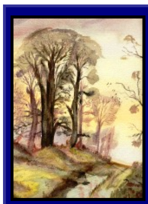


Pathways

Price £ 3.75 (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. 52 (Summer 2017)

You Write In: A selection of mail received at the Leger ME Office.

Norman Writes: Many thanks for sending me the Leger ME emails. If you remember about 20 years ago, which my daughter was sixteen you helped us with the DWP and other problems when she got ME/CFS. Eventually through time she recovered well enough to carry on a normal life, moved away and eventually ended up with a full-time administration job.

The bad news is that she has now succumbed to a relapse, and has been off work sick for the last six weeks now. You were realistic enough to tell me when she was first diagnosed that she had a good chance of recovery in ten years, which seemed an eternity to me then, given her age.

Do you think there's any hope of getting this relapse under control rapidly? I don't know what best to advise regarding PIP application, for example. Would she need a doctor to predict that she'll remain too sick to work for 9 months? I don't think she wants to think that way too soon!

I really did think she'd put it in the past, but here we are again, frustratingly at square one. Do you have any suggestions?

Since you were around Doncaster there has been quite a few changes in the way ME/CFS cases are handled. There are now national NHS ME/CFS clinics nationally should they be needed. Because it is twenty years of so that she has had a normal life, I think that real her first port of call should be a discussion with her GP. She will be in her late 30’s now. For ladies of this of age, it is the time in her life where a lot of changes in her body start to take place. A lot of other chronic conditions that commonly occur start to emerge as well. From her point of view, it is important to eliminate these first as most of these conditions are treatable.

The current diagnostic criteria require a three-month waiting period, and a batch of clinical tests to exclude these alternative conditions, and really if her doctor thinks what is happening is ME/CFS, then the next step is the local ME/CFS clinic in Sheffield.

I think given her history that she will be in a fragile state. The best thing she can do is to back off work now. One common finding in recent years is that many Leger ME group members have depleted vitamin D3. She needs her vitamin D3 levels checking by her doctor because although not directly the cause if ME/CFS, if her levels are depleted this can increase fatigue and pain. This should be carried out anyway as part of the diagnostic investigation of her health problem. If appropriate, her doctor could start her on a high dose of vitamin D3 for a short time, and then she would be maintained on 800 units a day. If she has difficulty with her GP, the vitamin D3 can be purchased over the counter. There is also a product called VegEPA which is specifically formulated for ME/CFS and that can make a difference with some people. VegEPA is not NHS prescribable.

Your daughter can still contact us if she wishes and take out membership of Leger ME. We can help her with the employers and other common issues like DWP matters if necessary.

Cover Photo
Dactylorhiza maculata, known as Heath Spotted Orchid. Taken on the north side of the Don Gorge.

Gillian Writes: I’ve been receiving some strange telephone calls over the past few weeks. They can occur anytime. When I pick up the phone a voice just says ‘goodbye’ and hangs up. Have you any idea about what is going on? The number displayed 016857498215, but when I call it back it just gives me an unobtainable tone.

This is a problem that many people experience. We think it’s malicious cold calling and a confidence trick to get money from you. We think that somewhere there is a mass dialer, which dials telephone numbers, hundreds at a time, and remembers if they have been answered. One member answered and reports that someone was contacting him claiming to be from BT Security about his computer.

In the version we heard the member had to allow a file download and allow it is run. The member was instructed to do things as though he were virus testing. Eventually after a while the computer stopped working, and he was advised *that for a fee of £300, they could get it working again. Fortunately, the credit card refused the payment, and the member was stuck with a computer that just displayed a message – with a phone number to call and have his credit card ready. Unfortunately, the operating system was corrupted and it cost money for a local computer shop to fix. Additionally, his internet link was mangled with malicious software which meant an new modem needed to be purchased. I've heard of this happening with some businesses, members phones and tablet computers. Where it happens to a business, it cripples that system making it cheaper to pay the ransom rather than get the system fixed and not being able to operate. Of course, the business couldn't operate until it was fixed and this would cause massive financially loses.*

Ooops, your files have been encrypted!

What Happened to My Computer?

Your important files are encrypted.

Many of your documents, photos, videos, databases and other files are no longer accessible because they have been encrypted. Maybe you are busy looking for a way to recover your files, but do not waste your time. Nobody can recover your files without our decryption service.

Can I Recover My Files?

Sure. We guarantee that you can recover all your files safely and easily. (But you have not so enough time.)
You can try to decrypt some of your files **for free**. Try now by clicking <Decrypt>.
If you want to decrypt all your files, you need to **pay**.

You only have 3 days to submit the payment. After that the price will be doubled.
Also, if you don't pay in 7 days, you won't be able to recover your files forever.

How Do I Pay?

Send 0.3 BTC to this address:
1QAc9S5EmycqjzzWDc1yiWzr9jJLC8sLiY

Just remember about the recent hack in the NHS system –and the Wanna Cry virus malware, and confusion that caused. So, what can you do to protect yourself.?

- *Phone wise it would be worthwhile purchasing a new 'phone with call blocking, a blacklist and a white list. Most mobile modern phones have this feature, but many wired phones don't. If you get a suspicious call, hang up.*
- *With computers, mobile phones and tablets ensure that you regularly update you operating system. The problem for the NHS was that the system which were blocked by Wanna Cry were Windows XP based which Microsoft stopped updating years ago. It didn't affect Windows 10 systems or example, the most recent version of the operating system.*
- *Install a third-party security software like Norton or MacAfee and ensure it is always updated. Beware of emails claiming to detect viruses or websites offering help. Many of the big banks offer free security software like Trusteer.*
- *Keep a regular backup of all important files on a separate hard drive. Do not leave it connect to the computer so that is cannot be hacked in the case of malware. This will allow file restoration.*

Jane Writes: Apart from having ME/CFS, I've just been diagnosed with type 2 diabetes (DM2). Since my doctor started me on metformin I've had tummy problems. They go away when the metformin is stopped. What should I do?

The first thing to do is to report this to you doctor or diabetic nurse.

I was at a health conference a few weeks ago on diabetes. Whereas in the past initially the 'medical fashion' was to treat early DM2 by diet alone, the research of many historical cases as found that the more intensive the early treatment the better the long-term outcome. Metformin has been around many years and the side effects are well known, but otherwise is safe and effective. The are several modified release variants which are intended to overcome this tummy side effect. Additionally, there are many manufactures of the medicines. All have different excipients like bulking agents, binding agents etc. which in some cases can cause the problems you are describing. Your doctor could prescribe by brand name e.g. 'Glucophage' and that would ensure that you always get the same formulation. There are plenty of other medicines around to treat diabetes, but I would recommend trying to stick with metformin if possible as it has a favourable side effect with ME/CFS via the AMPK system.

Joy writes: I seem to be have urinary tract infections one after another. They all clear up with antibiotics from my doctor—but no sooner one is cleared the next once starts. Any advice?

This is something many people with ME/CFS report. You need further investigations by your doctor as this could indicate your immune system is not up to scratch. It's also quite common in diabetes, hypothyroidism, and neoplastic disease. Once clear you could be re-infected by a sexual partner who is not showing any symptoms, so that needs checking out as well.

Welfare Rights Matters: Huge fall in DLA to PIP reassessments

With thanks to Work and Benefits

The number of Disability Living Allowance (DLA) claimants being forced to apply for Personal Independence Payment (PIP) has plummeted, DWP statistics released this week show. The DWP have said only that they are “managing capacity within the system.” The DWP PIP Official Statistics, published on 14th June show a massive drop in the number of claims registered in April 2017. Claims are registered either when a new claim is made or when a current DLA claimant is informed by the DWP that they must transfer to PIP.

For the current year, the number of PIP registrations was:

January 104,333
February 92,327
March 83,578
April 49,409

That means that there was a huge fall of over 50% in the number of registrations in April as compared to January. The explanation given by the DWP is that:
“In recent months reassessment registrations have decreased due to DWP managing capacity within the system.”

The DWP also claim that the number of new claims made in April was low due to Easter and a high number of weekends in April. Nonetheless, the main reason for such a drop must be that dramatically fewer DLA to PIP cases are being sent to Atos and Capita
.

To find numbers of PIP registrations as low as they were in April, you would have to look back to 2014, before the DWP began migrating claimants with indefinite DLA awards to PIP. We cannot know the precise number of DLA reassessments that took place in April, because the DWP do not give a monthly breakdown of how many registrations are new claims and how many are DLA to PIP reassessments. However, the DWP do give quarterly breakdowns.

So, we do know that in the three months to the end of October 2016, 158,400 DLA to PIP reassessments were registered.
In the three months to the end of January 2017, 178,300 were registered.
In the three months to April 2017, just 100,900 were registered.

So, there was a fall of 44% in the number of reassessments in the quarter to April 2017, compared to the quarter to the end of January. Most of that fall appears to have happened in April itself, meaning that reassessments must have plummeted by at least two thirds, if not more. The transfer of all working age DLA claimants to PIP was supposed to have been completed by April of this year. In fact, there are still around 500,000 DLA claimants waiting for the dreaded reassessment letter to drop through the door.

Benefits and Work
Guides you can trust

The DWP are clearly keen to get the transfer of DLA claimants completed, given that they are already so far behind schedule. The fact that they have had to call a temporary halt to the mass transfer of claimants suggests that the assessment providers may be failing to keep up with demand. It now seems likely that the transfer of all working DLA claimants to PIP will not be completed until sometime in 2018

Advice to members.

- *Do not fill out any DWP form without help from a welfare rights adviser.*
- *If you received a change over phone call or form contact us as soon as possible for guidance.*
- *Benefit and Work Guides are available for fully paid up members.*

Welfare Rights Matters and Mandatory Reconsideration Targets

When a member applies for welfare benefits there is a claim form to fill out. Then the big decision comes – fine if it is what you expect, but otherwise with a refusal you have a problem. The next stage involved a review or mandatory consideration. Unless further evidence is submitted at this stage, the decision is not usually not changed – and that then leads onto a tribunal.

I have for many years taken the view that only way to deal with the DWP is to flood them with evidence on the first application. The is why it is important to use a welfare rights advisor, someone who know the system. A couple of weeks ago the following was received from Benefits and Work

The DWP have as good as admitted that mandatory reconsiderations are a sham. In response to a recent Freedom of Information query, the DWP revealed that they have a target of upholding the original decision in 80% of all mandatory reconsideration requests. Worse still, they managed to exceed that target in the year to March 2017 by turning down 87.5% of all applications. The DWP have since claimed that PIP is not included in the 80% target. However, it remains the case that over 80% of PIP mandatory reconsideration requests also fail to get the decision changed however coincidental the DWP might claim that figure is.

