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Pathways

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



You Write In

A selection of email received at the Leger ME office.

Bill Writes: In Pathways 46 I wrote to you about my PIP form and said that 'Biteback' were going to help me with it. You asked me to let you know how things went on.

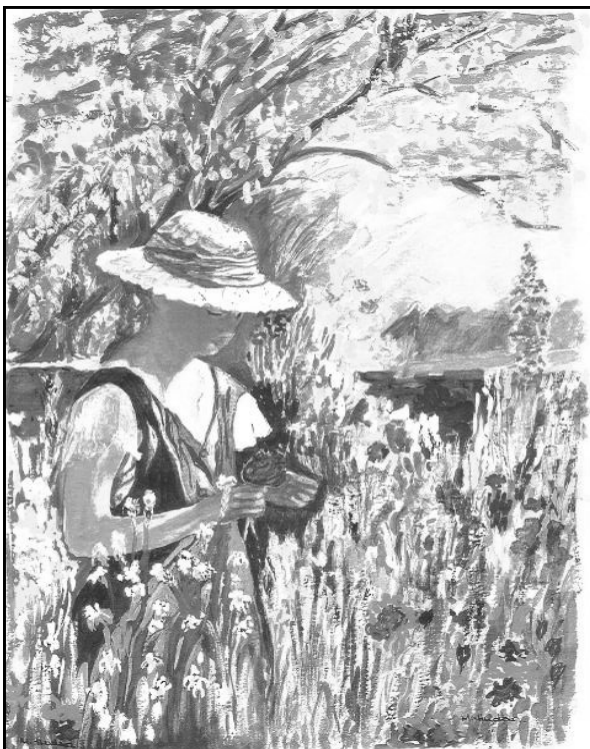
I was not overly impressed to be honest. I paid £50 and the form was done over the phone in an hour. It was typed out and copied onto loose sheets of paper which did not have any name or NINO number on it. It did give me a good starting point but I had to write it onto the regional form I was sent by the DWP. I also had to delete and add information which was inaccurate as I expected better.

I'm expecting a ESA 50 form in any time and I would like to access the information from 'Benefits and Work' regarding both PIP and ESA. Am I able to access it via Leger ME or do I need to purchase it myself?

Well easy answer first—the 'Benefits and Work' guides are on their way to you via email. As you have a printer, you'll be able to print off the pages you want if necessary. You don't need to buy the 'Benefits & Work' guides yourself as Leger ME has a Professional subscription to 'Benefits and Work', and part of the membership deal is access to these guides. For reasons of copyright and the licensing agreement we cannot publish them on our website. For the benefit of Leger ME readers, a copy of the 'Benefits & Work' guides can be emailed to you. All you need to do is request them by phone or email. We could print and post them out, but the cost would be around £15.

Secondly, with regard to your PIP, now your form has been posted there is nothing we can do but wait for a response. Usually for a first PIP claim people are called to a medical examination, but is possible some can be sorted just by return of post. Just let us know how things go.

Claire Writes: Hi Everyone. I e-mailed my MP yesterday regarding the ESA cuts. got a response within 4 hours! thought it would be of interest to you so I'm forwarding it to *Pathways*. This is what I wrote:



The front page picture 'Lady in the Garden' was painted by Mavis Hudson from the Redmond Centre Art Class

I note with dismay that you voted in favour of ESA benefit cuts. How can you believe that it is right and proper that ill and/or disabled people with little chance of being able to work at all or indeed to work enough hours to be able to afford life's necessities, such as food and utility bills, should receive the same amount of benefit as those on Job Seekers Allowance?

I have been unable to work due to my health since I was 25 years of age. was a Medical Secretary at a General Hospital for 9 years until I was medically dismissed. I have tried very hard to regain my health but have not been successful. I am now 42.

Amongst my various illnesses, I have ME/CFS - an illness which has had very little funding for research over the years. if it had, I would have a job, have a partner and have had children. I would be able to drive again, now I am left with the constant uncertainty regarding benefits whilst dealing with an isolating illness.

