



# Pathways

Price £ 4.00 (Free to members)

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

## ***Welcome to Pathways No. 57. (Autumn 2018)***





## You Write In

**Irene Writes.** Have you heard the news than the NHS isto update the classification system to reflect that M.E. is a neurological disease (*date is early August- Ed*).

It was confirmed last week by DX Revision Watch, that the recording of M.E. and CFS as examples of a '*multisystem disorder*' will be replaced in SNOMED CT by the more appropriate, '*disorder of the nervous system*'. This follows the welcome efforts of advocate Suzy Chapman, who writes the authoritative blog, DX Revision Watch, and Sonya Chowdhury, on behalf of Forward ME and Action for M.E.

Chronic Fatigue Syndrome classified under Neurological disorder in SNOMED CT International GP system updated to reflect M.E. as neurological SNOMED CT is a comprehensive electronic clinical classification system by the NHS, that records known diagnoses and symptoms with the aim of making clinical information consistent across healthcare settings. In some respects, it would seem to be more relevant to UK residents than the World Health Organisation international classification system, as electronic NHS patient records should be updated to reflect the change. While chronic fatigue syndrome unfortunately remains the parent term in this clinical vocabulary, M.E. is recognised as a synonym along with other recognised terms. The change will take place in the UK in September, and, as SNOMED CT is also used internationally, it will also be reflected in the United States, Canada, New Zealand, Australia and other European countries. It is too soon to say what practical effect, if any, this might have on patient relations and treatment within the NHS, but it at least means that ME/CFS will now be listed under a more appropriate heading.



A view of the South Yorkshire countryside in early autumn showing St Helens lane, taken from Hangman Stone Road near Barnborough Cliff. The boulders in the foreground are Dolomite. The field to the right has been harvested, and the field to the left has been ploughed, with the green tips of next year's crop showing,

The follow statement is from Dr Charles Shepherd, Hon. Medical Adviser, ME Association:

*"This is a subject that the Countess of Mar and the Forward ME group of charities have been closely following for some time. So, it is good news to see that M.E. will now be classified as a neurological disorder in the SNOMED CT system – a position that appears consistent with WHO classification of M.E." "As our summary states, it is difficult to know what practical effect this will have in the consulting room – because doctors are not normally following, or reading about, changes to the SNOMED classification system." "But it will be helpful when we still have to challenge a media or medical profession statement that ME/CFS is a mental health condition. It may also be helpful for people with ME/CFS when they are having to challenge a faulty benefit, insurance or legal decision which is again being based on an inaccurate mental health classification of M.E."*

**Bill writes.** We have heard a lot about Brexit. We've heard about stockpiling medicines. Do you have any idea how people with ME/CFS will be affected?

*It's difficult to say because at the time of writing it is not clear whether a **Deal** or **No Deal** Brexit will happen. Regarding NHS Staffing. The EU's policy of freedom of movement and mutual recognition of professional qualifications has enabled healthcare staff to migrate between the EEC and the UK. If a no deal Brexit exit is the case, it may result in staff shortages, especially in nurses. It may be possible that there are increased healthcare staff numbers from commonwealth countries. Regarding the reciprocal accessing treatment here and abroad. There has been a great deal of debate about this. Other countries health systems are not the same as the NHS—so it will always be necessary to get health insurance cover if going abroad irrespective of the Brexit outcome. There will be issues with cross border regulation and co-operation if a no deal Brexit occurs. One common fear is queueing of goods especially medicines at a border crossing. Some manufacturers and organisations are stockpiling, and this it's could lead to supply chain shortages. A No Deal Brexit could result in import levies (taxes), a bit like Donald Trump has done for steel and aluminum imports.*



## Welfare Rights Matters: PIP and loss of Motability Cars

Prior to the introduction of PIP (Personal Independence Payment) most people with ME/CFS were able to obtain DLA (Disability Living Allowance). Although it was not included in the initial concept for DLA, the inclusion of fatigue for the mobility component appeared to be based on interpretations and House of Lords rulings. For ME/CFS the most relevant rulings were from Commissioners Heggs and Jacobs which enable ME/CFS patients to claim DLA low rate care and high rate mobility, which at the time of writing was £82.40 per week. One of the main benefits of high rate mobility was the ability to lease a Motability car on contract hire in exchange for the DLA Mobility component.

Many people look at the cost of buy a new car versus a Motability car on contract hire. Here is an example of the costings at the time of writing based on a Toyota Yaris 1500 hybrid for three years of private ownership and Motability rental agreements. On first comparison, it appears to be a good deal.

<u>Three year cost comparison</u>	<u>Purchase outright.</u>	<u>Motability Rental agreement</u>	
New price on the road	£16,950	(£13,356 ex tax)	<i>Because Motability is a charity. Cars are bought exclusive of tax.</i>
Estimated 3 year value for trade in	£8,500	Nil	<i>Motability cars are returned at the end of the contract.</i>
3 year cost/devaluation	£8,445	£6,756	<i>The three year cost of the contract is approximately equal to depreciation less vat.</i>
3 year road tax	£420	<i>Included in contract.</i>	<i>There may be free road tax with PIP for privately owned cars.</i>
3 year insurance	£1,800	<i>Included in contract.</i>	<i>Depends on circumstances.</i>
3 year servicing and repairs	£ 800	<i>Included in contract.</i>	<i>Excludes unfair damage.</i>
<b>Total 3 year cost</b>	<b>£11,465</b>	<b>£6,756</b>	<b>£4,709 about 31.30 per week.</b>

This was an option in which quite a lot of Leger ME members engaged. However, it became quite clear to the government that this was too good a thing because of too many cases of abuse, so something had to be done to stop exploitation. However, any deal struck can be overridden by DWP decisions, be they right or wrong.

So, the government revamped the DLA concept and along came PIP. PIP has only two care components, the lowest being roughly equivalent to the middle rate of DLA. This meant that the low rate care component vanished, and so many people with ME/CFS lost out. The PIP mobility components have different criteria, which makes it difficult for people, even obligate wheelchair users to get a PIP mobility component. Under DLA, most Leger ME members qualified for high rate mobility and a Motability care. Under PIP, the outcome is more scattered. To date only the people with grade 3 ME/CFS plus another serious condition have qualified for the higher rate care component. Many have the lower mobility component which does not carry a Motability entitlement. Many have scored too few points to get any mobility payment at all. A common thread through all the claims we've deal with is Standard Care, which is a worth £57.30 at the time of writing, and no mobility component. So overall the average Leger ME member could see their weekly care related payment drop from £82.40 to £57.30 at week, which corresponds to a drop of about 30%.

There is a stated government intention to transfer all people receiving DLA to PIP. This will take place

- when either the DLA award ends or;
- a change in circumstances happens; (includes changes in address for example)
- or when the DWP decides to do so (this could include a spot audit for example.)

So, what happens if you have a Motability customer with a contract hire car. If the new PIP award is enhanced mobility the contract continues, otherwise the contract will terminate, with the loss of a Motability car. It was anticipated there would be a lot of genuine cases where this will cause hardship or loss of wellbeing. PIP is always paid in arrears, there is usually around about a month to sort things out.

This loss of a Motability car is something that we at Leger ME anticipated some years ago. As a matter of policy, we have encouraged members to consider buying their own car and using any DLA/PIP to fund their own car. There are two circumstances for the average Leger ME member where a Motability car is worthwhile.

- Where special adaptations are needed to enable driving of the car e.g. hand controls and/or where there would be complications for insurance cover.
- If there is enough savings or finance to buy the car if there were problems with the contract such as loss of DLA or PIP.

When the agreement stops for whatever reason, the car must be returned. It can be bought from Motability if the funding is available. At that point you must arrange your own insurance, which can be expensive as the Motability scheme is outside the No Claims discount scheme and start from zero again. You are responsible for road tax, repairs and maintenance. So, the loss of a Motability Car can be a disaster, particularly for someone solely on state benefits. Some motor dealers do operate a contract hire scheme, but the costing is somewhere between the bought outright and Motability rate.

### ***Transitional Support Package for Motability Scheme Customers***

*With thanks to the Motability Website (August 2018).*

If the DWP informs us that you are not eligible for the Enhanced Rate of the Mobility Component of PIP following an unsuccessful DLA to PIP reassessment, we will write to you about returning your car. For Scheme customers who joined before the end of 2013, there is a package of financial support available if you return the car to the dealership in good condition and by the agreed date. Here is what to expect:

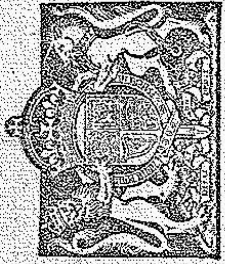
- a) Up to £2,000 financial support dependent on when you first joined the Scheme and the date you return the vehicle.
- b) No further lease payments.
- c) Potential Advance Payment refunded on a pro-rata basis.
- d) Where relevant, financial support to fit the same adaptations to a non-Scheme vehicle.
- e) Copy of the staying mobile after the Motability Scheme can be download, which is a resource, (guide which includes advice on buying a used car, information on insurance, maintenance and other mobility solutions.
- f) Full claims history letter from RSA Motability, an insurance broker who can provide insurance quotes where possible for customers leaving the Motability Scheme.
- g) A fair market price for your car in case you choose to buy it.

This package will be reviewed regularly, and changes may be made to it as a result. Additionally:

- a) For customers who joined the Scheme before 2013 and return the car within eight weeks, £2000 will be available. Alternatively, you can choose to keep the vehicle for 26 weeks, however in this case you will receive a reduced payment of £500.
- b) For customers who joined the Scheme during 2013 and return the car within eight weeks a transitional support payment of £1,000 will be available. Alternatively, you can choose to keep the vehicle for 26 weeks and receive a reduced payment of £250.
- c) For customers who joined the Scheme since 1st January 2014, when more information on PIP became available, a standard £250 Return to Dealer payment will be available if the vehicle is returned within eight weeks.



## 70 Years of the National Health Service



# THE NEW NATIONAL HEALTH SERVICE

\*

First get a recommendation from your family doctor that your eyes need testing. Then hand that recommendation to any doctor with special qualifications (lists will be available) or to any ophthalmic optician taking part in the new service. If you need glasses, these will be provided without charge. For re-testing you can go direct to any of the doctors with special qualifications, or to an ophthalmic optician.

The National Health Service will provide several kinds of spectacles of different types. For specially expensive types you will have to pay the extra cost.

**Deafness** Specialist ear clinics will be established as resources allow. At them you will get not only an expert opinion upon deafness but also, if necessary, a *new hearing aid* invented by a special committee of the Medical Research Council. Production of these aids is now going on, but will not meet all demands at once. They will be supplied free, when ready, together with a reasonable allowance of maintenance batteries.

**Home Health Services** Your local County or County Borough Council will, as soon as it can, make special provision for: (1) advice and care of expectant and nursing mothers and children under five (for particulars ask your doctor, health visitor, or Welfare Centre); (2) midwifery (ask your doctor or Welfare Centre); (3) home nursing where there is illness in the family (ask your doctor); (4) all necessary vaccination or immunisation (through your doctor or Welfare Centre); and (5) a health visitor service to deal with problems of illness in the home, especially tuberculosis.