Having a target for the percentage of requests that should fail almost certainly renders the mandatory reconsideration process unlawful. In legal terms, the DWP is fettering the discretion of decision makers, who should be free to decide every case on its merits, rather than worrying about being disciplined if they fail to hit their targets. Just how rigged mandatory reconsideration decisions are being made clear by one other statistic. 63% of claimants who have their mandatory reconsideration request turned down and who then go on to appeal to an independent tribunal, win their case. So, no matter what the decision is on your initial claim, and no matter how utterly you are turned down at the reconsideration stage, don't lose heart. You have a very good chance indeed of winning your appeal.

The only way I know to stack the odds in your favour is submit as many documents as possible. Please bring as many of these as possible to your appointment the sort of documents you need are as follows.

Your GP

☐ Record of Last Appointment with G.P. and make sure it was less than 3 months ago.
☐ Copy of Summary Sheet or NHS (Patient summary Record) from G.P. Surgery
☐ Copy of Repeat Prescriptions (MUR sheet, Prescription counterfoil or Surgery Printout)
☐ All medicines (conventional and alternative) you are currently taking irrespective of supplier.
☐ Copy of results of any tests e.g. Blood, or other diagnosis tests at the G.P. Surgery or Hospital.

ME/CFS/Fibro Specific

☐ Support letter from Sheffield, Leeds or another FMS/PVFS/ME/CFS clinic.
☐ 1 week Leger ME Daily Log sheet.
☐ Copy of appointment cards or letters from condition management clinic e.g. pain control clinic
☐ Copy of appointment cards or letters from condition management counsellor e.g. Clouds
☐ Copy of appointment cards or letters from community organisations e.g. SYCIL
☐ Copy of appointment cards or letters from private management clinic.

Other Conditions (All conditions must be stated no matter how trivial or minor as they all count)

☐ Support letter from Hospital or condition management clinic.
☐ Copy of appointment cards or letters from condition management clinic e.g. diabetic/asthma etc.
☐ Copy of appointment cards or letters from condition management counsellor e.g. Clouds
☐ Evidence of any medical devices or appliances used e.g. PFR or BM meter sheets and charts
☐ Evidence of use of any dietary or lifestyle management. (Diet, substance avoidance, pacing)

Daily Living

☐ Copy of appointment condition assessment or statement of care needs or letters from condition management clinic (e.g. Social services or SYCIL assessment report)
☐ List of any things used for cooking. e.g. kettle tipper, microwave oven. trolley
☐ List of any things used for continence control e.g. pads, commode, ostomy bags
☐ List of any things used for personal care e.g. Bath or shower aids, washing aid etc.
☐ List of any things used for night care e.g. Bedroom adaptations, bed hoist
☐ List of any things used for mobility. e.g. stick, scooter, wheelchair, blue badge, mobility car

Previous Claims or Tribunals

☐ Copies of Past Decision Letters, points breakdown, ESA 85 or portfolio as advised
☐ Copies of any appeal letters or other relevant documentation.

Support for DWP forms fillout is a membership service and well as access to work and benefit guides.

What are Antioxidants *(with thanks to Biocare)*

what exactly are antioxidants? We know we need them and we think they are good for us, but why do we need them? Why are they so crucial to help with preventing chronic disease and the ageing process? We use the term a lot, but do we understand what it means and its implications for health? Let's look…

An antioxidant is basically something that reverses or stops 'oxidation'. But **what exactly is oxidation?**

In scientific terms, oxidation is the gain of oxygen by a substance. Imagine a freshly cut apple or avocado turning brown, a nail becoming rusty or a copper statue turning green. These are examples of everyday oxidation. In most instances, the process of oxidation causes damage or destruction.

Oxidation creates **free radicals**, boisterous little things that have been freed from their usual home to go and wreak havoc in the neighborhood. These free radicals are unstable and need to be 'caught' before they can cause more damage to other healthy functioning cells. These free radicals negatively affect cell membrane health, proteins, and DNA expression which can trigger many human diseases. Antioxidants are our natural protectors.

Antioxidants are abundant in nature, because plants contain antioxidants to protect themselves too. The nutritional content of natural whole foods is just what our body needs to negate the effects of our own biochemical processes. However, we sometimes struggle to obtain sufficient antioxidants in the modern world due to a nutritionally deficient society – where urbanization, overuse of agricultural land, intensive farming, stress-fueled society and easy access to processed foods, we are unable to provide our body with the essential nutrition required to defuse this free radical activity.

Not only is it a natural process within that occurs within the human body but we also can take in free radicals from our environment. This can be in burnt or fried foods, chemicals as pesticides are in home and personal products and various other exposures through our environment.

Can you see now why antioxidants are implicated in healthy ageing, reducing the virulence of chronic disease, improving cognition and mental health and maintaining and improving general wellness?

So, what can we do to protect ourselves?

- Eat organic and/or local produce as much as you can afford.
- Base your diet on whole foods in forms of fresh fruit and vegetables and whole grains
- Minimise and ideally eliminate processed foods, usually void of any antioxidant nutrition.
- Keep a healthy mind by keeping it hydrated, happy and stress-free

Look after your gut. A healthy gut is a healthy body. Include key nutrients in your diet that help support high antioxidant activity, such as:

- **Turmeric** - containing the active ingredient **curcumin**. This spice is reputed to be antineoplastic, improving cognition and reducing the signs of ageing.
- **Vitamin C** - improves immune cell function (macrophages & T lymphocytes).
- **Vitamin D** - appears to enhance innate immunity and inhibits the development of autoimmunity
- **Grapeseed extract** - an excellent source of oligomeric proanthocyanins (OPCs). These antioxidant molecules have approximately 50 times more free radical scavenging ability than vitamins C and E. *Caution—his extract can interfere with conventional; medicines.*
- **Probiotics** – along with all the other reputed benefits of probiotics for digestive and immune health the friendly bacteria in our gut have been associated with reduced oxidation and inflammation.
- **Quercetin** - One of the most potent antioxidants that is used often by nutritionists to promote normal histamine release and support an overactive immune system.

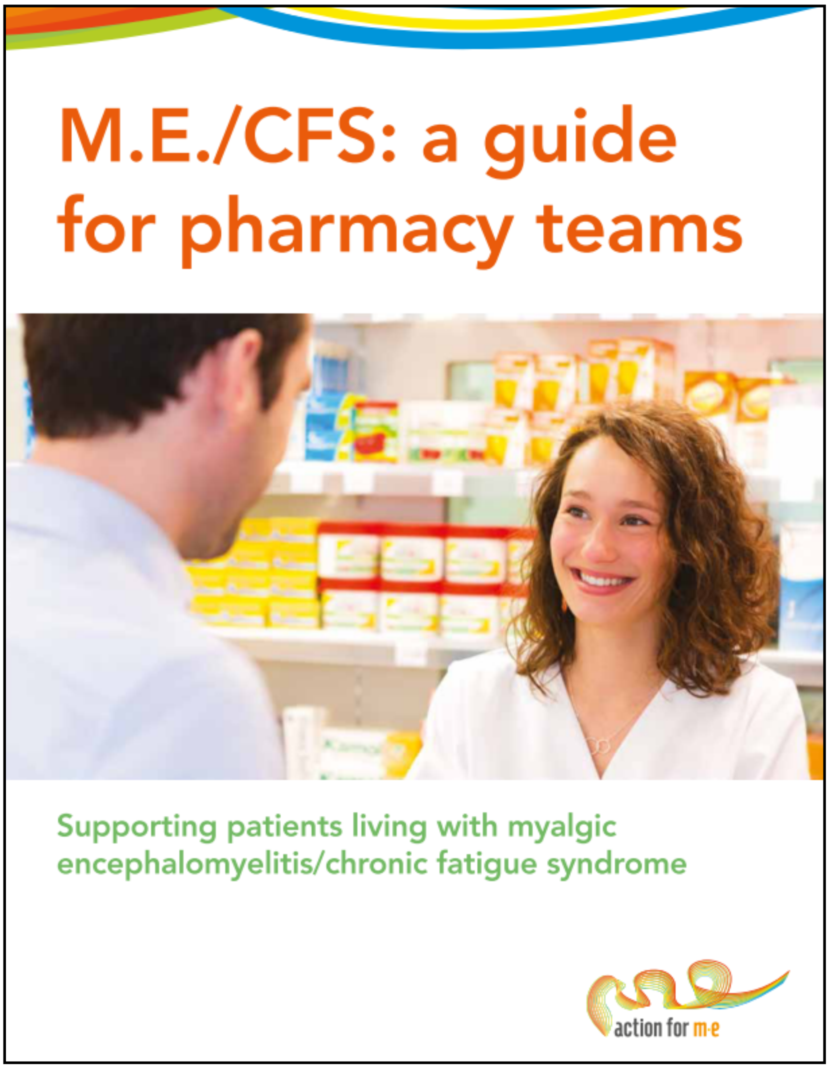
Publication Review: M.E./CFS: A guide for Pharmacy teams.

I was asked by Emma Bearsall, a professional colleague at 'Action for ME', a national charity supporting ME/CFS to review the original draft. Overall, I'm quite impressed by the outcome, and thanks go to AfME for a great publication. Apart from myself, two of my other colleagues, Stephanie and Mahindra have also had an input. I'm reproducing extracts that will be of interest to Pathways readers, but leaving out a lot of technical content. Copies of the original are available from the Leger ME Library or from Action f or ME, 42 Temple Street Keynsham BS31 1EH
T 0117 927 9551 E admin@actionforme.org.uk www.actionforme.org.uk

Thanks go *Action for ME

Essential M.E. facts

- M.E. is a complex, fluctuating, long-term condition affecting 250,000 men, women and children in the UK. A GP surgery with 10,000 patients will have around 40 people with M.E.
- Function levels for people with M.E. can range from being in work (this requires careful energy management) to not being able to wash or feed themselves.
- M.E. fluctuates in symptoms and severity, so people who seem well one day can be very unwell the next.
- The key symptom of M.E. is post exertional malaise, triggered by physical/ mental activity, so patients must carefully manage rest and physical/mental activity. General exercise programmes have no evidence base in M.E. and can cause harm
- M.E. is not easily recognisable from prescriptions alone as there's no specific treatment for the condition.
- Issues associated with multi-morbidity (other major health conditions) and polypharmacy (multiple medicines) are common in patients living with M.E.
- People with M.E. often have increased susceptibility to side effects, and the similarity of these and the symptoms of M.E., can result in misinterpreting them as new symptoms
- People with M.E. have difficulty accessing services, and pharmacy teams may be their only contact with health professionals. Support with ordering repeat prescriptions, deliveries and other pharmacy services can be invaluable
- Cognitive difficulties in M.E. can affect concentration and the ability to retain information, so offering a written summary, as per the Accessible Information Standard, is recommended, particularly for patients with severe M.E.
- You can refer anyone affected by M.E., including Carers, to Action for M.E. for information and support on all aspects of living with the condition, including applying for welfare benefits and accessing peer support.
- Call 0117 927 9551 or visit www.actionforme.org.uk



M.E./CFS: a guide for pharmacy teams

Supporting patients living with myalgic encephalomyelitis/chronic fatigue syndrome

action for m·e

Introduction

Myalgic Encephalomyelitis (M.E.) is a relatively common long-term condition with complex symptoms. It causes significant and, in some cases, profound disability. A lack of understanding and awareness about M.E. as a debilitating, physical, hidden illness means that patients can experience disbelief, and even discrimination, from friends, family, health and social care professionals and employers. Consequently, their health needs may be going unmet. We are hugely grateful to pharmacist and Action for M.E. volunteer, Emily Beardall, who wrote this resource and continues to devote considerable time, energy and expertise to engaging with health professionals and improving outcomes for people with M.E. Pharmacy professionals will be familiar with the guidelines for managing many of the symptoms of M.E. from other patients. For this reason, we have focused on special considerations when applying Pharmacies existing expertise to patients with M.E., non-pharmacological management, and the ways M.E. could affect delivery of pharmacy services for people with the illness.