I would like to quote the Work and Pensions Minister, Priti Patel who said regarding cancer patients "they will be supported, because they are in the support group and therefore obviously ill".

So what does that say about the Conservative party's view of those in the Work Related Activity Group??? People are placed in that group because they are ill and in need of extra support otherwise they would be placed on Job Seekers Allowance.

Do you realise that being ill adds a lot of extra costs? Do you realise that employers won't employ people who are unreliable due to their poor health? Personally, I know my poor health wouldn't stand a week in a job. The Work Capability Assessment for ESA sets the bar very high as it is.

Do you know the reason why the numbers on sickness benefits are still quite high? It is because people are genuinely ill. Reducing their money doesn't miraculously make them well, just places them in poverty and makes them more ill.

I would like to know why you felt comfortable with voting in favour of the cuts, knowing how much the ill and/or disabled have already been unfairly targeted by your Government. And I await your personal response with much interest.

Claire, Your Constituent

This is what I received back

"If you are on ESA now you are not impacted as the change is only for new claimants. The truth of the situation is that I voted to support more for disabled claimants in the system. The new PIP system guarantees higher funding for the most disabled and those who will never be able to look for work. Your comments that we have targeted the ill and disabled are disgusting and not worthy of response. We are providing more support to the most disabled.

In terms of ESA, the Support group will continue to receive the higher rate but the Work Related Activity group will not as that group of people is in the same position as somebody on Job Seekers Allowance. They are judged able to seek work but there is a recognition that they will require additional time and support to access work which is why the ESA group exists. There are a number of discretionary payments that can be offered to those in this group seeking work. If your argument is that you are simply not fit for work, then you need to appeal and try to be placed into a different group. As I said above however the changes only impact on those new claimants from next year.

We came to government with a massive debt and deficit to handle and that has required some tough decisions on benefits. I recently opposed the changes to tax credits and successfully protected those for local people. I'd be a hypocrite to just oppose every change to welfare. This was a change only to new claimants, whereas tax credit cuts would have affected those in the system, I took the decision that this was fairer.

We have, and will continue to have, one of the most generous welfare systems in the world. I sometimes think we should remember that!"

Well Claire, you know who not to vote for in the next election.

Neil Writes: I work in Junction 32 outlet shopping village and they have a ban on staff parking in the customer car park. The only problem is from where I work it's a 20 minute walk there and back from the staff car park. I cannot walk this far and as a result may struggle to get into work the next day. I have received a parking fine but I am unable to get to the doctors for a note for reasonable adjustments (to include me parking close to work) until Monday and I am in working tomorrow, Wednesday and Saturday.

I am going to appeal it but I was thinking it would probably be best to send a copy of my note from the doctor with it. But I don't know what to do in the meantime. Do you have any advice?

Well here are our thoughts:

a) Firstly Neil, you are not a paid up Leger ME member so I can't really intervene on your behalf and a don't really know anything about yourself or your circumstances.

b) Secondly you should NEVER put yourself in a position where you knowingly break the rules of your workplace or the law. Even people with blue badge get fines.

c) With ME/CFS, you may be able to do something, but there is a consequence. That is what ME/CFS is all about. To get the pacing right you have to be able to do little and often rather than do a full day. Almost people I know have to have some arrangement to accommodate their ME/CFS if they are fortunate enough to be able to work. For example, many people can't do mornings, whereas they can do things later in the day. If you don't get the pacing right, you render yourself susceptible to major health problems further down the line.

d) I had something similar to this a few years ago with a nurse in one of the Sheffield hospitals who was a member. It's impossible to park there with double yellow lines everywhere, it's worse than the local hospitals. The issue was that she really needed a blue disabled parking badge for them to take note. Because she was working she was not classed as disabled, that finally resulted in the job becoming untenable. I never really found out what eventually happened. She really needed a blue badge. It's almost impossible to get a blue parking badge for ME unless you have high PIP mobility - and the chances of getting that if you're working are remote.