**Health Centres** Special premises known as Health Centres may later be opened in your district. Doctors may be accommodated there instead of in their own surgeries, but you will still have "your own doctor" to give you personal and confidential treatment. He will still come to your home as necessary. At the Health Centre he will be able to use equipment supplied from public funds. These Centres may also offer dentistry and other services on the spot.

## WHAT TO DO NOW

1. Choose your doctor.
2. Get application forms from him or from the Post Office, Public Library, or office of the local Executive Council.
3. Fill one in for each member of the family.
4. Hand them to the doctor.

**ACT AT ONCE**

**Your new National Health Service begins on 5th July. What is it? How do you get it?**

It will provide you with all medical, dental, and nursing care. Everyone—rich or poor, man, woman or child—can use it or any part of it. There are no charges, except for a few special items. There are no insurance qualifications. But it is not a "charity". You are all paying for it, mainly as taxpayers, and it will relieve your money worries in time of illness.



This leaflet was circulated to every house on the country in June 1948

## Choose Your Doctor Now

You and everyone in your family will be entitled to all usual advice and treatment from a family doctor. Everyone aged 16 and over can choose his or her own doctor. A family need not all have the same doctor, but parents or guardians choose for children under 16.

Your dealings with your doctor will remain as they are now: *personal and confidential*. You will visit his surgery, or he will call on you, as may be necessary. The difference is that the doctor will be paid by the Government, out of funds provided by everybody.

Choose a doctor now—ask him to be your doctor under the new arrangements. Many will choose their present doctors. Any doctor can decline to accept a patient. If one doctor cannot accept you, ask another, or ask to be put in touch with one by the new “Executive Council” which has been set up in your area (you can get its address from the Post Office).

If you are already on a doctor's list under the old National Health Insurance Scheme, and if you do not want to change your doctor, do nothing. Your name will stay on his list under the new Scheme.

But for your family, and for yourself if you are not already in the old National Health Insurance Scheme, now is the time to decide. Get an application form for *each* member of the family from the doctor you choose, or from any Post Office, Executive Council Office, or public library. Fill in the forms and give them to the doctor.

Later, your local Executive Council will send a “medical card” to everyone who has been accepted by a doctor. If you want to change your doctor, you can do so at any time without difficulty. If you need a doctor when away from your own district, you can go to any doctor who is taking part in the new arrangements. You will not have to pay.

Help to have the Scheme ready by 5th July by choosing your doctor at once.

For any further information about these arrangements, ask at the offices of the local Executive Council.

## Maternity Services

An expectant mother can have the services of a doctor who undertakes maternity work (whether he is her usual doctor or not), and of a midwife, as well as general care before and after confinement. If her usual doctor does not undertake maternity work, he, or the Welfare Centre, will put the expectant mother in touch with another doctor. It will be the doctor's responsibility, with a midwife, to give all proper care and (if he considers it necessary or is called in by the midwife) to be present at the confinement.

## Hospital and Specialist Services

You will also be entitled to all forms of treatment in general or special hospitals, whether as an in-patient or as an out-patient. These include, for instance, maternity care, sanatorium treatment, care of mental health, and *all surgical operations*.

The help of consultants and specialists of all kinds will be made available to you as national resources allow, whether at hospital, at special health centres, or at your home.

Your doctor will arrange this help when you need it.

Hospital charges will cease on 5th July. Where accommodation permits, however, you can pay something for greater privacy (for example, in single rooms or small wards). Or, if you do not want to use the new service itself, there will be private pay-bed accommodation for which you can make your own private fee arrangements with doctors.

## Medicines, Drugs, and Appliances

Your doctor will give you a prescription for any medicines and drugs you need. You can get these free from any chemist who takes part in the Scheme. In some country areas the doctor himself may dispense medicines.

The same is true of all necessary appliances. Some of them will be obtainable through hospitals; some your doctor can prescribe for you. There will be no charge, unless careless breakage causes earlier replacement than usual.

**Care of the Teeth** A dental service will be provided, but at present there are too few dentists to make a full service available to all without delay.

After 5th July you can go to any dentist taking part in the new arrangements (there will be a list at your Post Office). You need no application form. Just call, by appointment, on the dentist of your choice when you need him. At his surgery you and he will sign a form for your treatment under the new arrangements. All necessary fillings and dentures will be supplied without fee, but if you want anything specially expensive, and beyond what is necessary, you will pay the extra cost yourself.

Until a full dental service, without delays, can be made available, a special priority service for expectant and nursing mothers and young children is being organised by local authorities (in addition to the school dental service). Full information about this priority service can be obtained at Welfare Centres.

**Care of the Eyes** Care of the eyes will be undertaken by specialists at hospitals, or at special clinics which will be part of the hospital service, as fast as these can be organised. Meanwhile, a Supplementary Eye Service will be available after 5th July.



## **ME/CFS Research Corner**

*As selection of research abstracts by Emily Beardall and with Thanks to Action for M.E.*

### **Post-exertional malaise (PEM)**

A study in the Journal of Health Psychology looked at the delayed post-exertional malaise (PEM) experienced by people with CFS/M.E. after exertion. The research was carried out as an online survey of 704 patients self-reporting as having CFS/M.E. which were recruited through patient groups, social media, and online forums. The authors found that there are two components of PEM; a general worsening of CFS/M.E. symptoms and specific fatigue of muscles, and that most of the patients experience both. However, a sub-group of patients did not have the muscle fatigue component, and these were more likely to be working full or part-time. The study also found that patients living alone had worse PEM, which the authors suggest is because they must do more to look after themselves compared with those who live with family or a partner.

### **Presence of abnormal biological findings relates to quality of life**

A study in the Journal of Translational Medicine compared the underlying biological abnormalities found in previous M.E./CFS research with how symptoms impair quality of life. Although this was a small study, there were marked differences between people with M.E./CFS and the healthy controls in biomarkers of the by-products of exercise, muscle function, oxygen use and the immune system. These differences corresponded with the quality of life scores. The authors concluded that linking these muscle and blood test results with scales for measuring health-related quality of life could be used as a way of assessing the severity level of a person's M.E.

### **Infections prior to development of CFS/M.E. in children**

This Norwegian study published in BMC Family Practice examined the primary care records of children with CFS/M.E. prior to diagnosis of CFS/M.E. to look for common factors which may have played a part in triggering their illness. Compared with the general child population in Norway, those with CFS/M.E. were found to often have diagnoses of depression, anxiety, migraine, muscle pain, and infections. 11% of the children had infectious mononucleosis, commonly known as glandular fever, within the two years before receiving their diagnosis. For around half of the children with CFS/M.E. it had taken a year or longer to receive a specific diagnosis of CFS/M.E. from a specialist. The authors comment that this delay in diagnosis and treatment is not optimal.

### **HPV vaccine side effects**

A study in the journal Drug Safety analysed a global database of reported cases of side effects of vaccines to establish whether there is a link between the HPV vaccine and the development of side effects such as headache, dizziness and fatigue, like those seen in complex regional pain syndrome (CRPS), postural orthostatic tachycardia syndrome (POTS), and CFS. A POTS specialist at the CMRC conference explained that the age people have the HPV vaccine is 12 and this coincides with the age that many people's POTS or CFS develops, so this may give the false impression that the HPV vaccine can cause CRPS, POTS or CFS. The study's authors also concluded that an association between the HPV vaccine's side effects and these chronic illnesses is uncertain and that more research is needed.

## **Flu Vaccinations: Now is the time**

Now is the time to book your flu vaccination with your GP. As many people with ME/CFS have other chronic conditions e.g. Asthma, it is important that this option be considered to avoid possible complications should some catch 'flu.

Where people with ME/CFS are concerned it is important to understand that any vaccination could cause problems with worsening of the ME/CFS, PEM or problems with allergic reactions to the vaccine. For example, many flu vaccines contain traces of egg from the manufacturing process. Certainly this is an important consideration for carers. Vaccines are changing all the time, and this year there is a multivalent vaccines available for older people. As always, you should discuss this with you doctor. Flu vaccinations are available at many Nurse lead clinics or some Pharmacies but they may not be aware of you ME/CFS issues, so you will need to discuss before agreeing to vaccination.



## Soya and health – the basics

### Soya foods are made from the soya bean plant, part of the pea family

Soya foods are a staple part of the Asian diet and have become part of the mainstream UK diet. In Asia, both unfermented soya foods (soya milk alternatives, tofu, soya meat replacements) and fermented soya foods (tempeh and miso) are eaten. In the UK unfermented soya foods are more commonly eaten.

### What do soya foods provide?

The soya bean contains a range of essential nutrients including high quality plant protein, fibre, essential fatty acids and a range of vitamins and minerals. Soya foods are readily available in formats that make them easy to incorporate into the British diet. Most commonly consumed soya foods include soya meat replacements and related products such as burgers and sausages, tofu, dairy alternatives to yogurts, milk and desserts, which are in the main fortified with calcium as well as vitamins B12 and D, and ice-cream. The plant protein of both fermented and unfermented soya foods is high in a range of essential amino acids and similar to animal protein. Soya is also the main dietary source of isoflavones (see below).

Table 1: Nutritional Profile of Commonly Consumed Soya Foods

<b>Soya mince / chunks (textured vegetable protein)</b>	<ul style="list-style-type: none"> <li>• High quality plant protein.</li> <li>• Low in saturated fats.</li> <li>• Source of fibre.</li> </ul>
<b>Milk alternatives: unsweetened, sweetened and flavoured</b>	<ul style="list-style-type: none"> <li>• Low in saturated fat.</li> <li>• Source of essential fatty acids – omega 6 and omega 3.</li> <li>• Source of high quality plant protein ~ 3g / 100ml.</li> <li>• Usually fortified with calcium and vitamins B12 &amp; D.</li> </ul>
<b>Yogurt alternatives: plain, vanilla and fruit flavours.</b>	<ul style="list-style-type: none"> <li>• Low in saturated fats.</li> <li>• Some are a source of fibre.</li> <li>• Some versions are now high in plant protein providing 5-6g plant protein per 100g.</li> <li>• Usually fortified with calcium and vitamins B12 &amp; D.</li> </ul>
<b>Desserts and custards: in a variety of flavours</b>	<ul style="list-style-type: none"> <li>• Low in saturated fat.</li> <li>• Source of high quality plant protein.</li> <li>• Often fortified with calcium and vitamins B12&amp; D</li> </ul>
<b>Tofu</b>	<ul style="list-style-type: none"> <li>• Low in saturated fat.</li> <li>• Source of essential fatty acids omega-6 &amp; omega-3.</li> <li>• High in high quality plant protein.</li> <li>• Source of calcium.</li> </ul>



### Isoflavones

Soya beans are the main dietary source of isoflavones. A large glass of soya drink (250ml) will provide approximately 25mg isoflavones, but not all soya foods contain isoflavones with some processing methods removing 80-90% of the isoflavones such as the case for isolated soya protein. Isoflavones are often termed as phytoestrogens as they have a chemical structure similar to the human hormone oestrogen. However, it is now well established that in the human body, isoflavones do not behave like the human hormone oestrogen: they are weaker, they only have effects on some body tissues and in some situations they can have opposite effect to oestrogen. Isoflavones may help reduce the symptoms of menopause.