What is M.E.?

Although the aetiology of M.E. is unknown, emerging evidence about the cause of M.E. includes autoimmune deficiencies, viral infections, autonomic nervous system dysfunction and genetic factors, among others. Evidence suggests a population prevalence of at least 0.2-0.4% which means that a general practice with 10,000 patients is likely to have up to 40 patients with M.E.1 They might be difficult to identify from their prescriptions because there is no specific treatment that is licensed for M.E. At present, there is only symptom management available, so you might see chronic pain, sleep, migraine, nausea, dizziness or depression treatments, among others, on prescriptions.

M.E. patients often have multimorbidity (multiple health problems), so even if they are not taking prescribed medication for their M.E. symptoms, you may still come across them. It is important to know how M.E. may affect the safe and effective use of medicines and the services you provide.

As a long-term, fluctuating condition, M.E. is categorised as a disability by the Equality Act 2010.3

Symptoms

There are many symptoms of M.E. affecting many body systems. See table. Not all patients will experience these symptoms all the time. Any new symptoms should always be checked, even if they may seem related to M.E. (see Red flags)

Symptoms can fluctuate and women with M.E. often find that symptoms worsen at different times in their menstrual cycle. If a patient appears better or worse at a given moment, this does not indicate a change in their overall condition. The characteristic symptom of M.E. which differentiates the illness from fatigue experienced in other conditions is post-exertional malaise, sometimes referred to as "payback." This is defined as the body's inability to recover after expending even small amounts of energy on simple physical or mental activity. The onset of post-exertional malaise is delayed for at least 24 hours or more, with slow recovery over several days. Some patients also experience widespread muscle and neuropathic pain, along with worsening of their other symptoms, as part of post-exertional malaise.

The fatigue experienced by people with M.E. is very different from ordinary tiredness or sleepiness. Simple physical and mental activities can leave patients struggling to function, and pushing through this can trigger post-exertional malaise. For this reason, the National Institute of Health and Care Excellence's guideline for M.E. (NICE CG53, see page 9) stresses that M.E. patients need to space out their activities and may find that their capacity is typically greater at a specific time of day.

Severity and function levels

NICE CG53 guidelines describes three levels of severity of M.E

.

- People with **Mild M.E.** are mobile, can care for themselves and can do light domestic tasks but with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits.
- People with **Moderate M.E**. 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 some of the time.
- People with **Severe M.E.** are unable to do any activity for themselves, or can only carry out minimal daily tasks (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. Complications can develop in severe M.E. as a result of being mostly bedbound, such as postural hypotension, deep venous thrombosis, osteoporosis, pressure sores and deconditioning.

Diagnosis

There is no specific single test to diagnose M.E., though potential biomarkers are being investigated. Diagnosis is currently made after other possible causes for symptoms have been excluded. This should be a positive clinical diagnosis based on well-characterised set of symptoms. These are post-exertional fatigue or malaise, cognitive difficulties, sleep disturbance and chronic pain, which have persisted for four months in an adult and three months in a child. Early diagnosis and management may aid recovery and prevent further worsening to severe M.E., so if you suspect from their symptoms that someone might have undiagnosed M.E., please refer them to their GP

Red flags (Danger Signs) for referral

Symptoms that can be caused by other serious conditions should not be attributed to an existing M.E. diagnosis as they may be part of an alternative diagnosis or comorbidity which should be investigated and treated. NICE CG531 lists the following red flags for referral:

- any new symptoms, including pain that is new or localised to a specific area
- sudden, unexplained weight loss - people with M.E. may have explained weight loss due to difficulty eating and this should be managed
- spatial disorientation
- localising/focal neurological signs
- signs and symptoms of inflammatory arthritis or connective tissue disease
- signs and symptoms of cardiorespiratory disease
- sleep apnoea
- clinically significant lymphadenopathy.

UK treatment guidelines

- National Institute for Health and Care Excellence (NICE) guideline CG53 and NICE pathway at www.nice.org.uk/guidance/CG53
- Scottish good practice statement on M.E./CFS, formally endorsed by RCGP (Scotland) and the Scottish Neurosciences Council at www.scot.nhs.uk/scottish-good-practice-statement-on-me-cfs
- Therapy and symptom management in CFS/M.E. published by The British Association for CFS/M.E. (BACME), a professional body for M.E. clinicians and multi-disciplinary teams, at www.bacme.info

Non-pharmacological (medicines) management

The following are used to manage the overall impact of symptoms as suggested by Treatment guidelines. *The local ME/CFS clinic is Sheffield majors on these.*

- Rest periods are a core component of all management approaches for M.E.; they can also be part of management of pain, sleep problems and comorbid stress or anxiety, especially for those who cannot tolerate medication.
- Pacing is a structured approach to managing activity and rest that people with M.E. repeatedly report that they find helpful.
- Research into the efficacy of individual dietary regimens has been inconclusive,7 so there is no specific dietary advice for people with M.E., though some report finding exclusion diets helpful, in which case a dietician should be referred to for advice on preventing malnutrition.1
- Graded exercise therapy (GET) may be helpful for a specific sub-group of patients, though some patients report adverse effects on symptoms and functioning.1-6 CG53 says GET should be completely avoided in people with severe M.E. and, for those with mild/moderate M.E., only be delivered by appropriately trained professionals. General exercise programmes are not evidence based for M.E. patients and can cause harm.
- Cognitive behavioural therapy (CBT) is used to support people through long-term conditions, including M.E. Its use does not imply that the cause of the illness is psychological but it can help some cope with the challenges of living with M.E.
- There is insufficient evidence regarding the use of complementary and alternative medicines (CAMs) to treat M.E. However, some patients report using complementary approaches to help them manage their symptoms, so being aware of this is important for checking interactions and reviewing medication.

The most frequently self-prescribed interventions were pacing, rest (including bed-rest), vitamin and mineral supplements, and dietary changes. Other symptoms are managed as in usual clinical practice.

Pharmacological (Medicines) management

There is very little evidence of the safety of pharmacological treatments in people with M.E. for symptoms or comorbid conditions, so the response may be unpredictable and should be monitored, for example with the New Medicines service. There are no treatments for the symptoms of post-exertional malaise, fatigue, cognitive dysfunction, or recurrent flu-like symptoms.

- It is recommended that sleep disturbances are treated if possible, as a priority. Low-dose tricyclics (e.g. amitriptyline up to 75mg) and/or anti-epileptics are used for their sedating and pain-relieving effects but guidelines state they should only be initiated after referral to specialist M.E. care, as these are unlicensed indications. Tricyclics are not effective as an antidepressant at this low dose. If sleep management strategies do not improve sleep, the possibility of an underlying sleep disorder such as sleep apnoea should be considered.
- Any vitamin deficiencies should be treated. For example, vitamin D deficiency, which may contribute to fatigue and pain, is common due to lack of sunlight, and the lack of weight-bearing exercise and possible dietary restrictions due to food intolerances.
- Drug treatment in children and young people with M.E. should be initiated by a paediatrician but may be continued in primary care. Drug treatments sometimes prescribed for children include melatonin, amitriptyline, gabapentin, NSAIDs and analgesia.
- There are a few drugs in clinical trials for M.E., including the disease-modifying anti rheumatic drugs (DMARDs) cyclophosphamide and rituximab, currently in phase III. Other trials include CNS stimulants, low-dose naltrexone, antibacterials, antivirals, and antihypertensive.

Issues with polypharmacy (Taking many medicines all at once)

A significant number of people with M.E. take medication for individual symptoms. One patient interviewed had 20 different regular prescription items to manage severe M.E. and co-morbid conditions. (other major health problems). Organising and taking medication, along with coping with side effects, may add to the burden of living with M.E. Although sometimes appropriate, polypharmacy could occur due to the following factors in someone with M.E. Please also refer to your region's relevant polypharmacy guidance.

- Managing numerous symptoms individually can result in many medicines being prescribed over time.
- People with M.E. can attend many different specialists, especially during investigations at the start of the illness to establish a diagnosis, and each may prescribe medication.
- Increased susceptibility to side effects, and the similarity of these and the symptoms of M.E., can result in misinterpreting them as new symptoms and medication being prescribed to alleviate them, resulting in a prescribing cascade.
- A high occurrence of multimorbidity (someone having more than one condition) can contribute to the number of medicines prescribed.
- Some symptoms may fluctuate over time, so it is possible that the indication for which medication has been prescribed is no longer current.

Delivering pharmacy services to ME/CFS patients

People with M.E. have difficulty accessing health services, and pharmacy teams may be the only contact they have with health professionals. Bear in mind, especially with new patients, that it's not possible to identify some with M.E. by their prescription alone. Even if they do not take medication for M.E. symptoms, you may come across them taking medication for comorbidities (other health problems), presenting for over-the-counter (OTC) medicines, or using one of your pharmacy's services. The following points and Common medication issues quick reference table the original documentation should be considered in the delivery of pharmacy services to people with M.E. We know that policies and procedures for pharmacy services may differ across pharmacy sectors and/or in England, Wales, Scotland and Northern Ireland. We have used general terms here, while acknowledging that there may be regional variation.

Ordering repeat prescriptions

The cognitive difficulties that come with M.E. can make it difficult to be organised and remember when to re-order medication, so assistance with ordering medication may be helpful, if this service is available. The patient could also be referred to their GP to organise NHS Repeat Dispensing.

Prescription deliveries

Many people with M.E. find prescription deliveries an invaluable service. Approximately a quarter of people with M.E. are housebound and those with mild or moderate M.E. may look well when they pick up their prescription, but can also have periods of being housebound. Driving can be hazardous and draining for people with M.E., and reaction times may be affected by medication, so they may have difficulty picking up their repeat prescriptions, especially if there is not a carer available.

Accessible information and communication

NHS England's Accessible Information Standard may apply to someone with M.E., depending on individual need. Cognitive difficulties can affect concentration and the ability to retain verbal information, so offering a written list of points covered is recommended, particularly for patients with severe M.E. Communication may be impaired by speech, concentration and word-finding difficulties, so people with M.E. may need to take their time and have longer consultations. Use of the consultation room, including for OTC consultations may be helpful, both for seating due to weight-bearing difficulties, and because many people with M.E. have light and sound intolerance so find it more difficult to concentrate in a busy environment. M.E. patients need to space out their activities to avoid exacerbating their symptoms and may find that their functioning is greater at a specific time of day, so consultations could be arranged to fit this.