e) I think that you have to remember that driving to work from Doncaster to Pontefract is very stressful, and it may be that this is hidden stress and you don't realise what is happening particularly drive up the A1/M62. This is going to add to your overall stress levels, and will certainly be detrimental to your work performance and employability. Have you looked at a railway station close by have you considered going by railway, and getting lifts or taxis? It may be more economical and sustainable in the long run? Does the company you work for have a local branch in Doncaster?

f) The next step is for you to see your doctors, and get yourself on the system. You really need to be referred to the Sheffield ME/CFS clinic for assessment. You can alternatively make private arrangements also with the York Fatigue clinic.

g) I could see you at the Redmond Centre for a 1:1 session and look into your problems in more detail. One option is that we would look and see if it was worthwhile to apply for Personal Independence Payment or whether there is the possibility of a blue parking badge.

Kelly writes: I'm a Leger ME member, but my wife is not. She works in a local office, but has difficulty in walking due to intermittent claudication. Like me with ME/CFS she can walk a short distance to where she parks just outside work which is about 50 yards away. If she walks any further she gets pain in her legs which just get worse the further she walks.

The company she works for has just been taken over, and there are likely to be changes which would mean that she would have to park around half a mile away. I've spoken to her about PIP, and she doesn't want to go down that road possibly because of pride. She thinks however that a blue badge would be helpful.

For the benefit of Pathways readers intermittent claudication is a pain in the leg that a person experiences when walking or exercising. The pain is intermittent and goes away when the person rests. It is usually caused by occlusive arterial disease restricting blood flow. It is a serious condition, and usually all the major arteries are involved. Blue badges are available for this problem on a discretionary basis to people who have problems like this. She has to be able to walk more than 50 metres but less than 200 metres.



I think the way forward is for your wife to go and explain the situation to her doctor. Hopefully he will agree that she needs a blue badge and be prepared to write the appropriate supporting letter. You'll need to send the letter along with any application form to the local council office. Your wife may be required to attend a medical examination. The criteria are similar to that for low rate PIP mobility, so if she does swallow her pride and applies for PIP she would have a head start.

Welfare Rights and State Benefits Matters*with thanks to 'Benefits and Work'***Benefits and Work**
Guides you can trust**ESA cuts passed by the House of Lords**

The House of Lords this afternoon gave its assent to a cut of £30 per week for new claimants in the work-related activity group (WRAG) of Employment and Support Allowance (ESA).

The House of Lords had twice voted against reducing the level of payments for claimants, many of whom have degenerative diseases or serious mental health conditions, to the same level as Jobseeker's Allowance. However, on its third return to the Lords, the House of Commons claimed Financial Privilege for the cuts. By tradition the Lords do not overrule the Commons where a bill relates to finance. The cut is due to be introduced in April 2017 and the DWP have said it will not affect current claimants. The government's cynical claim is that by cutting ESA WRAG claimants' income to the same level as Job Seekers Allowance, they will be encouraged to go out and find work.

The proposals about PIP being made harder to claim dropped, but what next?

Following the resignation of Ian Duncan Smith, what does the future hold for claimants? Many people will have their doubts about the claim by the new Work and Pensions Secretary, Stephen Crabb, that there will be no more benefits cuts in this parliament. And, as we have suggested elsewhere, there is no certainty that either Crabb or Chancellor George Osborne will still have a post following the EU referendum. But if they do manage to hang onto their jobs, what are the prospects of changes to the major sickness and disability benefits?

Attendance Allowance. As we reported back in January, the Government was planning to launch a consultation on abolishing attendance allowance for all new claims and giving the money saved to local authorities instead. It seems highly likely that this plan will now be dropped.

Disability Living Allowance. It is exceedingly improbable that the transfer of claimants from DLA to PIP will be halted. Even the dawning realisation that PIP may cost more than DLA is unlikely to make any change to that. It is now far too late to stop the PIP juggernaut.