There is now scientific agreement that the controversy around isoflavones' potential to have bad side effects in humans is fuelled only by findings from laboratory or animal studies using pure isoflavones or high doses. It is well established that animals metabolise isoflavones in a different and much more efficient way to humans and results from such studies cannot be compared to any human outcomes. Additionally, using high doses of pure isoflavones cannot be compared to consuming isoflavones from whole soya foods as they provide lower quantities and are a combination of many biologically active molecules. Comprehensive reviews by the European Food Safety Authority, World Cancer Research Fund and the World Health Organisation all conclude that soya foods as part of a healthy balanced diet are safe.

### Absorption of nutrients from soya foods

Some of the other plant chemicals found in soya beans like oxalate and phytates have potential to impair the absorption of minerals such as iron, zinc and calcium.



However, studies show these minerals are usually well absorbed from soya foods when eaten as part of a mixed diet, and the human body adapts to absorb more of these minerals when reserves are low. In addition, the phytate content can be significantly reduced during the processing of soya foods and many soya foods in the UK are fortified with additional calcium and vitamin D meaning calcium content and absorption compares favourably with dairy foods.

## Soya and plant-proteins for a more sustainable planet and better health

The government's new dietary recommendations, the Eatwell Guide (2016), clearly recommends a significant shift towards more plant-based eating both for the nation's health as well as a more sustainable planet. Over 75% of the Eatwell Guide is dominated by plant foods with the most notable change to the protein section, where plant-based proteins are recommended over animal proteins. As soya provides a high quality protein source, this is an ideal option for the nation.

## Soya and heart disease

A major risk factor of heart disease is having too much 'bad' low density lipoprotein (LDL) cholesterol by 4-6%. Soya foods are naturally low in saturated fats and often displace high saturated foods in the diet and it is also thought that the soya protein itself helps to lower the body's natural LDL cholesterol producing capacity in the liver.

## Soya and menopausal symptoms

Many women undergoing the menopause experience 'hot flushes'. Consuming 40mg of isoflavones daily, equivalent to 2 glasses of soya milk or 100g soya mince, may help to reduce hot flush frequency by 20.6% and severity by 26.2%. Additionally, during the menopause, women's risk of heart disease is doubled, and consuming soya foods can also help lower the risk. Read more in the BDA Menopause Food Fact Sheet.

## Soya and cancer

A review by the American Institute for Cancer Research, the American Cancer Society and the World Cancer Research Fund all indicate that soya foods as part of healthy balanced diet are perfectly safe for women with and without cancer diagnosis and there is a potential for soya food consumption to reduce breast cancer recurrence. Additionally, the protective effect of soya against breast cancer seems to be related to consuming soya foods as a child or teenager.

## Soya and bone health

Some studies have shown that people who regularly eat soya appear to have higher bone density and lower rates of fracture than those with low intakes. However, more evidence is needed.

## Phytoestrogens and men's health

Studies consistently show that eating soya foods does not raise oestrogen levels, upset hormonal balance or reduce testosterone concentrations in men; no adverse effects on fertility or sexual health have been reported. Controversy around this has been fueled by animal and laboratory studies which as stated cannot be compared to any human outcomes and just two case studies where the men consumed high doses of soya foods and followed an unbalanced diet.

## Phytoestrogens and thyroid function

A review of 14 studies has confirmed that there is no harmful effect of soya food consumption in healthy humans with a normal functioning thyroid gland. Soya foods do not interfere with thyroid function but they can interfere with the absorption of thyroid medication levothyroxine like many herbs, drugs, fibres and calcium supplements. For this reason, thyroxine medication is always advised to be taken on an empty stomach and soya should not be excluded by those with an underactive thyroid gland as their medication dose can easily be modified.

## Soya milk on a dairy free diet

Soya alternatives to milk are dairy and lactose free and therefore suitable for children over six months of age and adults with lactose intolerance and with other adverse reactions to cow's milk. Choose soya products that are fortified with calcium to replace dairy foods from the diet.

## Summary

Research on soya foods is ongoing, but it is clear that soya is a nutritious, safe and palatable part of the diet which fits well with healthy eating guidelines and may have multiple health benefits.

### Further information:

Food Fact Sheets on other topics are available at

[www.bda.uk.com/foodfacts](http://www.bda.uk.com/foodfacts)

### Useful links:

#### NHS Choices

[www.nhs.uk/conditions/vitamins-minerals/Pages/vitamins-minerals.aspx](http://www.nhs.uk/conditions/vitamins-minerals/Pages/vitamins-minerals.aspx)



This Food Factsheet is a public service of The British Dietetic Association (BDA) intended for information only. It is not a substitute for proper medical diagnosis or dietary advice given by a dietitian. If you need to see a dietitian, visit your GP for a referral or: [www.freelancedietitians.org](http://www.freelancedietitians.org) for a private dietitian. To check your dietitian is registered check [www.hcpc-uk.org](http://www.hcpc-uk.org)

This Food Fact Sheet and others are available to download free of charge at [www.bda.uk.com/foodfacts](http://www.bda.uk.com/foodfacts)  
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The information sources used to develop this fact sheet are available at [www.bda.uk.com/foodfacts](http://www.bda.uk.com/foodfacts)

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### ***Asthma Treatment: An update.***

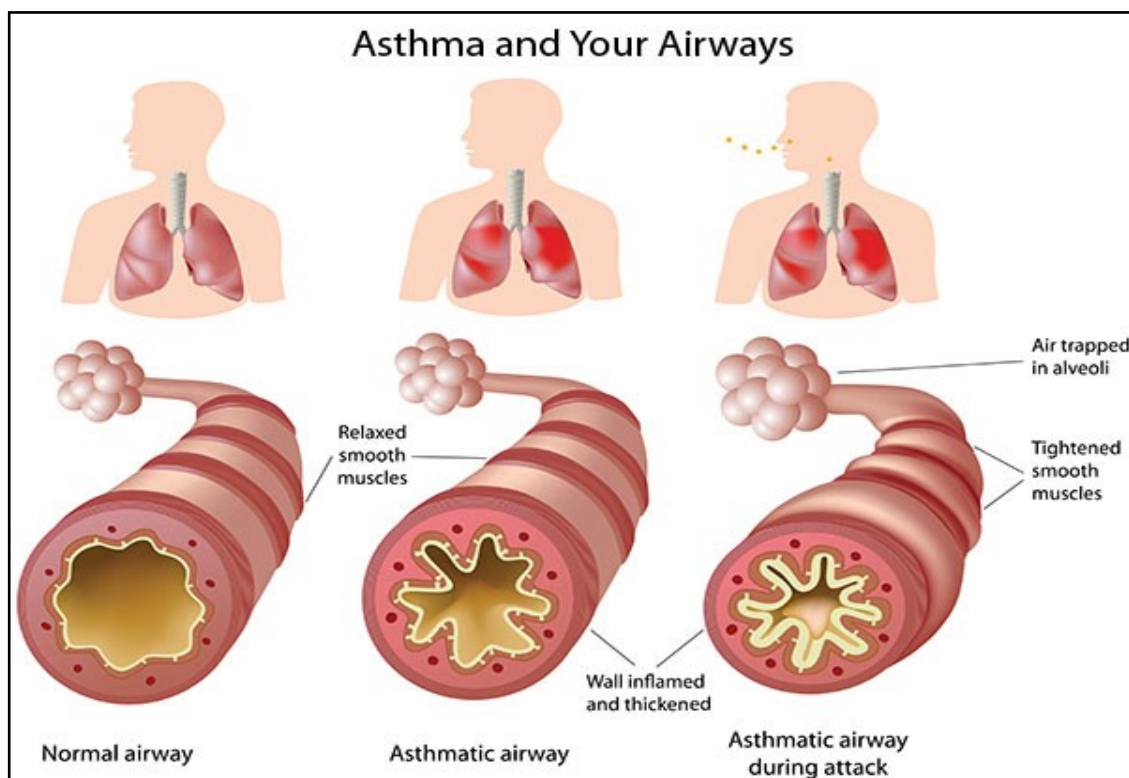
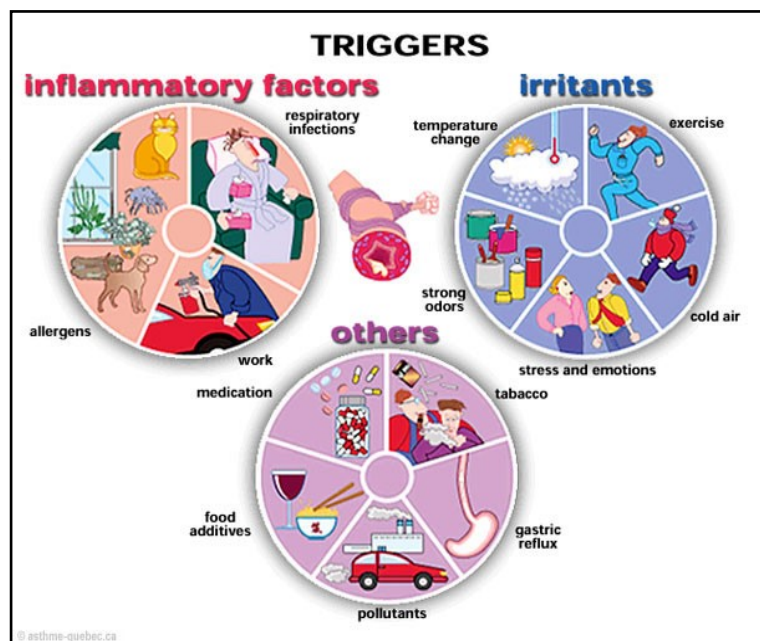
Many Leger ME members also suffer from Asthma. Most often these people have an atopic tendency themselves or somewhere in their family history. Atopy is a predisposition toward developing certain allergic hypersensitivity reactions. Atopy may have a hereditary component, although contact with the allergen or irritant must occur before the hypersensitivity reaction can develop. Other atopic reactions include eczema, angioedema and allergic reactions. In some cases, fatigue is a hypersensitivity reaction.

Over recent weeks, we have experienced a heatwave, and many members have had breathing difficulties. Many have used a blue reliever inhaler e.g. salbutamol which has been prescribed by their GP or asthma nurse, but, in some cases either acquired from another family member or via the internet. These types of inhaler are intended to control an asthma attack, which it does quite well. However, there are hidden dangers. Unlike ME/CFS, asthma still kills about 1,200 people a year. For a 12-month period in 2012, UK deaths from asthma in the UK were investigated, and it was concluded that 90% were preventable. You can find further information at the following reference:

<http://www.rcplondon.ac.uk/projects/national-review-asthma-deaths>

I've seen a local case of an asthma death quoted of a young adult. The person concerned had a history of childhood asthma. He never needed oral steroids (a sign of severe asthma). There were no hospital admissions or limitations on lifestyle. They never smoked. They used a blue inhaler twice daily and needed 3-4 four week. In fact, what seemed a well-controlled case of asthma on the surface. But the person suffered a bad asthma attack one night and died at home before the ambulance arrived. Where such unexpected deaths occur, there is usually an inquest. What turned out to be the case was his lung function, spirometry and peak flow had never been checked by an asthma clinic, and his only treatment was effectively a blue inhaler.