Medicines Use Reviews

People with M.E. may benefit from a Medicines Use Review (MUR) in England to discuss any problems with their medication, such as side effects, remembering to take medication, polypharmacy, and other Common medication issues.

New medicines (Newly prescribed)

With the increased susceptibility to side effects, giving advice on what side effects to expect with any new medication, how to cope with them, and what to do if they cannot be tolerated, will likely improve adherence. Explaining that a low-dose antidepressant has not been prescribed for depression, but rather pain or sleep difficulties, is also likely to improve adherence. Patients would be eligible for the New Medicine Service (NMS) in England if the medicine is on the NMS medicines list.

Domiciliary (home) visits

Severely affected house- or bedbound patients with M.E. are unlikely to be able to come into the pharmacy for a MUR but might have complex medication problems, such as managing polypharmacy. NICE identified concerns that patients made housebound by severe M.E. received little or no care or support because they are unable to access potentially effective care. The guideline states these patients would benefit from domiciliary healthcare visits, so where possible a visit by a domiciliary medicines optimisation pharmacist could be helpful, especially for those with polypharmacy. Action for M.E.'s 2014 survey found that 63% of people with severe M.E. said home visits would make a real difference to their healthcare.

Common or minor ailments and OTC (over the counter) prescribing

People with M.E. often take a range of supplements and herbal medicines, which may cause side-effects or interact with prescribed medication. OTC preparations containing caffeine and other substances may not be well tolerated, so patients should be advised to purchase "plain" preparations with a single active ingredient to avoid potential side effects. Red flags for referral on page 9 details the circumstances in which a person with M.E. should be referred to their GP.

Flu vaccinations

People with M.E. may be eligible for the free flu vaccination service if they have comorbidities (e.g. asthma). Anecdotally, some people with M.E. don't want to have the vaccine because they are worried it might make them relapse. However, the vaccine has been shown to be both safe and effective in people with M.E.10 Research shows that many more patients who had never been vaccinated against flu reported fears of a relapse than those who had.11 Carers of people with M.E. will be eligible if they are in receipt of Carers Allowance, or if the welfare of the person they care for would be put at risk if he carer becomes ill.

Supporting Carers

Family and partners are the most frequent Carers of people with severe M.E. and community pharmacy teams can help make life a little easier for them. Advice on giving medicines might be helpful, such as when and how to give them, and what to do if the person they care for has difficulty taking medicines or using devices; it may also be helpful to invite a carer to attend an MUR with the patient. NICE CG53 (see page 9) recommends that people with M.E. should be offered information about local and national self-help groups and support for people with M.E. and their Carers

Signposting patients and carers.

Action for M.E.'s Online M.E. Centre (www.actionforme.org.uk) offers information, advice and support on most aspects of living with or caring for someone with M.E., including a searchable directory of local M.E. support groups and specialist healthcare services. The charity also offers printed information resources, specialist welfare benefits advice, and peer-support forums for children and adults affected by M.E.

Promotion of healthy lifestyles to people with M.E.

Although people with M.E. inherently live a relatively sedentary lifestyle due to their physical limitations, a study has shown that people with M.E. tend to live healthier lifestyles than the general population, possibly to manage symptoms, and that an unhealthy lifestyle does not influence the severity or duration of M.E.13 There are several factors to be considered when promoting healthy lifestyles to someone with M.E.

Diet

The effort required to buy food and prepare nutritious meals can mean that people with M.E. find it difficult to maintain a healthy diet. It can be made more difficult by loss of appetite or intolerance to some foods. If they are experiencing significant problems with their diet or struggling to maintain an adequate food intake, your patient with M.E. could ask their GP for a referral to a dietician.

Exercise

NICE CG53 states that advice to undertake unsupervised, or unstructured, vigorous exercise (such as simply "go to the gym" or "exercise more") should not be given, as it may worsen their symptoms.1 People with M.E. must pace themselves and stay within a safe baseline of physical, mental and emotional activity to manage their illness, and the patient is the most knowledgeable about their own limits.

Smoking

As nicotine is a central nervous system stimulant, someone with M.E. who smokes may have inadvertently self- medicated with nicotine to treat cognitive difficulties and symptoms related to the autonomic nervous system, such as gastrointestinal symptoms. Being aware of these issues may help health professionals support people with M.E. to quit and allow the patient to be more prepared so that they can manage any changes in symptoms.

Alcohol

Some with M.E. report intolerance to alcohol, with consumption exacerbating their symptoms.

Research has found that 38% reduce their alcohol intake and around a quarter stop drinking alcohol altogether.14 Tolerance may improve as symptoms improve and it would be advisable for people with M.E. to be aware of the depressant effect of alcohol, considering depression is a common comorbidity (additional major health problem).

Information tables
The original content then includes a number of quick reference tables on Pathophysiology, Symptoms and management of common medication issues.

Problems remembering medication
Cognitive dysfunction affects memory and concentration, and can cause confusion, so tips for organising and remembering to take medication may be helpful.
Non-adherence Medication issues such as side effects, dysphagia, previous experiences with medication, and the burden of polypharmacy are potential contributing factors to non-adherence in M.E. patients. Shared decision making and an open dialogue about treatment preferences, concerns and previous experiences should take place throughout care and could avoid non-adherence.

Case studies
One the original document there are case studies. These case studies use a combination of information from people with M.E. who kindly volunteered their medication histories, with their names changed. These are listed in full in the original document.

References
A comprehensive list of references is available on the original document.

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Recipe Corner *by Carolyn*

Zingy salmon and brown rice salad

Preparation time: 15 mins
EASY Cook: 25 mins
SERVES 3-4
Nutrition: Kcal 497, Fat 15g, Saturates 3g, Carbs 61g, Sugars 6g, Protein 34g

Cooking Method

Heat the oven to fan 170 or equivalent, and while it is heating up place two lengths of tin foil on a baking tray, put a salmon fillet on each of the lengths and fold along the top, then fold up edges to make a parcel of each fillet which will not leak any juices. Place them half way up the oven on the baking tray and cook for 15/20mins.

When they are cooked allow to cool slightly, remove the skin with a fork and then flake the salmon.

Cook the rice following the pack instructions and 3 minutes before it is done add the soya beans. Drain and cool under cold running water. Gently fold the cucumber, spring onions, coriander and salmon into the rice and beans.

In a separate bowl, mix the lime zest and juice, chilli and soy sauce, then pour over the rice before serving.

Ingredients

200g brown basmati rice
200g frozen soya beans, defrosted
2 salmon fillets
A cucumber, diced
Small bunch spring onions, sliced
Small bunch coriander, roughly chopped
Zest and juice of 1 lime
1 red chilli, diced and deseeded or a sprinkle of chilli powder to your taste
4 teaspoons of light soy sauce

Supplementary Personal Notes for the Leger ME Lead

by Mike Vakentine

- As well as being a Pharmacist I am the Doncaster ME group chair. I have many private patients who I see mainly for welfare rights matters. The first thing I do is ask for copy of the patient summary record.

- Almost all the ME/CFS patients I see have a family history of atopic tendency – so somewhere there be a history of asthma, psoriasis, coeliac disease or eczema. If this history is absent, I am always a little cautious about the accuracy of the diagnosis.

- About 40% of our members are asthmatic, mainly of the seasonal kind. Many use inhalers (mainly SABA) from a relative to save prescription charges. I frequently refer these people to the practice nurse for a check-up. Usual inhaler technique checks show up difficulties with dry powder inhalers which require more effort to use.

- About 20% of our members are diabetic or have glucose intolerance. Some ME/CFS have unstable blood sugars where 'hypo' symptoms are present at normal blood sugar levels. It is possibly related to reduced HPA Activation (Demitrek et al 1992). Many of the patients I have known for 20 years plus have slipped into type2 diabetes than would be expected as a proportion of the general population.

- Many patients I know report faster heart rates than would be expected compared to the normal population. When patients have had investigations, no serious pathology has been found. IA beta blocker may be prescribed but very often increases fatigue. f possible I encourage a yearly MOT with a patients GP.

- I find that in cold damp weather with a weather depression system that patients are worse, and are far better when the weather profile is anticyclonic.

- Most people with ME/CFS have low or borderline thyroxine levels and it is always worth checking that the GP has checked T4 levels. Some patients are prescribed T3 and Armour thyroid privately – but be careful because it is difficult to know if these are a psychological crutch or a real treatment is unclear. There may be thyroid resistance.

- I treat IBS (irritable bowel syndrome) as a complication of ME/CFS and likewise reactive depression.

- Many people with ME/CFS have a history of allergies and sensitivity to volatile organic compounds (e.g. perfumes). It is worth checking for these. Allergic profiles tend to drift and change. Many patients report patch tests inconclusive. However standard allergic treatment very often helps. Many patients resort to private clinics.

- Many ME/CFS patients have high blood lipids. Very often statins are prescribed, and many will not comply because of increased fatigue, possibly because of Ubiquinone (Coenzyme Q-10) depletion. Simvastatin is the worst, and Atorvastatin is less so
.

- I ask my patients to have their Vitamin D level checked by their GP if it has not been done. In many cases when corrected fatigue and pain have been significantly reduced.

- In the absence of other neurological conditions, fasciculation, myoclonus and non- epileptic absence seizures are markers for poor pacing. This very often confuses many health professionals.

Research Cormer: Could we finally have a definitive biomarker for ME/CFS ?

With Thanks to ME Research UK

It’s a recurring theme, but the diagnosis of ME/CFS is severely hampered by the lack of a test that can distinguish people with the illness from those without. This is a challenge in many diseases, but particularly in ME/CFS which affects so many different systems of the body. ME/CFS is currently identified by the presence of specific signs and symptoms, but there are several different criteria in use, and much debate over which are the most precise or appropriate. The quest for a biomarker is therefore a top priority since an accurate diagnosis is essential for patients to receive the medical care they need.

Generally speaking, biomarkers are measurable substances or processes in the body that can indicate the risk, presence or severity of a disease, or how well it will respond to a specific treatment. For example, a high white blood cell count may indicate the presence of an infection, while raised levels of prostate-specific antigen in the blood are associated with an increased risk of prostate cancer. Researchers have looked at a number of different measures as potential biomarkers for ME/CFS, including brain imaging findings, ECG abnormalities, and immunosignatures based on antibodies in the blood.

In fact, ME Research UK has recently funded work to look for an immunosignature that can predict patients’ responses to rituximab therapy. New research from a team in Australia, led by Prof. Brett Lidbury at the Australian National University in Canberra, has added another potential biomarker to this list. Prof. Lidbury has a longstanding interest in the search for biomarkers for ME/CFS, and ME Research UK recently awarded his group funding to analyse genetic data which might provide clues about the mechanisms of the disease. But in this recent study, published in the Journal of Translational Medicine, the team focused on a different potential biomarker: activin.