Personal Independence Payment. The recent attempt to cut points for some aids and appliances for PIP was rushed through. If the DWP had done its usual job of softening up MPs and the public with briefings and press releases attacking their target claimants first, this could actually have been a relatively easy cut to sell. All it required was a welter of publicity suggesting that some people with mild conditions just had to buy themselves a long-handled shoe horn, a raised toilet seat and a perching stool and they could claim £3,000 a year in benefits. It would have been a lie, but it would almost certainly have worked. Even now there is some wriggle-room in the statement by Crabb. The DWP may well introduce changes to PIP regulations which they will say are not cuts but are simply intended to clarify the law and ensure that the original intention of Parliament is followed. The probability of more changes to PIP before the end of this parliament is high, we suspect.

Employment and Support Allowance. Will the cuts to the Work-related Activity Group still go ahead? The answer has to be that it is extremely likely that they will. They have already passed into law and IDS indicated in his interview with Andrew Marr that he remained in favour of them. It would take an extraordinary amount of pressure to make the Tories reverse this cut.

Universal Credit. IDS lost a court case on the day he resigned, which orders the DWP to publish documents which are likely to show that IDS misled parliament about what a mess Universal Credit (UC) was in from a very early stage. IDS would almost certainly have appealed this decision, Crabb may not. There has long been speculation that the treasury, and George Osborne himself, see UC as an expensive shambles that they would like to axe. And that might well have been true until very recently. However, when Osborne was forced to reverse his planned tax credit cuts earlier this year he managed to get away with leaving them in place for UC. This means that when claimants get moved from tax credits to UC the cuts will still hit them and the treasury will still save billions. So, under the circumstances, it looks improbable that UC, however much of a mess, will get the chop.

Whatever happens, *Pathways* will keep you updated.

Recipe Corner by Carolyn

For a change here is a Supper dish:- Stuffed Vegetables

This meal, if served as 10 portions, provides 249kcal, 5g protein, 39g carbohydrate (of which 6g sugars), 7.5g fat (of which 1.5g saturates), 4g fibre and 0.2g salt per portion.

Cooking Method

- Preheat the oven to 160C/140C Fan/Gas 3.
- Start by preparing the vegetables for stuffing.
- Cut the tops off the peppers and tomatoes to create lids, set the tops aside.
- Scoop out the pepper seeds and discard.
- Scoop out the tomato flesh and seeds and reserve.
- Cut the aubergines and courgettes lengthways and scoop out the seeds and flesh inside, leaving a boat-shaped shell ready to fill.
- Add the flesh from the courgettes and aubergines to the tomato flesh and seeds and chop well.
- In a large pan over a medium heat, warm 3 tablespoons of the olive oil and fry the onion and garlic for 3–5 minutes until soft. Add the chopped vegetable flesh and the tomato purée. Cook for about 10 minutes until softened.
- Add the rice and 150ml/5fl oz of the vegetable stock, raise to a simmer and cook for 10 minutes, stirring occasionally. Season with salt and pepper and stir in the herbs and chillie flakes.
- Arrange the vegetable shells on a roasting tin or ovenproof dish and spoon the rice mixture into them.

Ingredients

1 green pepper
1 red pepper
1 yellow pepper
2 large tomatoes
2 small–medium aubergines
2 green courgettes
6 tbsp olive oil
1 large onion, finely chopped
2 garlic cloves, finely chopped
2½ tbsp tomato purée
400g/14oz long-grain rice, rinsed
250ml/9fl oz vegetable stock
large handful flat leaf parsley
large handful fresh mint
1 tsp dried oregano
½ tsp chillie flakes
salt and freshly ground black pepper



- Place the lids on the peppers and tomatoes and drizzle them all with the remaining olive oil.
- Pour the remaining stock into the tin, cover with foil and bake for 1 hour.
- Remove the foil and bake for another 15–30 minutes until the vegetables and rice are cooked.
- Serve hot, warm or cold.

Online Market Research Surveys and ME/CFS by Stephen Smart.