So, what had gone wrong? Asthma is an inflammatory condition whereby the lung airway become thickened and inflamed during an asthma attack. The action of the blue inhaler is to open the airways, so the person can breathe better. What it doesn't do is treat the accompanying airways inflammation. It is just like treating a broken leg with strong painkillers, and not bothering to put on a plaster cast. If the young adult in question had been treated with something to reduce the inflammation it is highly likely he/she would be still alive today.

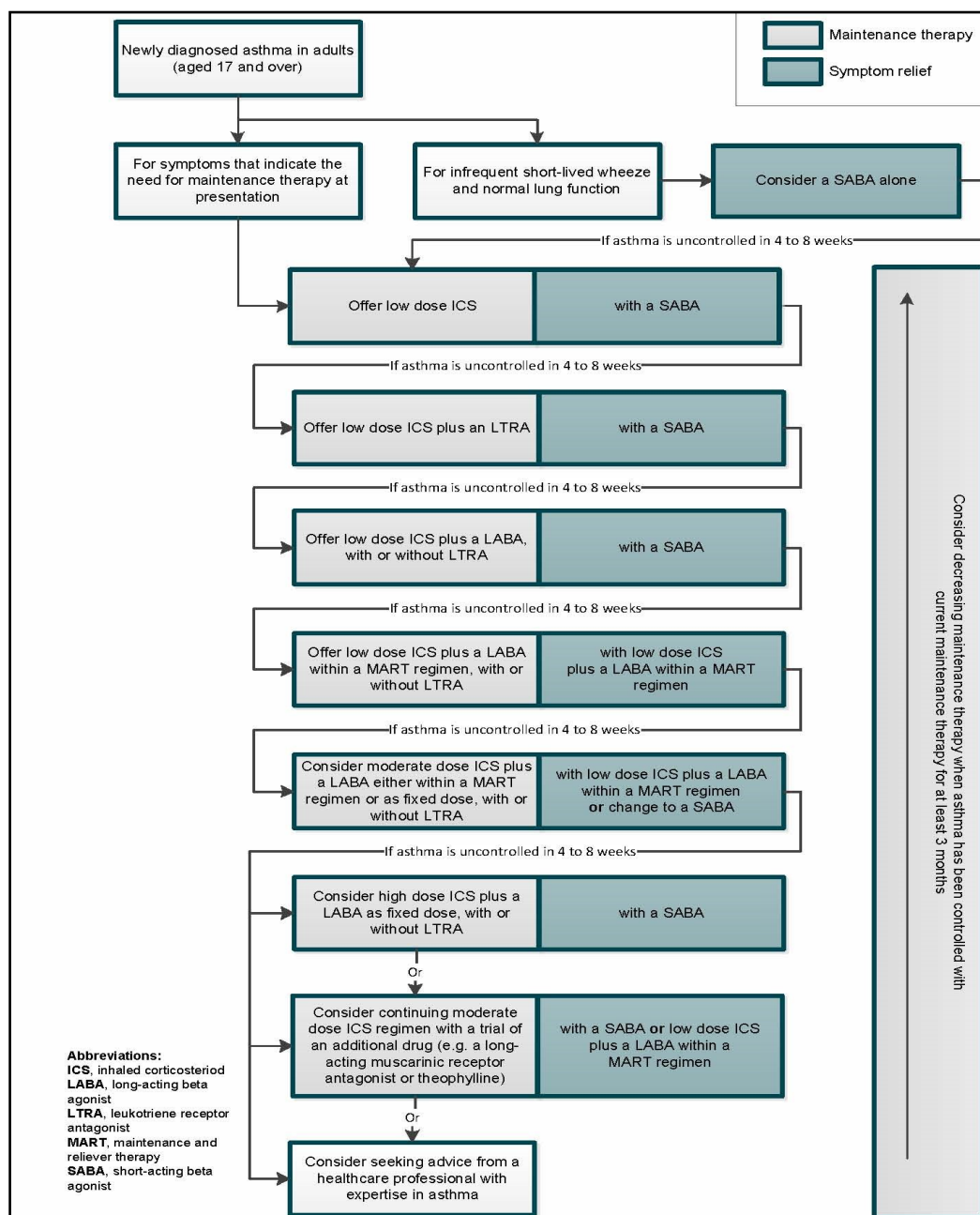




There are various ideas around the world, and the following is a generalisation of how asthma should be treated. At the time of writing, current in the UK the guidelines are being revised. Generally, the following applies:

- SABA inhaler (Short acting beta agonists for example salbutamol) type inhalers are used to treat an asthma attack or in the initial stages of assessment. If this is not enough to control asthma attacks, then add:
- ICS Inhaler (Inhaled Corticosteroid, for example fluticasone) usually at a low dose. This is a preventer inhaler and is usually coloured brown. The SABA inhaler is then reserved as a rescue inhaler. If this is not enough to control asthma attacks, then add:
- LTRA (leukotriene receptor antagonist). This is a white tablet given by mouth. The SABA inhaler is then reserved as a rescue inhaler. If this is not enough to control asthma attacks, then add:
- LABA (long acting beta agonist for example formoterol) This is long acting version of the rescue inhaler. If this is not enough to control asthma attacks, then add go to the next stage etc.

Most people find that they are given combination inhalers MART, maintenance and reliever therapy inhalers. The blue SABA is always kept as a rescue or emergency use. Throughout treatment, a peak flow meter should be monitored to assess how effective the treatment is working.



The 2017 NICE guidelines



An example of the blue SABA salbutamol preventer inhaler.



An example of the brown ICS inhaled corticosteroid preventer inhaler. Combination inhalers may be different colours e.g. Red

**Take Home Messages:**

For complete control of asthma there should be:

- no daytime symptoms
- no night-time awakening due to asthma
- no need for rescue medication
- no asthma attacks (i.e. no need to use the rescue inhaler)
- no limitations on activity including exercise
- no lung function abnormality (FEV1 or PEF > 80% predicted or best)
- no or minimal side effects from medication



Yellow Flag warnings are an indication the treatment is not effective, and attention is needed. This means that the asthma is getting worse if you are experiencing,



- Symptoms coming back (wheeze, tightness in my chest, feeling breathless, cough).
- Waking up at night.
- Symptoms are interfering with usual day-to-day activities (e.g. at work, exercising).
- Using the reliever inhaler three times a week or more.
- The Peak flow reading drop to below the usual level.

Red flag warnings are an indication that emergency action is needed. They are



- When the reliever inhaler is not helping, or it needs to be used more frequently than every four hours.
- Difficult to walk or talk.
- Difficult to breathe.
- Wheezing a lot or having a very tight chest or;
- Coughing a lot.
- Peak flow is below half the best reading.

**Remember if you have Asthma:**

- If you use a rescue SABA or blue inhaler, it will only make breathing easier. It does not treat the inflammation associated with asthma. If used alone, too often without the preventer medication, this carries a substantial risk of harm.
- You need some sort of preventer medication in the form of a brown or other combination inhalers or a SMART type of inhaler or tablets.
- You should have an asthma treatment plan supplied by your Doctor or Asthma nurse.
- You should have a Peak Flow Meter and record the reading as instructed by your Doctor or Asthma nurse. Charts are available from the office.
- Avoid known triggers as far as possible.
- You should see your doctor or asthma nurse frequently, at least once a year.
- Report any yellow flag symptoms act as advised and contact your Asthma nurse or GP.
- Report and red flag symptoms, act as advised or dial 111 or 999.



## An example of an Asthma Treatment Plan. *With thanks to [www.asthma.org.uk](http://www.asthma.org.uk)*

Very often GP Practices and Hospitals will use similar documentation provided by manufacturers or their own local guidelines.

### ! My asthma triggers

Taking my asthma medicine each day will help reduce my reaction to these triggers. Avoiding them where possible will also help.

**i** People with allergies need to be extra careful as attacks can be more severe.

### ! My asthma review

I should have at least one routine asthma review every year. **I will bring:**

- My action plan to see if it needs updating.
- Any inhalers and spacers I have, to check I'm using them correctly and in the best way.
- Any questions about my asthma and how to cope with it.

Next asthma review date: \_\_\_\_\_

### GP/asthma nurse contact

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

### Out-of-hours contact number

(ask your GP surgery who to call when they are closed)

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_



HA1080216 © 2016 Asthma UK registered charity number in England and Wales 802364 and in Scotland SC039322.  
Last reviewed and updated 2018; next review 2019.

\*Adams et al; Factors associated with hospital admissions and repeat emergency department visits for adults with asthma; Thorax 2000;55:566-573

## How to use it

Your written asthma action plan can help you stay on top of your asthma.

To get the most from it, you could...

**1 Put it somewhere easy for you and your family to find** – like your fridge door, noticeboard, or bedside table.

**2 Keep a photo of it on your mobile phone or tablet** – so you can check it wherever you are. You can also send it to a family member or friend, so they know what to do if your asthma symptoms get worse.

**3 Check in with it regularly** – put a note on your calendar, or a monthly reminder on your phone to read it through. Are you remembering to use your day-to-day asthma medicines? Do you know what to do if your symptoms get worse?

**4 Take it to every healthcare appointment about your asthma** – including A&E/consultant. Ask your GP or asthma nurse to update it if their advice for you changes.

### Get more advice & support from Asthma UK:

**Speak to a specialist asthma nurse** about managing your asthma on: **0300 222 5800**

**Get news, advice and download information packs** at: **[www.asthma.org.uk](http://www.asthma.org.uk)**

**Follow us on Facebook** for news and tips about your asthma: **[www.facebook.com/asthmauk](http://www.facebook.com/asthmauk)**

**Follow us on Twitter** for news and tips about your asthma: **[@asthmauk](https://twitter.com/asthmauk)**

The step-by-step guide that helps you stay on top of your asthma

## Your asthma action plan

Fill this in with your GP or nurse



If you use a written asthma action plan you are four times less likely to be admitted to hospital for your asthma.\*

Name and date: \_\_\_\_\_



Any asthma questions? Call our friendly helpline nurses

**0300 222 5800**

(9am – 5pm; Mon – Fri)

**[www.asthma.org.uk](http://www.asthma.org.uk)**



### Every day asthma care:

#### My asthma is being managed well:

- With this daily routine I should expect/aim to have no symptoms.
- If I've not had any symptoms or needed my reliever inhaler for at least 12 weeks, I can ask my GP or asthma nurse to review my medicines in case they can reduce the dose.
- My personal best peak flow is:

#### My daily asthma routine:

My **preventer** inhaler (insert name/colour):

I need to take my **preventer** inhaler every day even when I feel well

I take  puff(s) in the morning

and  puff(s) at night.

My **reliever** inhaler (insert name/colour):

I take my **reliever** inhaler only if I need to

I take  puff(s) of my reliever inhaler if any of these things happen:

- ★ I'm wheezing
- ★ My chest feels tight
- ★ I'm finding it hard to breathe
- ★ I'm coughing

Other medicines and devices (eg spacers) I use for my asthma every day:



### When I feel worse:

#### My asthma is getting worse if I'm experiencing any of these:

- My symptoms are coming back (wheeze, tightness in my chest, feeling breathless, cough).
- I am waking up at night.
- My symptoms are interfering with my usual day-to-day activities (eg at work, exercising).
- I am using my reliever inhaler three times a week or more.
- My peak flow drops to below:

**! URGENT! If you need your reliever inhaler more than every four hours, you're having an asthma attack and you need to take emergency action now.**

#### What I can do to get on top of my asthma now:

If I haven't been using my preventer inhaler, I'll start using it regularly again or if I have been using it...