The two types of activin (A and B) are produced in several organs in the body, and have a number of different roles, including regulation of the menstrual cycle, and involvement in metabolism and wound repair. Prof. Lidbury is interested in two of its functions which have particular relevance to ME/CFS, namely the control of inflammation and muscle mass. Inflammation is important because the immune system is thought to be involved in the illness, while muscle mass will have an obvious influence on muscle weakness and pain.

The researchers took blood samples from 45 patients with ME/CFS (as defined by the Canadian Diagnostic Criteria) and from 17 healthy controls. Concentrations of both activin A and activin B were measured (as they have some different functions), as well as follistatin (a binding protein that regulates levels of activin). Levels of activin B in the blood were markedly higher in the ME/CFS patients than in the healthy individuals (and also higher than in a previously studied normal group), whereas activin A and follistatin levels were no different.

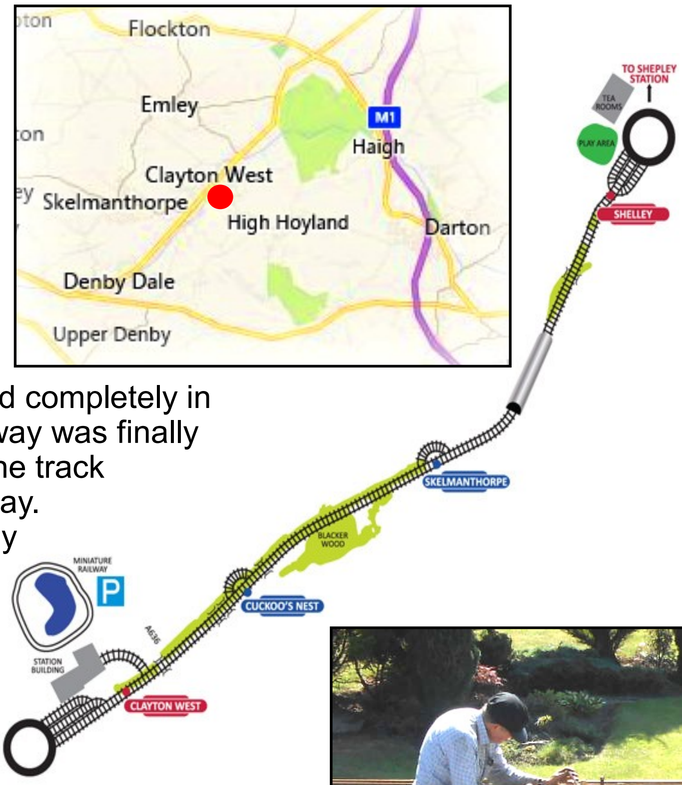
This exciting finding suggests that the combination of elevated activin B and normal activin A may represent a useful biomarker for the presence of ME/CFS, although this would need to be validated in larger groups of patients. Another intriguing prospect is whether follistatin might have some value as a treatment for ME/CFS since it can inhibit the actions of activin B. In fact, follistatin could have a two-pronged attack because it also blocks myostatin, a protein that inhibits muscle cell growth.

Prof. Lidbury’s study has certainly borne fruit, giving us a potential diagnostic biomarker for ME/CFS, as well as some hope for a new treatment. It’s early days on both fronts, however, so we will be keeping a close eye on further developments from this group.

Follistatin also known as activin-binding protein is a protein that in humans is encoded by the FST gene. Follistatin is an autocrine glycoprotein that is expressed in nearly all tissues of higher animals.
Its primary function is the binding and bioneutralization of members of the TGF-β superfamily, with a particular focus on activin, a paracrine hormone.
An earlier name for the same protein was FSH-suppressing protein (FSP). At the time of its initial isolation from follicular fluid, it was found to inhibit the anterior pituitary's secretion of follicle-stimulating hormone (FSH).

Out and about: The Kirklees Light Railway

The Kirklees Light Railway opened to the public on the 19th October 1991 but the foundations of the line date back to the mid 19th century at the time of rapid expansion by railway companies which led to colourful politics and protectionism. Previously it had been a branch line with two thriving communities each with a colliery to serve. Coal traffic was the backbone of the railway and ensured that it survived Dr Beeching's modernisation plan of the 1960s which saw many similar lines closed. The coal traffic ceased completely in 1979 and with dwindling passenger numbers the railway was finally closed in 1983, the track being lifted during 1986. The track bed has been re-laid as a 15 inch narrow gauge railway. Currently it is privately owned focusing on a family day out attraction rather than a preserved heritage railway. There are two request stop stations as well as two min stations. The Clayton West site has a big car park and is the most accessible from then Barnsley side.



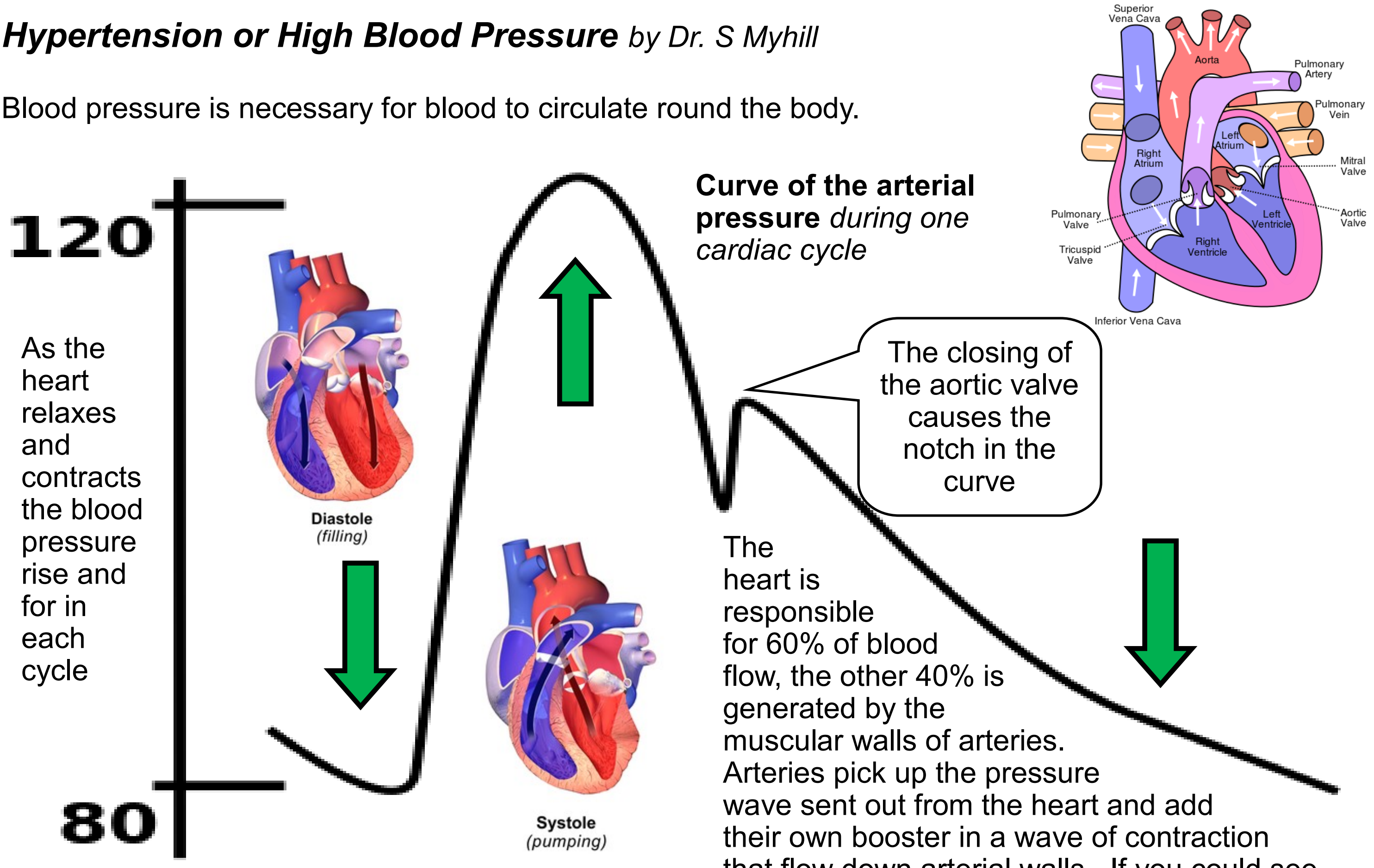
On the day we visited, it was a very hot sunny day in June. The car park is more than ample with disabled spaces. However there is a 300 yard walk to access any of the facilities. We passed a steam enthusiast loading coal into the model engine with a teaspoon. The is a booking hall/shop, café with outdoor spaces. A old DMU has been converted into a children's event room. A number of specifically built steam engines operate the railway. The carriages are either open air or enclosed. They are about two seats wide and the suspension is basic. People in wheelchairs cannot be accommodated, but a portable wheelchairs can be carried in the guards van. The first part of the route is in a high embankment, with views of the surrounding area. Emely Moor TV mast is a prominent feature.

The gradient is steep and makes the engine work hard the to intermediate stops are request stops and passing places. After Skelmanthorpe the line goes into a cutting and then a tunnel. The tunnel is wide enough to take two standard gauge tracks. It is dark and the echo of the engine reflect uncannily off the walls. If you were I like ourselves in an open carriage the whistle is deafening. You also get dust originating from the smoke in your hair! The tunnel itself could be very useful for Murder Mysteries, Halloween and Santa Grotto trains. After exiting the tunnel, we ride on an embankment until reaching Shelley station. Here, like at Clayton West, there is a kids playground with suitable amenities. The turn around time is about 15 minutes. On arriving back at Clayton West we had food in the open air part of the café. Walking on the way back to the car we passed a guy with a model tram giving rides on the model railway. The model steam guy was still feeding his model engine with teaspoonfuls of coal….

Verdict: A good local afternoon out, about 25 miles from Doncaster. Apart from the issues about poor wheelchair accessibility on the train it should be fine for most of our members. To get the best out of the day—take a couple of kids.

Hypertension or High Blood Pressure *by Dr. S Myhill*

Blood pressure is necessary for blood to circulate round the body.



Curve of the arterial pressure *during one cardiac cycle*

As the heart relaxes and contracts the blood pressure rise and for in each cycle

The closing of the aortic valve causes the notch in the curve

The heart is responsible for 60% of blood flow, the other 40% is generated by the muscular walls of arteries. Arteries pick up the pressure wave sent out from the heart and add their own booster in a wave of contraction that flow down arterial walls. If you could see arteries working they would look like wriggly snakes!

Blood pressure is created as a combination of three factors, in order of importance:

1. Peripheral resistance - i.e. how open are the arteries and smaller blood vessels.
2. The output of the heart.
3. The blood volume. Anaemia or diuretic drugs reduce the blood volume.
4. The "thickness" of the blood - if there is too much blood (as in smoking) the pressure will be high.