I only joined Leger ME very recently. I was originally given the idea about surveys by another member of Leger M.E. when looking for ways to supplement my income after the recent acquisition of a new car, which left me much tighter on expenditure every month. I set about researching what doing these surveys would entail, what the pay was like, the time frame they would take to complete and ultimately which companies I should do these surveys for and which companies I should avoid.

After coming across an article titled 'Top 20 Online Survey Sites' on moneysavingexpert.com that importantly outlined all the dos and don'ts I set about joining a number of companies. Looking back now I joined far too many companies at that time (10) that ultimately left me stressed and exhausted as I couldn't cope with the number of surveys that were being sent my way.



Instead of just giving up I scaled down the number of companies I was associated with over a month or so until only four remained. The four I was left with still send me enough surveys every day that if I'm not careful I could still be on the laptop over an hour on occasion if I don't pay attention to the time. Fortunately, though I am getting much better at judging how I'm feeling when I'm doing the surveys, how long they are taking me and also no longer getting stressed if I get 'screened out' of surveys when not having the right criteria.

The four companies that I have found both enjoyable and fruitful to work with are: -

yougov.co.uk, globaltestmarket.com, panelbase.net and ipoll.com.

The surveys these companies send are varied and more often than not interesting. There are some companies out there that I would recommend you avoid, these being:

populuslive.com, opinium.co.uk and responsepanel.com

simply because the surveys they send are so few and far between and the threshold that you need to achieve is so high that it is just not worth your time.

It is an important lesson to learn that you're doing these surveys for you and not for the companies. Meaning if you only want to do half an hour's worth of surveys or if you don't want to any at all on a certain day that is not a problem, it doesn't matter and you mustn't beat yourself up about it. Another important lesson to learn is picking the right companies for you according to what sort of income you are looking for, as some don't pay out for months, all have thresholds to achieve and many will only pay out in vouchers that you may not want.

After five months of doing this myself I am earning an average of £40 per month that I use as Amazon vouchers for films and books, iTunes vouchers for my latest music tastes and cash pay-outs that I put into a separate account going towards petrol for my car. Many of you will be looking to these surveys for different pay outs than the ones I have listed above; again it is important to do your research.

The way I have achieved this is to compartmentalise these surveys into the way I 'pace' my day. Whether it is through exercising, reading and going on the computer I have to know when I've had enough, meaning I can continue at a level without booming and busting, again just another way in which I manage these surveys for me.



Finally, it is important to remember that this will not be a quick fix, this will not make you rich. It will take you a good two to three months before you start seeing any reward and that it is only ever going to be a little extra spending money.

I hope that sharing my experience, other members will find this useful.

Best of luck and happy surveying!

Prescription Charges Increase

There will be an increase in the prescription charge to £8.40 in England on April 1st 2016. It is bad enough to have a chronic health problem like ME/CFS, but when medicines are required it's just adding insult to injury. There are corresponding increases to other NHS service charges, the most significant one being the increase on the cost of a dental check-up to just under £20

When the NHS first started in the late 1940's, prescriptions were free—but due to the high demand and post-war austerity, a charge of a shilling per form was implemented. I've seen examples where as many as 14 items were crammed onto a form. The Labour government then in power introduced a one shilling per item charge which drastically reduced numbers. The introduction of the prescription charge prompted the resignation of Harold Wilson, (later Prime Minister) as Minister of Health. Since then, many different strategies have been tried to justify the charge. In the later 1970s, the prescription charge was 20p per item, which was drastically increased to 70p by the incumbent Conservative government of Maggie Thatcher. She also introduced sweeping reforms and the implementation of a 'black list' to restrict prescribing of medicines that were of questionable value to the NHS. Since then there has been an increase in the prescription charge every year. In recent years the announcement is made towards the end of the year, buried within other media interest very near Christmas. Personally, I view the NHS prescription charge as a sickness tax or disincentive to use NHS services. Since devolution, different arrangements have applied in Scotland. For example, there prescriptions are free. However, in England the charges still apply.