Increase my preventer inhaler dose to  puffs  times a day until my symptoms have gone and my peak flow is back to my personal best.

Take my reliever inhaler as needed (up to  puffs every four hours).

I carry my reliever inhaler with me when I'm out.

**URGENT! See a doctor or nurse within 24 hours if you get worse at any time or you haven't improved after seven days.**

Other advice from my GP about what to do if my asthma is worse (eg SMART/MART or rescue steroid tablets):



### In an asthma attack:

#### I'm having an asthma attack if I'm experiencing any of these:

- My reliever inhaler is not helping or I need it more than every four hours.
- I find it difficult to walk or talk.
- I find it difficult to breathe.
- I'm wheezing a lot or I have a very tight chest or I'm coughing a lot.
- My peak flow is below:

#### What to do in an asthma attack



**1 Sit up straight** – try to keep calm.



**2 Take one puff of your reliever inhaler (usually blue)** every 30 - 60 seconds, up to a maximum of 10 puffs.



**3 If you feel worse** at any point OR you don't feel better after 10 puffs call 999 for an ambulance.



**4 Repeat step 2 after 15 minutes** while you're waiting for an ambulance.

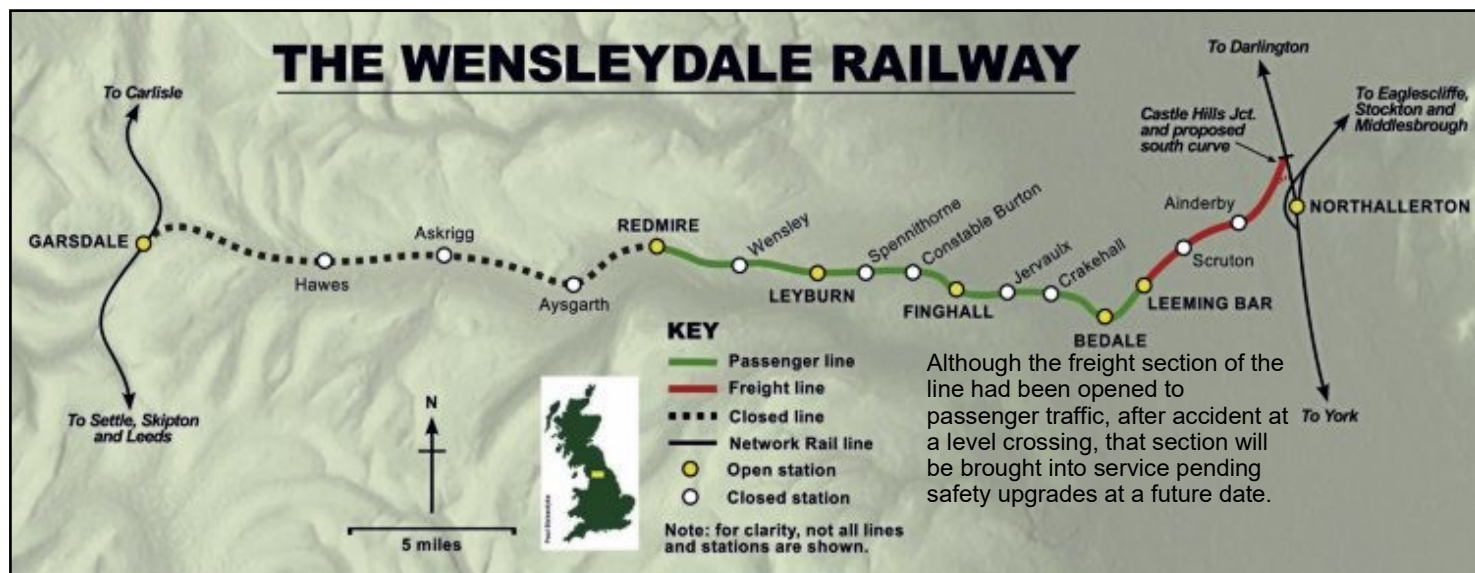
#### After an asthma attack:

See your GP within 48 hours to make sure you're not at risk of another attack. If you get worse see them urgently. Finish any medicines they prescribe you, even if you start to feel better. If you don't improve after treatment, see your GP urgently.

What to do in an asthma attack if I'm on SMART/MART:

## Out and About: Wensleydale Railway

The Wensleydale Railway is a tourist and heritage line starting at the County town of Northallerton to Redmire on the edge of the Yorkshire Dales National Park, passing through the Georgian market town of Bedale and the Dales market town of Leyburn, with constantly changing scenery, from the arable lands of the Vale of Mowbray in the east to hills of the Yorkshire Dales in the west. The line is a predominantly heritage diesel line, with steam services operating over selected weekends, special events and the summer months. Operation is seasonal, with three to five trains per day on running days.



Our visit to the railway was on a grey day in June. We were to start our journey from Leeming Bar station. The station is on Leases Road, Leeming Bar. We put in the Satnav postcode: DL7 9AR and followed the directions Leeming Bar Station is approximately half a mile from junction 51 on the A1(M) and is the main centre of the railway where maintenance to rolling stock is carried out. The station has both a small buffet serving a selection of hot drinks and snacks, with a static railway carriage as a shop and car parking. Currently the station is undergoing renovation, and there were temporary toilets in operation the day we visited. Car parking was adequate. We purchased our tickets from the stop, a static converted railway carriage. Eventually our train arrived. The carriages were old stock British Rail types with four seats to a table. With the railway being a single line throughout, passing loops are needed and both end and other points to allow the locomotive to get to right end of the train for the direction of travel. Our engine was an industrial diesel of the camel back type, with a cab in the middle and coupling rods like a steam engine. Sometimes preserved railways hire in from other



### Recent history

The railway lost its passenger services in 1954, and almost half its route mileage by the early 1960s, the line survived until 1992 by carrying limestone to the smelters on Teesside. When that traffic finished, the Ministry of Defence decided to use the line for the occasional transport of military vehicles and this traffic kept the line alive long enough for the Wensleydale Railway Association (formed in 1990 and converted to the Wensleydale Railway Association (Trust) in 2015) to build support and eventually form a company to take a 100 year lease on the 22 miles of line from Northallerton (Castle Hills) to Redmire.

similar railways. We learned that their steam engine was under overhaul to the disappointment of some passengers.

We departed. On leaving Leeming Bar station we could see sidings containing renovation projects. We passed under the new A1 bridge, then the train crosses the A684 road at Aiskew crossing with its new LED based crossing lights can be seen and heard, letting the traffic know here is a train passing. Very shortly we approached Bedale station, with a curve shaped platform with rockery on the right-hand side that in typical railway fashion spells out the name of the station. We stopped to pick up passengers.



After passing under the Bedale Bypass bridge we see out into open country, with fields and woods on either side of the train. The trees almost touch the carriage windows. The old Crakehall Station is passed on the left, with some old railway vans used in the lovely gardens. There is also a crossing here that is manually operated by one of the railways crossing keepers. The next village we pass is Newton-le-Willows, after this we start to climb and see some spectacular views out of the right of the train, with the valley leading back to the Vale of Mowbray and giving views of the North York Moors and Cleveland hills beyond. We arrive at Finghall Lane, this is the road that leads up to Finghall village, and on the right, there are some great views across the valley towards Akebar and Constable Burton.



*Finghall was used in the 1970s and 1980s by the BBC Television series All Creatures Great and Small. It was renamed Rainby Halt for the show, with passengers bound for nearby Darrowby requested to alight there, but no passenger trains called at the station during that time.*

Next, we enter Croft wood, and within it Constable Burton loop passing loop. Suddenly out of the trees came diesel hauled train, passed us. Moving on, next on the left looks out for the views across Wensleydale and to Middleham and its castle. We saw the former Spennithorne station, which is now a private house. Just before arriving at Leyburn the caravan park on the right has been built in a small quarry, incorporating some original lime kilns, and on the left is the famous Tennants auctioneers. On arrival at Leyburn we saw a new passing loop under construction, and as we found out later, new water tower, footbridge, platform and signal box are being constructed.

Leaving, we entered a deep cutting. On emerging, the landscape has changed to Dales scenery. On approaching the disused station at Wensley, on the right can be seen the spoil heaps from the smelt mill and mine at Keld Heads. We then started to drop down Redmire bank, with superb views of Pen Hill on the left, and glimpses of Bolton Castle dead ahead. We then approached the present end of the line at Redmire station. Here there is a passing loop, where our locomotive uncoupled and shot off around a bend. There were extra sidings, which someone told us were used by the Army when move heavy military equipment. The locomotive came back on the opposite track, passed the coaches, disappearing again for a minute finally reversing to link up to the Leybourne end of the train. The was about half an hour, and just time to have a quick look around the station, there was a pub nearby. The station house had been converted to a private dwelling. The journey took about one hour. On the return journey, the train stopped at Leybourne station, and we were able to get off and have a good look around the station precinct.

Over all, considering it is only just an hour's drive from Doncaster, it is a worthwhile day out.

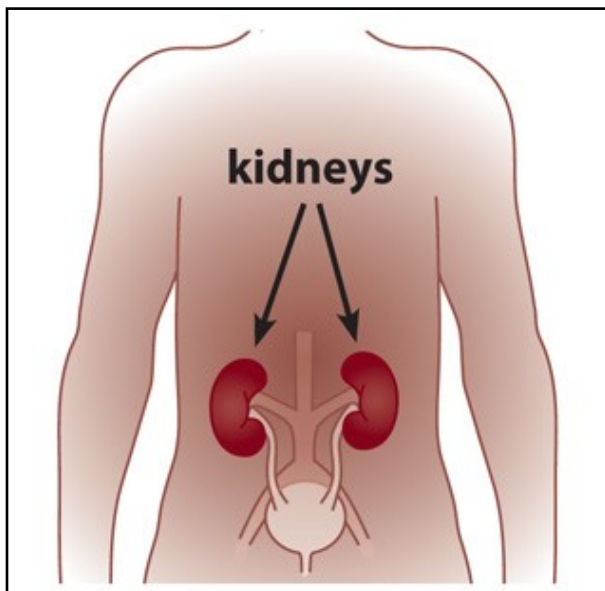
As preserved railways go, there is still some way to go, with plenty of development happening. It's the sort of journey for a ride out in the country, rather than for the serious rail enthusiast. With regards to disabled facilities, give them a few more years before you visit.



## The Kidney and How It Works.

Most of us at one time or another will have had a pet goldfish, which would have been kept in a bowl. The goldfish would be fed fish food and consequently excrete waste into the water. Quite quickly the water will become dirty and the bowl will need cleaning and the water changing. If a suitable plant were introduced, the plants would use the fish water to grow and use up the fish's waste, keeping the water cleaner. In bigger fish tank and aquariums, there is a filter system which takes the water, cleans it and returns it to the tank.