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While to little pressure causes fatigue, high blood pressure is dangerous

Causes of high blood pressure

Arterial narrowing. Arteries can be narrowed for two reasons. Firstly they may be narrowed and stiffened as a result of arteriosclerosis. If this is the case, then the blood pressure is fairly fixed and there is a wide pulse pressure reflecting stiff arteries - that is to say, the difference between the top reading (systolic) and bottom reading (diastolic) is high. A typical reading would be 170/100. Furthermore every time it is measured it is about this level. These are the hardest patients to treat since all one can do is prevent deterioration by aggressively tackling the arteriosclerosis. These patients need drugs to keep their blood pressure down and prevent accelerating arteriosclerosis, whilst one puts in place nutritional interventions.

The second reason for arterial narrowing is spasm or thickening of the muscle walls. This is what happens in the early stages of high blood pressure and this is reversible. There are several reasons for this spasm. Firstly hypo glycaemia (low blood sugar) causes stress and adrenalin release.
Stress - causing adrenaline release. Lack of sleep could do this, especially sleep apnoea syndrome. Secondly allergies, thirdly Mineral imbalance, especially magnesium deficiency and excess salt (sodium) in the diet, fourthly Hypothyroidism (low thyroid hormones). Other hormones cause this particularly female sex hormones as in the Pill and HRT - cause muscle thickening.

You can tell the difference between the two causes of blood pressure by measuring your blood pressure regularly. Arteriosclerosis causes a fixed blood pressure and wide pulse pressure (because the arteries are stiff and do not absorb the pressure wave created by the heart beating). Muscle spasm causes a variable blood pressure with a narrow pulse pressure (e.g. 120/90 one day, 135/104 another). In practice, the two problems often co-exist and all the possible causes of high blood pressure need tackling at the same time.

The problem with spasm of the arteries is it creates local high blood pressure, this increases turbulence of the blood within vessels and this damages the delicate lining of the blood vessels. Arteriosclerosis is the body's attempt to heal and repair this damage. It is essential to do this to prevent the blood vessel bursting. The healing and repair involves sticking a fibrous patch over the damage and this scar tissue slightly narrows and stiffens the artery resulting in permanent narrowing. The point here is that the reversible reasons for arterial narrowing result in the irreversible reasons for arterial narrowing! Once one has this irreversible narrowing, prescription medication is an essential part of treatment otherwise further damage caused by high blood pressure results.

Hypoglycaemia in my view, is the single most important cause of high blood pressure. The problem with sugar and carbohydrates is that they are addictive. In the short term a high blood sugar brings desirable effects on the brain because it allows the brain to work efficiently whilst at the same time releasing the happy neurotransmitters that improve mood. We all lead stressful lives and in stressful situations one needs one's brain to be working efficiently but feeling cool, calm and chilled out at the same time. To achieve this we go for our comfort foods which nearly always are comprised of carbohydrates such as chocolate, sweets, crisps, bread, bananas or whatever. The problem with running a high blood sugar is that it is potentially damaging to muscles. The little arteries that supply blood to muscles constantly monitor levels of blood sugar and if the levels rise too high then these arteries will contract, thereby cutting off the blood supply to muscles, increasing the peripheral resistance and this results in high blood pressure. At the same time insulin is released to bring the blood sugar down, which it does by shunting sugar into fat. So the sufferer tends to gain weight easily. As the blood sugar falls, the sufferer ends up with foggy brain and inability to think clearly combined with irritability and mood swings and therefore goes for their comfort food again, and so the cycle repeats itself.

Rare causes of high blood pressure

These should always be considered at the first sign of high blood pressure, but in practice they are often overlooked because they are uncommon causes. However, especially if your blood pressure does not respond to treatment, then they should be reconsidered as causes:

- Any kidney disease - These can be checked in the doctors surgery with multistix urine testing.
- Overactive thyroid - diagnosed by blood test for thyroid hormones.
- Overactive adrenal gland as a result of a tumour (phaeochromocytoma). This is suspected if there are recurrent odd attacks of flushing, sweating, anxiety, headache and/or palpitations. May be misdiagnosed as a panic attack. This is tested for by doing \urinary VMA.
- Overactive adrenal gland as a result of autoimmunity - Cushing's syndrome. Check for by doing blood cortisol level.
- Overactive adrenal gland causing Conn's syndrome (very, very rare!) - low blood potassium levels. This test cannot be done on a sample from the doctors surgery, and needs to be sent to hospital.
- Poor blood supply to the kidneys (renal artery stenosis) can present with high blood pressure. A narrow aorta causes the same problem for the same reason. These diagnoses are difficult to make - they must be suspected clinically and tested for by rapid magnetic resonance angiography in hospital.

Thus the carbohydrate addicts end up with middle-aged spread, high blood pressure, mood swings and fatigue. In the longer term these are all major risk factors for heart disease, cancer and accelerated ageing.

Stress. Arterial muscle spasm is a normal response to stress. Homo sapiens evolved leading a very physical life fraught with danger. He had to be able to react, at a moment's notice, to physical danger. This would mean some intense physical activity - running, fighting or whatever. To prepare for this the heart would beat faster and stronger and the arteries would narrow to "hold back" the extra blood (thereby creating blood pressure) so that the blood could be made immediately available to wherever it was needed - usually the muscles. So there would be a momentary rise in blood pressure, followed by a fall as the blood was utilised. These changes would be mediated by the stress hormones adrenaline, noradrenaline and in the longer term cortisol.

The trouble nowadays is that we have plenty of stress, which causes the "fight or flight" response, but we don't burn it off. So we have high circulating levels of stress hormones which cause blood pressure through muscle spasm. This probably explains why the "type A" personality (the aggressive go-getter) is more prone to arteriosclerosis. The problem is compounded when the go-getter turns to sugar, fast carbs and junk food or alcohol or smoking to help control his/her stress symptoms.

A certain amount of stress is good for you. It is a case of getting the balance right.

Allergies to foods and chemicals can certainly cause arterial muscle spasm. Indeed, this is the mechanism by which allergies cause migraine. Allergies to foods can also cause the heart to go faster and, in some cases, palpitations.

Mineral imbalance. Magnesium is necessary for muscles to relax. So a deficiency will cause arterial muscle spasm with consequent rise in blood pressure. Calcium probably also has a lesser role. It has been known for years that drinking hard water (rich in calcium and magnesium) is protective against the development of heart disease.

Salt (sodium chloride) has long been recognised as a cause of high blood pressure. The trouble is that the food industry loves to add salt to food firstly because it disguises poor quality food, secondly because it makes you thirsty so you then need to buy an expensive drink - wonderful for profits!

Kidney problems Blood pressure is largely controlled by the kidneys - they do this partly because they must secure a good energy supply for themselves! The kidneys consume a lot of energy and are highly dependent and sensitive to regular good energy supply - if this falters the kindey fails. To prevent this they will increase the blood pressure via hormones renin and angiotensin to secure a sure energy supply. Anything that compromises mitochondrial function therefore will impact on the kidneys and their response to this could result in high blood pressure. Indeed many drugs used to control blood pressure inhibit these hormones.

Another issue has to do with heavy metals. The kidneys are a favourite dumping ground for heavy metals. This may cause problems for two possibly reasons - firstly direct toxicity by inhibiting mitochondria. Secondly heavy metals may act as haptens to switch on allergy and/or auto-immunity. This results in useless inflammation which gets in the way of normal renal function. The glomerular filtration rate will slow - an early sign of kidney disease.

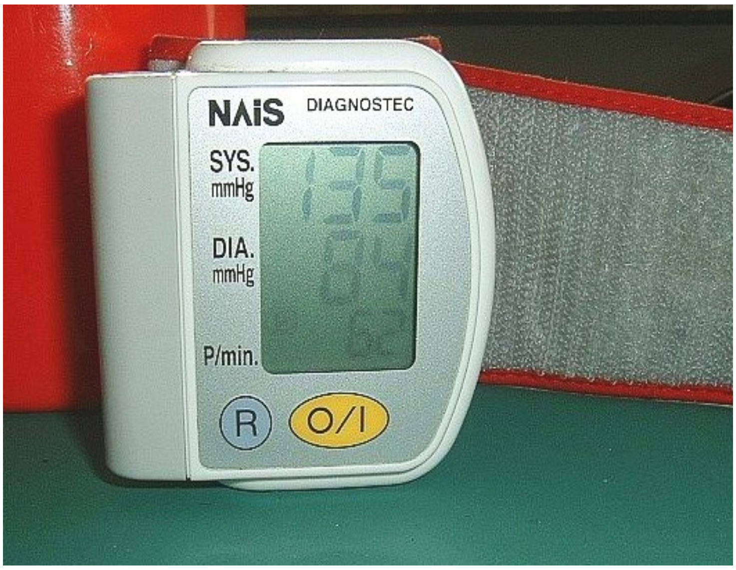
Making the diagnosis of high blood pressure

Measure it. I would want to see at least three readings consistently high before diagnosing high blood pressure. You could leave this to your doctor. The only problem is that some people suffer from "white coat" hypertension, ie the stress of going to see their doctor puts their blood pressure up. The other possibility is to measure it yourself. There are now many excellent idiot proof blood pressure cuffs on the market and this is the best solution. It also helps you to identify situations where your blood pressure peaks - so, for example, you would be more likely to pick up an allergy problem (often allergic reactions are accompanied by an increase in pulse rate and this would also raise blood pressure).

In the early stages of raised blood pressure it is possible to correct the problem with nutritional interventions. In the late stage, when the arteries are stiff with arteriosclerosis, the nutritional inputs will do no harm but may not reduce blood pressure. At this stage one is in a vicious cycle of impaired blood supply to the kidneys resulting in a release of hormones that increase blood pressure (in an attempt to increase renal perfusion). This causes further damage to blood vessels! So late stage high blood pressure, especially when accompanied by kidney disease, does require medication. The problem is that most doctors treat all cases of blood pressure as if they were late stage problems, thus committing many people to lifelong medication when, in fact, simple nutritional interventions would do the trick. Again early hypertension is a warning sign that not all is well!

