medicines which block the effect of acetylcholine have been around for many years. Atropine and hyoscine are found in many plant species and block the tightening muscle mechanism and secretions from the lungs. They are effective, but again there are side effects. Modern synthetic drugs like tiotropium have been made with cleaner and safer side-effect profiles. They are known as LAMAs (long acting muscarinic antagonists) These medicines are used for more severe cases due to side effects.

Atropa belladonna

Asthma attack prevention. It would be better if asthma attacks could be prevented in the first place. This is fine if a cause can be identified, but very often it can't. The drugs used today are based on the cortisol class of medicines which are anti inflammatory and immuno-suppressive. What are used are insoluble versions of these medicines, which act locally in the chest. These are known as inhaled corticosteroids, and common examples are betamethasone and fluticasone. The systemic version are only used in the more severe cases because of side effects like bone-thinning and high blood pressure. More recently leukotriene antagonist tablets have been introduced. These are monoclonal antibodies which specifically block the asthma attack pathway mechanism.

Treatment Strategies Within the NHS all treatment strategies are based on the British Thoracic Society guideline. However, there are local variations. I'm not going to go into details because that is your doctor's job. However, this is what you should expect from your doctor's surgery: -

1) A regular check up with the specialist nurse.
2) A Peak Flow Meter for you to check how well your treatment is working.
3) Regular review where your treatment is adjusted.
4) Always carry around a treater (rescue inhaler). These are usually blue or grey. You should use preventer inhalers (usually brown) daily.
5) At your pharmacy or asthma clinic you should have your inhaler technique checked. There is a specific device called an 'In check' to check how well you can inhale.



Specific issues with Asthma and ME/CFS

- There are two types of inhaler. The first sort is a dry powder type which requires substantial effort to breath in, for example the turbohaler. Some people with ME/CFS have weak chest muscles or suffer pain (particularly if you have fibromyalgia) and find these products difficult to use. The second type of inhaler is the aerosol type like most salbutamol inhalers. These require less effort to inhale and are often preferred for this reason.

- Technology has moved in, and there are now combined inhalers containing combinations of LABA, ICS and LAMA 's. These generally only need to be used twice daily, although currently a once a day version is being trialled.

- I frequently come across people who are using a treater inhaler only, which has been prescribed for a family member usually because of the prescription charge. This is strategy is dangerous because it is unmonitored.

- Daily use of preventer inhalers is associated with sudden deaths, usually in perfectly otherwise healthy individuals. If you are using a preventer (salbutamol) inhaler more than three days a week it means you need a review, possibly addition of a daily ICS or LABA inhaler.

North of Doncaster *Personal comment by Trevor Wainwright*

Following England's exit from Euro 2016, I came up with the following idea whilst chatting with friends on the subject of who would replace Roy Hodgson. I'm thinking of applying for the job of England Football Manager. I may not know much about football but it seems like the past ones didn't either, that's what I'll say if I get to the interview stage. Asked what my tactics were I would say:

1. I would get the players on the pitch, explain that the green area inside the outer line is what they play on.
2. I would place a ball on the green area saying "this round object is a football, which can be propelled by the foot hence the name "adding" it can also be propelled by the head, usually the front top (forehead).
3. Those rectangular thing at the far ends are called goals.

Break to let it all sink in.

4. One goal is ours, one belongs to the other team, our opponents.

Long break to let it sink in.

5. One half of the team is called the defence; it is their job to stop the ball going into our goal. The other half is called the attack; it is their job to put the ball into our opponents' goal using either of the afore mentioned methods.

Even longer break to let this sink in

6. The locked box on the table is your wages; you will not get them until you have learned the above basics.

Give the team the rest of the day off to let this sink in

Second Day as England Team manager:

1. Thank all who have decided to give playing football for their country another go. Explain that we are going to start with the basics beginning with attacking.

Break to let this sink in

2. Divide the squad into attack and defence, put the defence on the side lines for the moment take the attackers onto the field, show them a ball and explain that they have to get it into the goal at the end, by kicking with foot or hitting with head.

Longer break to let this sink in.

3. Take the attackers to the goal line let them have a few kicks of the ball into the goal so they get the idea.

Slightly longer break to let this sink in.

4. Once they have got the idea move them further back from goal and get them to practice the same, gradually moving further back.
5. Once satisfied encourage passing and moving into open spaces to receive these passes before shooting for goal.

Leave them to practise and go talk to the defence.

Talk to the defence who have hopefully been taking an interest in the attacking aspect, and explain:

1. This is the attacking aspect of football where the team scores goals thus hoping to score enough to win the match.
2. Their role is equally as important as it is to stop the opposing team doing likewise and us losing the match.

Short break to let this sink in, and allow questions.

3. Explain that being a defender requires equally as good if not better observation skills than an attacker, particularly when the opposing team is attacking.

Wait for puzzled looks to subside then continue:

4. The purpose of an attacker moving into an open space is to receive the ball, the defender's role is to watch for the attacker doing this and move to stop him getting the ball, which is called 'interception'.

Wait even longer for even deeper puzzled looks to subside.

5. Explain Oxford Children's Dictionary definition of 'interception', in simple terms, and ask if there are any questions, allow plenty of time for this.
6. Summarise the role as simply as possible saying a good defence never lets the opposition anywhere near the goal.
7. Move to the goal keeper and explain his role of importance as the final link between victory and defeat in as much as the more balls he stops going into the goal, the better chance we have of winning.
8. Tell him he is allowed to use his hands and any part of his body to prevent this happening, but hands are best as they can hold the ball prior to passing it to own team thus beginning another attack.
9. Explain how it is in his best interests to watch where the ball is going and move to be in a good position to make such a save and carry out the afore mentioned manoeuvre and that it also helps if he is able to get his body behind the ball too.

Tell the team to limber up as we now hope to put the afore-mentioned into practice, with attack and defence playing their respective roles against each other. Give them the incentive that should they do well and grasp these rudiments we shall practise both sides together against another team from the lower divisions so the process is not too taxing, and with the incentive of financial remuneration should they do well.

Allow a good limbering-up time while I find somewhere quiet, get on my knees, put my hands together, close my eyes and pray like I've never prayed before.