Most of our body is made of water, which is kept within a closed system of blood and lymph vessels. All our body cells are bathed within tissue fluid, which supplies nutrients and takes away waste products. The main job of the kidney is to control the internal environment and eliminate waste products from the blood just like a fish tank filter system. Alternatively, you can think of the kidney as the sewage works of the body.



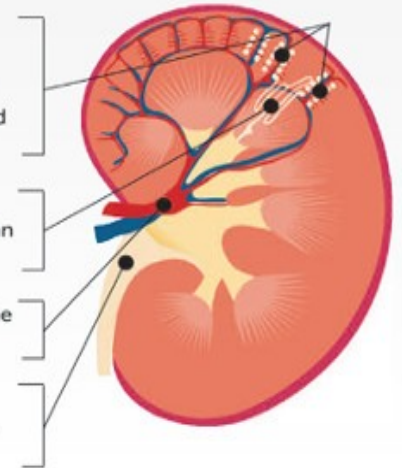
### How Kidneys Work

Inside each nephron, a special blood vessel called a glomerulus works like a strainer to keep blood cells and needed substances in while letting extra fluid and wastes out.

Each kidney contains about one million nephrons—tiny filtering centers that clean the blood.

Blood enters the kidney here, through the renal artery.

Drop by drop, urine is produced and travels to the bladder through this tube, called a ureter.



### How is the kidneys performance measured?

*With thanks to the Kidney Foundation Website.*

Glomerular Filtration Rate (GFR) is the best way to measure the level of kidney function and determine if any problems are present. There is no easily way to measure GFR directly, e.g. as with temperature or blood pressure. GFR is normally calculated from the result of a Urea and Electrolyte (U & E) blood tests by the laboratory.

Age in years	Average estimated GFR
20–29	116
30–39	107
40–49	99
50–59	93
60–69	85
70+	75

STAGES OF CHRONIC KIDNEY DISEASE		GFR*	% OF KIDNEY FUNCTION
<b>Stage 1</b>	Kidney damage with <b>normal</b> kidney function	90 or higher	90–100%
<b>Stage 2</b>	Kidney damage with <b>mild loss</b> of kidney function	89 to 60	89–60%
<b>Stage 3a</b>	<b>Mild to moderate</b> loss of kidney function	59 to 45	59–45%
<b>Stage 3b</b>	<b>Moderate to severe</b> loss of kidney function	44 to 30	44–30%
<b>Stage 4</b>	<b>Severe</b> loss of kidney function	29 to 15	29–15%
<b>Stage 5</b>	<b>Kidney failure</b>	Less than 15	Less than 15%

\* Your GFR number tells you how much kidney function you have. As kidney disease gets worse, the GFR number goes down.



## ME/CFS, Non-Steroidal Anti-Inflammatory Drugs and Acute Kidney Injury

Non-Steroidal Anti-inflammatory drugs (NSAIDs) are a drug class that reduce pain, antipyretic, prevent blood clots and, in higher doses, decrease inflammation. But they come with side effects which increase include an increased risk of gastrointestinal ulcers and bleeds, heart attack and kidney disease. Individual drugs have their own specific side effects. The term nonsteroidal distinguishes these drugs from steroids, which while having a similar eicosanoid-depressing, anti-inflammatory action, have a broad range of other effects. They were first used in the 1960, the term served to distance these medications from steroids.

NSAIDs work by inhibiting the activity of cyclooxygenase enzymes (COX-1 and/or COX-2). In cells, these enzymes are involved in the synthesis of key biological mediators, which are involved in inflammation, and in blood clotting. There are two types of NSAID available: non-selective and COX-2 selective. Most NSAIDs are non-selective and inhibit the activity of both COX-1 and COX-2.

**Paracetamol** is generally not considered an NSAID because it has only little anti-inflammatory activity. It treats pain mainly by blocking COX-2 mostly in the central nervous system, but not much in the rest of the body.

These NSAIDs, while reducing inflammation, also thin the blood (especially aspirin) and increase the risk of gastrointestinal ulcers/bleeds. COX-2 selective inhibitors have less gastrointestinal side effects but promote thrombosis and substantially increase the risk of heart attack. As a result, COX-2 selective inhibitors are generally contraindicated due to the high risk of undiagnosed vascular disease. These differential effects are due to the different roles and tissue localisations of each COX isoenzyme. By inhibiting physiological COX activity, all NSAIDs increase the risk of kidney disease and through a related mechanism, heart attack. The most prominent NSAIDs are aspirin, ibuprofen and naproxen, the first two being available over the counter in most countries.

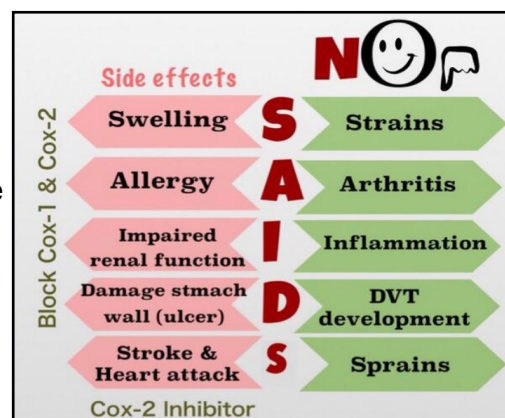
Acute kidney injury can vary from nothing appearing to be wrong to complete renal failure. Acute kidney injury is characterised by a rapid fall in glomerular filtration rate (GFR) over hours to days. There are no specific signs or symptoms for NSAID induced acute kidney injury. Symptoms of acute kidney injury can be non-specific and may include shortness of breath, fatigue, confusion, nausea, decreased urine output and ankle/leg swelling. Therefore, for people with ME/CFS any new symptoms should be reported to you GP for assessment. People with pre-renal injury may have signs of volume depletion (e.g., tachycardia, absolute or postural hypotension, low jugular venous pressure, dry mucous membranes) which is a common finding in ME/CFS. People with interstitial nephritis may have features of a systemic hypersensitivity including fever, arthralgia and an itchy red rash. Eosinophilia increased number of eosinophils a type of white blood cell associated with may also be present often associated with substance sensitivity

All non-steroidal anti-inflammatory drugs (NSAIDs) have been associated with the development of acute kidney injury. Some more than others. NSAIDs can cause two different sort of acute kidney injury.

- Haemodynamically mediated (e.g., pre-renal injury and/or acute tubular damage).
- Immune mediated (e.g. acute interstitial nephritis where the immune system attacks the kidney).

### Why kidney damage occurs, who is at risk.

NSAIDs reversibly inhibit the production of renal prostaglandins via their inhibition of COX-1 and COX-2 pathways. In aa level playing field, maximum inhibition occurs in steady state plasma concentrations, usually within 3-7 days (usually 3–7 days). The Renal prostaglandins cause dilatation of the renal afferent arteriole the small blood vessels inside the kidney which feed the glomerular filtering network. This mechanism is important for maintaining GFR when renal blood flow is reduced in older people with health problems. Therefore, an NSAID use is likely to have a greater effect on renal function in patients with other risk factors. It is not known how NSAIDs induce acute interstitial nephritis. However, it has been suggested that cyclooxygenase inhibition causes preferential conversion of arachidonic acid to leukotrienes, which may then activate helper T cells.



### The risk factor for NSAID induced acute kidney injury are:

- Increases with age especially over 65, chronic hypertension and atherosclerosis
- Narrowing of renal arterioles which may reduce their capacity for renal afferent dilatation
- Pre-existing glomerular disease or renal insufficiency
- Renal afferent dilatation is likely to be required to maintain GFR
- Fluid Volume depletion true volume depletion (i.e., GI or renal salt and water losses, blood loss, diuretic water tablet use) or effective volume depletion (i.e., cirrhosis or heart failure) there is a blood volume problem is PoTS and ME/CFS.
- Lowers afferent glomerular arteriolar pressure and stimulates secretion of angiotensin II
- The concurrent use of ACE inhibitors and ARBs (type of mediacies used to control blood pressure) prevent efferent arteriole vasoconstriction which is also important in maintenance of GFR.

**Treatment:** In cases of group members who have suffered from NSAID renal, renal functions has gone back to normal once the NSAID was been stopped. If goes without saying that NSAIDs use should be avoided in the future in such patients.

**Types of NSAIDs.** NSAIDs are available as tablets, capsules, suppositories (capsules inserted into the bottom), creams, gels and injections. Some can be bought over the counter from pharmacies, others are a prescription. The main types of NSAIDs include: Ibuprofen commonly sold over the counter (e.g. Brufen), Naproxen (Naprosyn), Etoricoxib (Arcoxia), Indometacin (Indocid), high-dose aspirin (low-dose aspirin is not normally considered to be an NSAID)

**Who takes NSAIDs?** It's a good idea to ask a pharmacist or doctor for advice before taking an NSAID if you:=-

- are over 65 years of age
- are pregnant or trying for a baby
- are breastfeeding
- have had a reaction to NSAIDs in the past
- have had ulcers in the past
- have any problems with your heart, liver, kidneys, blood pressure, circulation, bowels
- are taking other medications
- are looking for medication for child under 16 (any medication that contains aspirin shouldn't be given to children under 16 due to risk of Reyes syndrome)

Some NSAIDs can react unpredictably with other medications. This can affect how well either medicine works and increase the risk of side effects. It's particularly important to get medical advice before taking an NSAID if you're already taking: another NSAID

- low-dose aspirin or warfarin – medicines used to prevent blood clots
- ciclosporin – a medicine used to treat autoimmune conditions such as arthritis or ulcerative colitis
- diuretics – medicines sometimes used to treat high blood pressure like ACE or ARB
- lithium – a medicine used to treat bipolar disorder and severe depression
- methotrexate – a medicine used to treat rheumatoid arthritis
- a type of antidepressant medicine called a selective serotonin reuptake inhibitor (SSRI)

Over-the-counter NSAIDs generally have fewer side effects than stronger prescription medicines. Possible side effects of NSAIDs include: indigestion– including stomach aches, feeling sick and stomach ulcers– these can cause internal bleeding and; extra medication, such as proton pump inhibitors (PPIs), prescribed to help reduce this risk a hole forming in the wall of your stomach or, headaches, drowsiness, dizziness, allergic reactions.

If you are taking any NSAID for any reason and need to take it for an extended period, the you must have your GFR and Kidney function (U&E) checked by you doctor.





## ME/CFS and Autonomic Nervous System Dysfunction.

The autonomic nervous system - this is the bit of the body which does things automatically such as control of body temperature (sweating), heart rate, digestion, blood vessels (therefore blood pressure, flushing, fainting, feeling hot). these functions we have no conscious control over.

The Symptoms that are related to autonomic nervous system dysfunction in ME/CFS include:

- Dizziness, light-headedness and feeling faint on standing (postural hypotension).
- Orthostatic intolerance (being unable to stand for long periods).
- Palpitations.
- Cold hands and feet.
- Irritable bladder symptoms.
- Gastric and irritable bowel type symptoms - including nausea.