Measurement of Blood pressure

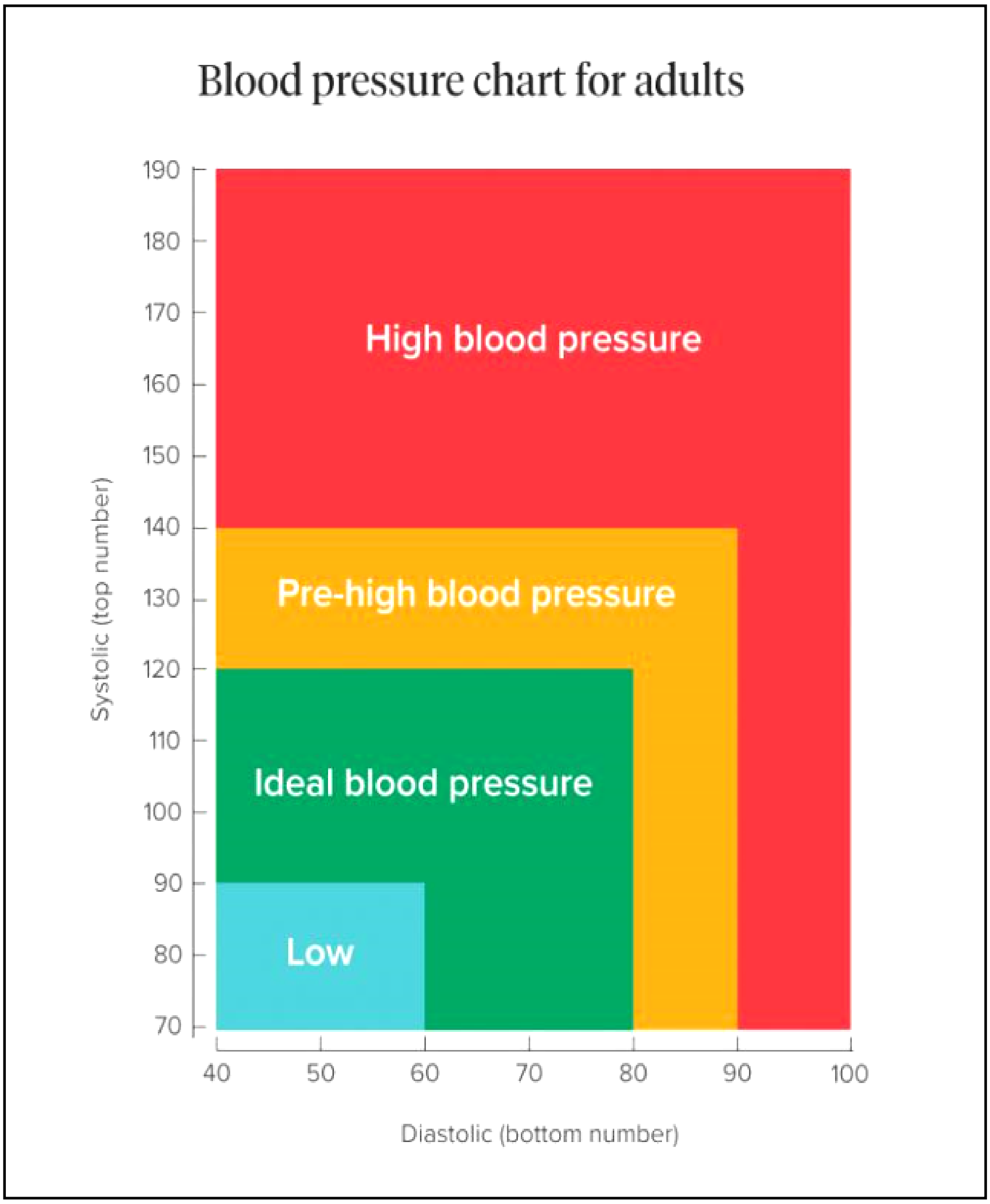
Normally blood pressure readings are take with a sphygmomanometer. There are two basic types. The first on the left is usually used by a health professional. While the second a typical automatic type suitable for home use. A series of reading are takens with both types before and treatment decisions are made.



What blood pressure readings mean?

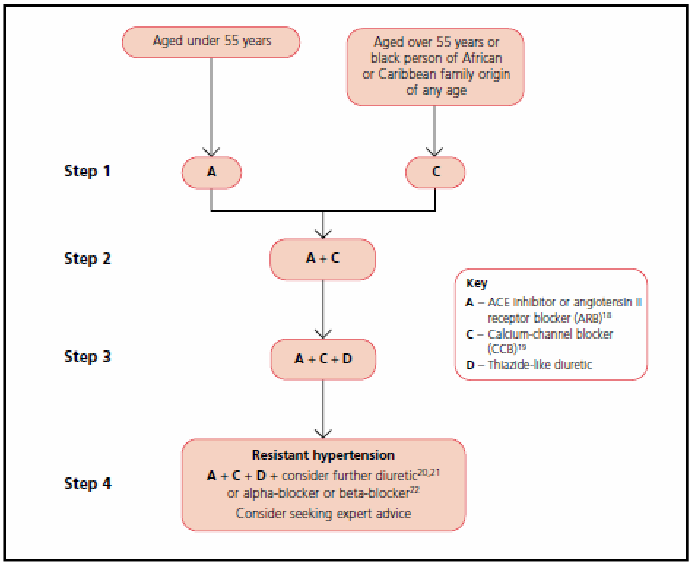
As you can see from the blood pressure chart, only one of the numbers has to be higher or lower than it should be to counted as either high blood pressure or low blood pressure:

- 90 over 60 (90/160) or less: You may have low blood pressure.
- More than 90 over 60 (90/160) and less than 120 over 80 (120/80): Your blood pressure reading is ideal and healthy.
- More than 120 over 80 and less than 140 over 90 (120/80-140/90): You have a normal blood pressure reading but it is a little higher than it should be, and you should try to lower it.
- 140 over 90 (140/90) or higher (over a number of weeks): You may have high blood pressure (hypertension).



Treatment of High Blood pressure (Hypertension)

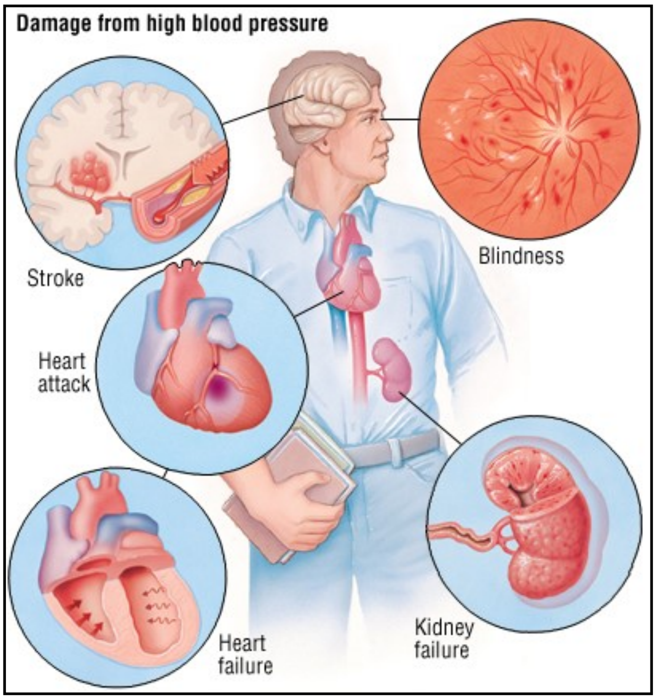
High blood pressure is not usually something that can be cured, but it can be managed successfully. Medications used to lower blood pressure are known as antihypertensive. There are a large number of different types of antihyptensives, all working in different ways within the body to lower blood pressure.. The table on the right is the most recent at the times of writing. Antihypertensive medices come in families, and clinic 'fashions' change with time and are different for each area.



Implications nationally.

Hypertension is very common, affecting up to 1 in 4 of the adult population of the UK . A small number of people have what is called secondary hypertension, which means that there is an underlying cause of their high blood pressure. However, for most people there is no definite cause of their high blood pressure and it is classed as 'Essential. Some groups of people with certain lifestyles or hereditary factors are more likely to develop hypertension. These include:

- Those with a family history of high blood pressure
- Men - men are more likely to develop hypertension than women
- Ethnicity- black African, Caribbean and people from the Indian sub-continent are more likely to develop hypertension
- Those with an unhealthy lifestyle - people who are overweight, eat too much salt and not enough fruits and vegetables, take little exercise, drink too much alcohol and caffeine or smoke are more likely to have high blood pressure
- Older people - blood pressure tends to rise with age
- Those who suffer from stress



Symptoms

Usually the only way to know if someone has high blood pressure is to have it measured. Most people cannot tell if their blood pressure is high any other way. It is recommended that all adults should have their blood pressure measured at least every 5 years. Those with high normal values or with other risk factors such as diabetes or smoking should be measured at least annually.

Lifestyle interventions

- Give up smoking
- Cut down on the amount of salt you eat - no more than 5 grams a day.
- Don't add salt to food at the table or in cooking
- Avoid eating salty, processed foods
- Keep alcohol intake below the recommended limits
- If overweight try to shed a few pounds
- Eat a diet low in saturated fat and high in fibre
- Take regular exercise

High Blood Pressure and ME/CFS

High blood pressure is not part of the ME/CFS problem profile. If you are found to have it, it is a separate problem which can be treated.

The most common ME/CFS patient with hypertension are usually type 2 diabetics.

Garden Watch – Springtime by Carolyn

When I last wrote it was still cold and after that it became dry, very dry, and then a few weeks ago it rained for days. People I met kept saying to me `isn`t the weather awful` and got the reply `no, it`s wonderful` and yes, I did get some funny looks!

After much extra watering the native bluebells planted in the orchard strip last year did put in a first appearance, I had planted 50 and 40 came up which is a good start and I am hoping for a better display next year, but the real excitement on the orchard strip this year is that for the first time since Mike planted it in 2010, the half Victoria Plum/half Greengage tree has fruit growing. Which half is fruiting we are not quite sure but hopefully we will soon find out – my money is on the Plums! (This is now the first year that we have all the trees in fruit, Plum, Pear, Apple, Cherry and the Blackberry bush is doing well too.)

The Aquilegia have been lovely this Spring and the bees have been busy gathering nectar from them. I need to add some other colours for next year. Does anyone grow a pink or white they could recommend?

Along the trellis on the side border Clematis Tibetana Tangutica (I know, it is a mouthful) easier to remember as `Bill MacKenzie - Orange Peel` is just coming into full bloom now at the end of May with its yellow bell shaped flowers and delicate leaves. It will flower through to September and after that will come a show of silvery seed heads which are as striking as the flowers. It is a very good value clematis one of the best for training over a wall, trellis or archway. Two ladybirds were mating on one of flower heads the other day and what was interesting was that they were very different in the spots on their backs. Made me wonder which one is native and which one is the interloper?

A new summer container on the patio is planted up with `Centradenia`, shades of dark rose and mauve along with `Blue Bacopa`, a pretty trailing plant already in bloom.

The front garden is still a project in frustratingly slow motion due to `no energy left usually`, but the good news is that the two Maples in planters beside the front door are doing really well this year.

Avian Garden Visitors

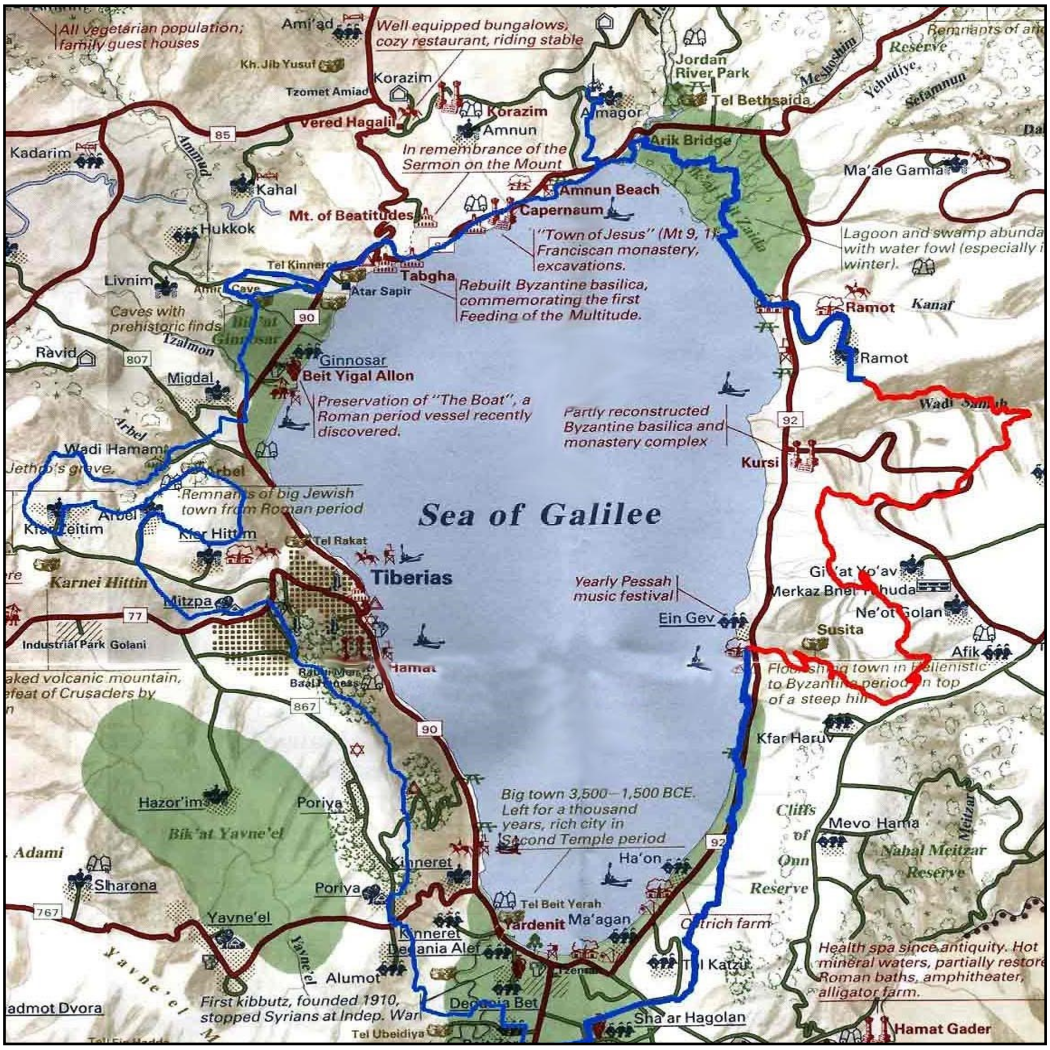
The bird feeding station has still been busy, especially through the very dry spell when they couldn`t get worms etc., I just kept feeding them, though slowly reducing the food for them as time goes on. It was lovely to see Blackie and Squirrel having a feed together the other day. I don`t encourage Squirrel but she tends to appear when peanuts are around! The hedgehogs have returned which is an absolute joy though they are shy and so far I haven`t been able to get a picture of them. I bet we have bats in the garden at dusk very soon but there is no way of photographing them, far too fast! *Happy Gardening*

North of Doncaster by Trevor Wainwright

A travel diary to the Holy Land Part 3: Mount of the Beatitudes, Capernaum and Sea of Galilee

The morning began with the customary cup of coffee on the balcony. After breakfast, we boarded the bus. After a short ride, we found ourselves walking through the gardens, flowers in bloom and with views of the lake.

We made our way to the church a modern day church built near the site of the fourth century Byzantine ruins, Neo-Byzantine in style with an octagonal floor plan the eight sides representing the eight Beatitudes. We were free to have a look round, before our open-air service, on entering my attention was drawn to a picture of Jesus preaching, looking up I saw the dome was also octagonal with a beatitude on each of the surfaces, in Hebrew. This was followed by a walk round the gardens again where we saw the beatitudes written in both English and Latin. Another highlight of the garden was a small fountain with a text based on John and a mosaic of two fish depicting Jesus saying to his disciples "I will make you fishers of men".

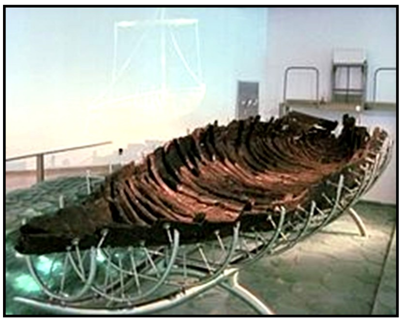


We set off to visit Tabgha. This is where the Church of the loaves and fishes, where Jesus is believed to have fed the 5,000, also known as the Church of the Seven Springs. The first church being round about 350 AD, its altar being the rock on which Jesus is said to have laid the loaves and fishes before feeding the 5,000. The modern church reached via a courtyard where the information board tell the history of it, previous churches and the area. It is a low building great in colour the same inside and beautiful in its simplicity, with many of the 5th century mosaics having been restored. One of them in front of the altar depicting the loaves and fishes, others on the floor depicting the plants and animals found in Galilee. We left the way we came passing many old relics (not the pilgrims by the way), On an old stone olive press and a large stone container looking like a giant Aladdin's style lamp.

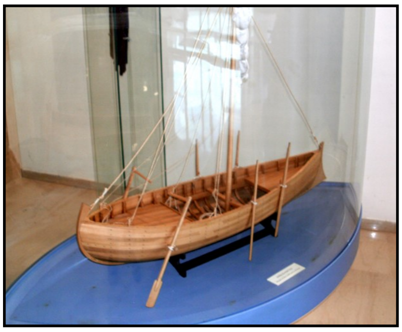
Getting off the bus we walked past previous excavations and a small steam that fed the Sea of Galilee. Then we were there, a small dark grey stone church built over the rock where Jesus cooked his disciples breakfast after rising from the dead. Going inside again it was a case of 'beauty in simplicity' the stone forming an altar with a plain white alcove and two stained glass windows at the back, the Jerusalem Cross in between above the altar table. The stone then carries on through the south wall of the church with a panoramic view of the lake, some of us walked to the water's edge then away from the crowd as if trying to imagine what it would have been like on that day. Just before coming away I was drawn to a statue beneath a large tree, it depicted Jesus commissioning Peter, Jesus asked Peter three times if he loved him, one for each of Peter's denials.

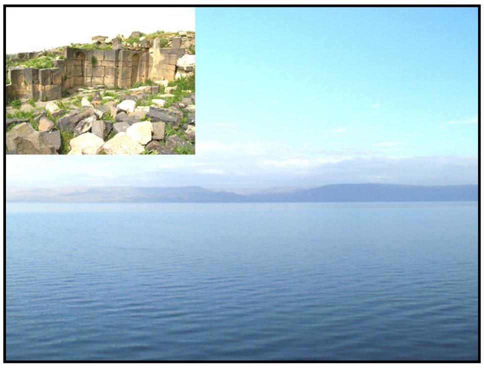
After lunch, we drove to the other side of the lake to visit Capharnaum, known as The Town of Jesus. Once a thriving fishing community now a walled tourist attraction, mostly ruins due to being cursed by Jesus due to the residents' lack of faith. Entry via a gate and toll booth. We found the dress code notice, consisting of coloured figures, allowed dress was shown as purple, not allowed was shown as red. The town was the scene of when the Centurion approached Jesus and where the paralyzed man was lowered through the roof of the house so Jesus could heal him. As we walked among the ruins some of the walls had been rebuilt, the remainder was the lower floor bases in inner walls. Over what was said to be the ruins of Peter's house is looking somewhat like a flying saucer, a Modern Catholic Church. Inside this Modern Memorial Church, is a glass enclosed 5th century church foundation which like the new church is octagonal in shape.

Our next stop was a museum situated in the grounds of the Kibbutz Ginnosar, named after Yigal Alonmember of Kibbutz Ginnosar, military and political leader, and believer in coexistence and peace. The museum hosted changing exhibits of art by Jews and Arabs. There were a few modern style sculptures to do with water and sailing but we had gone to see the remains of The Sea of Galilee Boat, also known as the Jesus Boat, which was found by brothers Moshe and Yuval Lufan, fishermen from the Kibbutz Ginnosar. The brothers were keen amateur archaeologists with an interest in discovering artefacts from Israel's past. Said to be a significant find of great archaeological importance we looked at what was left of it and the model of what it would have looked like. One of our party had worked on the Mary Rose and was able to explain so wonderfully how the timbers were preserved, by coincidence her name was Mary too.



Above: Remains of The Jesus era Boat
Below: How it would have looked like original.





View of Gadarene from the boat, inset : the ruins of the town

Then it was our turn to go for a sail, across the Sea of Galilee back to Tiberius. We boarded our boat and set off, there were some comments about a boat we passed its name "Noah's Boat", among the comments "Lasted, well hasn't it?" Our boat was called King David, and the trip afforded us good views of the far side of the lake as we sailed at a gentle pace, views of the Hippus (often pronounced Hippos) Mountains in Syria also Gadarene' or Gadara where Jesus released the demons from the possessed man into the pigs. It is feasible as it was a Gentile area, as pigs would not have been bred on Jewish land. As we sailed gently on it began to rain, we weren't too bothered. Eventually we landed at Tiberius and disembarked. We walked back to our hotel, to enjoy another good dinner. I returned to my room made a coffee and on the balcony completed my writing for the day, had one last look at the far back of the lake and turned in to be woken later by a thunderstorm. I watched it from the balcony for a while before returning to my bed.

In the morning, it was raining gently as we loaded the bus for the next stage of our journey which would begin with a trip to the Baptismal Site. Once boarded we held a short service and then were away. The sun came out the roads dried as we drove past palm and fruit plantations the latter were covered in netting to prevent parasites, there was no use of pesticides which probably explained why the fruit tasted so good. We drove along the west Bank past Israeli settlements on our right apparent by the barbed wire round them. On our left, The Jordan Valley and No Man's land going from a fence at the side of the road right to the river, a road patrolled regularly by the Israeli Military who have a shoot first policy. However there looked to be no, No Man's land on the Jordanian side, their land seemed to run straight to the river. Inspiration was growing as we passed remnants of the Six Day War of 1967, which reminded me of Bosnia between 1994 and 1996 when I did aid missions there. No Man's land was also heavily mined; we would find this out and more when we arrived at the Baptismal site. *To be continued.*