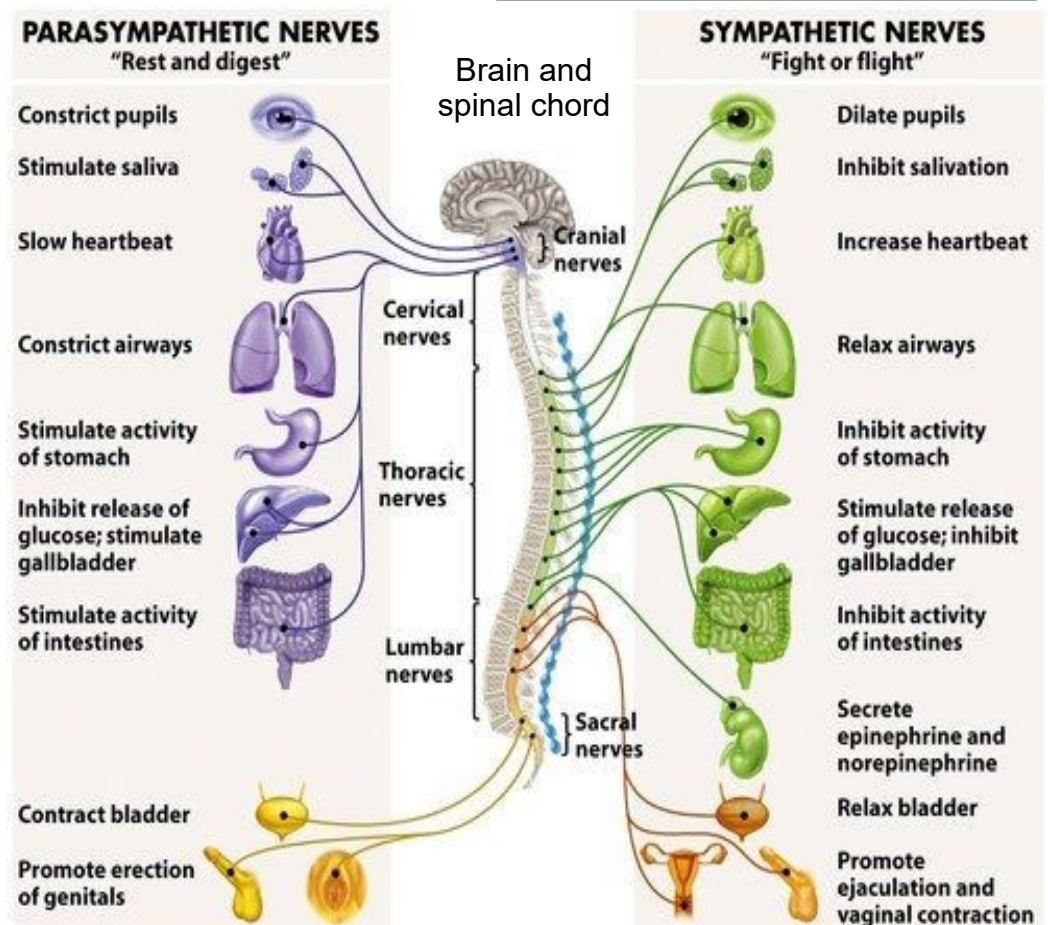
In addition, there may be nerve damage known to the autonomic nervous system which is known as autonomic neuropathy. There may be a great many symptoms because the autonomic nervous system controls a great number of functions

- blood pressure falls when you can't stand up
- too much or too little sweating poor temperature control,
- Flushing
- inability to become sexually aroused
- heart rate too fast or too slow
- constipation or diarrhoea
- dry mouth
- dry eyes

A condition known as postural orthostatic tachycardia syndrome (POTS) also occurs in a sub-group of people with ME/CFS. Autonomic neuropathy is often blamed for PoTS (postural orthostatic tachycardia syndrome).

However, Dr Sarah Myhill believes that the situation is the other way around. The autonomic nervous system is fine, and the low blood pressure is a symptom of low cardiac output - blood pressure and postural hypotension. The autonomic nervous system has synapses outside the brain involving neurotransmitters. These can be "mimicked" by substances such as nicotine and caffeine. They may also be "mimicked" by proteins leaking from a leaky gut. This may cause a host of confusing symptoms for the sufferer, as can be inferred from the above list.

*In some case of people with ME who have died, inflammation of the dorsal root ganglia (blue dotchain) has been found on port mortem. This explains lot, but not everything*



*A diagram of the autonomic nervous system, and the internal organs it controls.*

## ME/CFS and Postural Orthostatic Tachycardia Syndrome (PoTS)

A few Leger ME members have a PoTS diagnosis. Many more have similar symptoms.

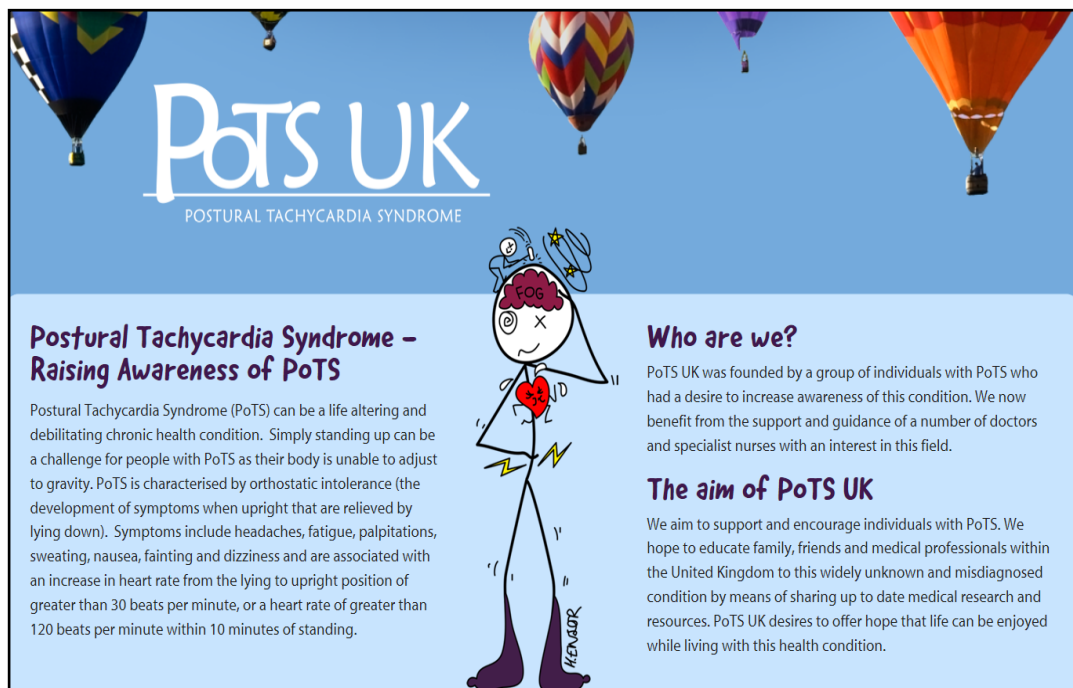
**What is PoTS?** PoTS stands for postural tachycardia syndrome first characterised and defined in 1993. Its prevalence estimated to be 0.2% of the population. Abnormal response by the autonomic nervous system to upright posture. In some, mechanism is lack of vasoconstriction on standing causing pooling of blood in abdomen and limbs, reduced venous return to heart, compensatory tachycardia and altered cerebral circulation. It is most common in females age 15-50. In terms of disability it is equivalent to disability in heart failure and chronic obstructive pulmonary disease. It is associated with hypermobile Ehlers-Danlos Syndrome and hypermobility spectrum disorder, chronic fatigue syndrome/ME, autoimmune conditions and growth/puberty in children. PoTS should be investigated in patient with medically unexplained symptoms, CFS/ME and hypermobile patients. This was a common problem before Chief Medical Officers report and NIHCE guidelines.

**PoTS Signs and Symptoms** The three commonest symptoms are, lightheadedness (presyncope), fatigue palpitations. Other symptoms include fainting, nausea, bloating, abdominal pain, cognitive dysfunction, 'brain fog', poor sleep, exercise intolerance, shakiness, sweating, postural headaches and migraines the clinical signs occur on standing/prolonged sitting, and these are tachycardia, acrocyanosis - red/purple puffy hands and feet which occur in 50% of patient.). Most of these problems are common to ME/CFS except for acrocyanosis

**Diagnosis:** PoTS is diagnosed by a sustained increase in heart rate of 30 beats per minute (40 bpm in teenagers) from lying to standing associated with symptoms of PoTS. This is checked by the stand test -with the patient rest supine and record heart rate and blood pressure. Then stand in a safe place and record BP and HR every 2 minutes to 10 minutes. Investigations must exclude anemia, hyperthyroidism, postural hypotension and pheochromocytoma (adrenal tumor). The mean time to diagnosis is 7 years, with half of the patients receiving a psychiatric misdiagnosis e.g. anxiety, depression, hypochondriasis. Other misdiagnoses - CFS/ME. The nearest specialist is in York. For ME/CFS the diagnosis is all about new fatigue being present, and all other conditions that could cause fatigue being excluded.

**Condition management:** Where possible avoid heat, large meals, alcohol and medicines that lower blood pressure. Patients should drink at least two litres of fluid a day, and unless contraindicated take in about 6 grams of salt. Exercises can take up to two months to improve symptom. Precautions need to be taken to avoid fainting like avoiding prolonged standing, elevate legs, tense buttocks and thighs, fold arms, tiptoe). Compression stockings or tights class 2 may help. Medicines that may help are include  $\beta$  blockers, calcium channel blockers, ivabradine, midodrine, fludrocortisone, clonidine, SSRI, desmopressin, pyridostigmine, octreotide. Cognitive behaviour therapy may help the patient to help adjust to chronic illness. In a medical emergency intravenous fluid may be needed to maintain blood volume. With ME/CFS, the keystone to management is adaptive pacing. It is a combination of cognitive behavioral therapy and paced activity. There are no medicines or any surgical interventions known to control ME/CFS or modify the disease process.

For further information please see <http://www.potsuk.org/>



**POTS UK**  
POSTURAL TACHYCARDIA SYNDROME

**Postural Tachycardia Syndrome – Raising Awareness of PoTS**

Postural Tachycardia Syndrome (PoTS) can be a life altering and debilitating chronic health condition. Simply standing up can be a challenge for people with PoTS as their body is unable to adjust to gravity. PoTS is characterised by orthostatic intolerance (the development of symptoms when upright that are relieved by lying down). Symptoms include headaches, fatigue, palpitations, sweating, nausea, fainting and dizziness and are associated with an increase in heart rate from the lying to upright position of greater than 30 beats per minute, or a heart rate of greater than 120 beats per minute within 10 minutes of standing.

**Who are we?**

PoTS UK was founded by a group of individuals with PoTS who had a desire to increase awareness of this condition. We now benefit from the support and guidance of a number of doctors and specialist nurses with an interest in this field.

**The aim of PoTS UK**

We aim to support and encourage individuals with PoTS. We hope to educate family, friends and medical professionals within the United Kingdom to this widely unknown and misdiagnosed condition by means of sharing up to date medical research and resources. PoTS UK desires to offer hope that life can be enjoyed while living with this health condition.



**Recipe Corner** by Carolyn**Minestrone**

*This classic Italian soup will chase away the Autumn Blues.*

**Cooking Method:**

- Heat the oil in a large pan.
- Add the onion and garlic, and cook for 3-4 minutes, stirring once or twice.
- Add the potatoes, cover and cook for 5 minutes, stirring occasionally.
- Add the carrot, cover and cook for 3 minutes, stirring occasionally.
- Add the courgettes and stock and bring to the boil.
- Simmer for 10 minutes, then add the borlotti beans, tomato puree and macaroni. S
- Simmer rapidly for 7 minutes.
- Add the peas and simmer for a further 2-3 minutes.
- Serve with the parsley, and low-fat pesto, if liked.

296 calories per serving. 42.6g carbs per serving. (serves 4)

**Rainbow chard peanut stew**

280 calories per serving, 26.3g carbs per serving.  
Serves 4.

**Cooking Method:**

- Heat the oil in a large pan over a high heat.
- Add the onion and rainbow chard to the pan and sauté for 2 minutes until the onion begins to soften.
- Add the garlic to the pan, along with the chili flakes, cumin and ginger and cook for 1 minute.
- Tip in the tomatoes and spoon in the peanut butter.
- Reduce to a medium heat.
- Add the red kidney beans and soy sauce to the pan.
- Stir regularly to prevent burning and cook for 8 minutes. Spoon into bowls and scatter with the chopped coriander, to serve.

TIP: For a gluten free version of this dish, use gluten free tamari in place of the soy sauce. (Tamari is widely available in the supermarkets)

**What is Rainbow chard**

Chard is also known by many common names, such as Swiss chard, silver beet, perpetual spinach, beet spinach, seakale beet, or leaf beet.

**Ingredients:**

2 tbsp olive oil  
1 onion, peeled and finely chopped  
2 garlic cloves, peeled and finely chopped  
2 small potatoes, peeled and cubed  
2 large carrots, peeled and diced  
1 courgette, halved lengthways and sliced  
1.5L hot vegetable stock  
140g can borlotti beans  
2 tsp tomato puree  
100g macaroni  
100g frozen peas  
Fresh flat leaf parsley, chopped to serve

**Ingredients:**

1tbsp sunflower oil.  
1 onion, roughly chopped  
100g rainbow chard  
3 cloves garlic, crushed  
1tsp dried chilli flakes  
1tsp ground cumin  
1tsp ground ginger  
140g can chopped tomatoes  
4 rounded tbsp. crunchy peanut butter  
240g can red kidney beans, drained and rinsed  
1 tbsp light soy sauce  
Generous handful fresh coriander, roughly chopped to serve





**North of Doncaster.** *Personal comment by Trevor Wainwright*

## Travel Diary to the Holy Land Part 7:

Our last full day began with a visit to St Georges Cathedral; consecrated by the Bishop of Salisbury in 1898 we were there for a joint service with fellow Christians, it also housed visiting pilgrims in what was once the Clergy's quarters we walked through the courtyard. I noticed the Christmas decorations were going up

We walked in to the main body of the Cathedral to the sound of Bach's *Wachet Auf "Sleepers Wake"* one of my favourite pieces, I remembered the time when on hospital radio. I had borrowed a hymn book from church recited the first verse then played the music. The service began, part of it was the reading of one of my



*After mass refreshments in the tranquillity of the Cathedral Garden*

earlier poems "Risen Today" by Jenny, one of our party, from the same trilogy as "Denial" telling the story through Mary's eyes the morning they took spices to the tomb to find it empty and the messenger saying Jesus had risen and they should tell all.

After the service we had a look round the cathedral to the left of the main altar was the Blyth Chapel dedicated to Bishop George Blyth, the fourth Anglican Bishop in Jerusalem who following strained relations with the Orthodox Church under Bishop Samuel Gobat, he was eager to restore relations with the Patriarch and as an Anglo-Catholic he had a great respect for the Patriarch's office. Because of this he always called St George's a collegiate church rather than a cathedral, saying that the Church of the Holy Sepulchre was the one and only cathedral church of the city of Jerusalem. To the right The Chapel of St John slightly smaller. We took refreshments in the form of coffee and small cakes. In the garden which well-tended was like an oasis, of plants, palm and fruit trees it was nice to enjoy the silence.



*Entering the Cathedral of St George for morning mass*



*Yad Vashem. Entry to the main museum, the largest devoted to the Holocaust in the world, with extensive archives. main exhibition, photography is forbidden inside.*

Then it was to The Holocaust Museum, Yad Vashem meaning "as a place specifically to memorialise" It is said three and a half hours are recommended to visit it.

Many say it is not enough, it was true. In the main part of the museum, photography was forbidden. Looking at the exhibits and reading the story and statistics I wondered why and how it could have happened while a world appeared to ignore it. Bishop Tony having read a poem came up to me and said "I've just realised, Trevor how poets can say so much about such things with so little" "and artists too" I replied remembering a documentary I had once seen.



I walked down Heroes Promenade, where each tree is said to represent a Gentile who died helping Jews during the Holocaust to a tall pan tile shaped steel memorial whose inscription read "Now and forever in memory of those who rebelled in the camps and ghettos, fought in the woods, in the underground and with the Allied forces; braved their way to Eretz Israel; and died sanctifying the name of God". Placing a stone on a circular metal framework as is the Jewish tradition in memory of someone I then made my way to The Children's Memorial, hollowed out from an underground cavern, is a tribute to the approximately 1.5 million Jewish children who perished during the Holocaust

At the entry was a carved image of a cherubic looking young boy, his name was Uziel Spiegel who perished in Auchwitz, at the age of two and a half, one of many in what I referred to as a 20th Century massacre of the innocents. His parents Abraham and Edita who survived had donated the memorial, the garden

and an amphitheater in memory of Uziel, and that the memory of the children who perished in the Holocaust would not be forgotten. Further along was a memorial to

1,100 Jews of Hodoziej in the Ukraine, who when it was occupied by the Germans in 1941 were put into a ghetto, after 13 months of oppression and abuse the ghetto was liquidated when the occupants were rounded up and murdered in nearby killing pits. It had been donated by Moises Grajew a survivor and his wife Anneliese in memory of his family and the community. Further along was an engraved train track showing the distance to Horodziej from Paris (22 hrs.) and Moscow (9.5) Then it was time to make our way back to the hotel for our final evening in Jerusalem and some free time. Tomorrow we would be heading home.

*The heroes promenade, each tree is said to represent a Gentile who died helping Jews during the Holocaust.*



*Uziel Spiegel in whose memory it was created by his parents*

Back at the hotel with another member of the party I set out to find the Garden Tomb. Going out through the Jaffa Gate, we walked on the outside of the Old City Wall, we stopped first at a place called Gordon's Calvary, named after General Charles Gordon a well-known British leader who in 1883 was visiting the home of Horatio and Anna Spafford, founders of the American Colony in Jerusalem. From their quarters atop the northern wall of the Old City, Gordon had a view of a rocky escarpment in which he identified the features of a skull. He identified this location as the "Place of the Skull" (Aramaic: Golgotha; Latin: Calvary). Around the corner was an ancient tomb which he believed was the empty tomb of Christ. (The Garden Tomb). Many experts since 1743 had disputed that the Church of the Holy Sepulchre was indeed the real tomb of Christ.



*Gordon's Calvary, what he saw as the place of the skull*



A map showing the site outside the city walls gave credence to this as the words from the hymn "There is a Green Hill far away without a city wall" came to mind, however it was also said that at the time of the crucifixion the site that is now the Church of the Holy Sepulchre was outside the city walls.

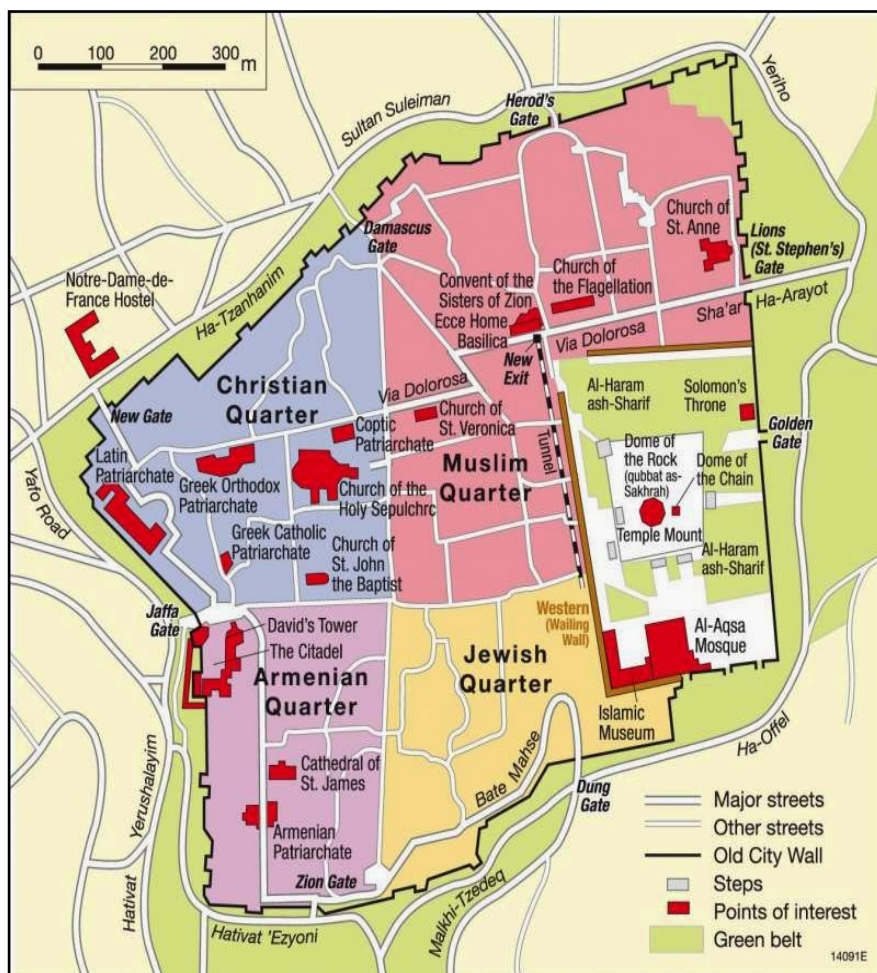
We found the entrance, admission was free but sadly it was not open due to it being Sunday, although from pictures I had seen of it could have so easily been the place where Jesus was buried, unspoiled there was a channel in which the stone would have sat to allow for easy rolling to both open and close the tomb. I would read later that many experts had cited the account of John the Evangelist: "Now in the place where he was crucified there was a garden; and in the garden a new sepulcher, wherein was never man yet laid"; consequently, an ancient press been cited as evidence that the area had once been a garden.

General Gordon himself argued regarding the slot that once housed a stone, corresponding to the biblical account of a stone being rolled over the tomb entrance to close it. As he wrote to his sister in 1883 on his second day in Jerusalem, "Now, the place of execution in our Lord's time must have been, and continued to be, an unclean place so, to me, this hill is left bare ever since it was first used as a place of execution. It is very nice to see it so plain and simple, instead of having a huge church built on it". I would get to know some other comments later.



*The Garden Tomb, we could not get in but this is what it looks like, if front is a channel for the stone that covered the entrance.*

*To be continued....*



*Above The Garden Tomb close up, with thanks to Phillip Benshmuel.*

*Below ,the inside from the 1930's photo.*