Free Prescriptions

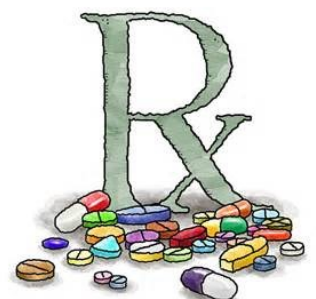
For adults of working age the charge still applies. Children under 16 years of age and men and women aged 60 years and over are automatically entitled to exemption. People with certain medical conditions can get free NHS prescriptions if they hold a valid medical exemption certificate. This is not automatic and has to be applied for. At the time of writing the conditions are as follows

- a permanent fistula (for example, caecostomy, colostomy, laryngos-tomy or ileostomy) which needs continuous surgical dressing or an appliance;
- a form of hypoadrenalism (for example, Addison's Disease) for which specific substitution therapy is essential;
- diabetes insipidus and other forms of hypopituitarism;
- diabetes mellitus, except where treatment is by diet alone; *
- hypoparathyroidism;
- myasthenia gravis;
- myxoedema (that is, hypothyroidism which needs thyroid hormone replacement); *
- epilepsy which needs continuous anticonvulsive therapy;
- a continuing physical disability which means you cannot go out without the help of another person; or †
- cancer and are undergoing treatment for cancer; effects of cancer; or, the effects of cancer treatment.

You can only get a certificate if you have a condition on the list. If you are not sure about the name of your condition, check with your doctor. Doctors may advise you about free prescriptions. However, it is up to you to find out if you are entitled to an exemption certificate. Where ME/CFS is concerned there is not automatic exemption, but many people with ME/CFS have additional conditions which are marked with an asterisk(*). Some severe case of ME/CFS may qualify if certain criteria are met(†).

Please remember that an award of ESA, DLA or PIP does not automatically give people exemption from prescription charges unless you have a statement from the DWP. The entitlement is usually based on a means-tested benefits e.g. income-dependent ESA, and is not automatic. Slightly different arrangements apply also to dentist's and optician's charges.

Please remember that fraud checks are now carried out by the NHS, and quite a hefty fine has to be paid in the case of fraudulent claims.



Prescription Prepayment Certificate (PPC)

If you know you'll have to pay for a lot of NHS prescriptions, it may be cheaper to buy a Prescription Prepayment Certificate (PPC) – effectively a prescription 'season ticket'. A PPC covers you for all of your own NHS prescriptions, including dental prescriptions, no matter how many items you need. However, this does not include other health costs, for example the provision of wigs and fabric supports which are only provided through the hospital service. There are two PPC options to choose from:

- A three month PPC costs £29.10 and could save money if you need more than three prescribed items in three months
- A 12 month PPC costs £104.00 and could save you money if you need more than 12 prescribed items in a year

What are the savings?

- If you need two items monthly, you can save over £90 with a 12 month PPC
- If you need three items monthly, you can save over £190 with a 12 month PPC
- If you need four items monthly, you can save over £285 with a 12 month PPC

There are several budgeting payment options. For a 12 month PPC, you can pay by 10 monthly direct debit instalments. Application forms are available only from various NHS or DWP establishments or see <https://apps.nhsbsa.nhs.uk/ppcwebsales/patient.do>

When I do a case review, I do a check for medicines charges and look at suitability and if there is a need. Some medicines e.g. paracetamol are best bought over the counter. Here are some examples.

<u>Medicine type</u>	<u>Active ingredient</u>	<u>Typical supermarket price</u>
antihistamine (hay fever)	loratadine 30 tablets	£2.50 (for 30 tablets)
anti diarrhoea	loperamide 2mg	£1.00
analgesic	ibuprofen 200mg	25p
analgesic	paracetamol 500mg	19p

An alternative is for a private prescription—but depending on the doctor there may be an upfront prescription fee charged by the doctor.

Prescription Charges Coalition,

The Prescription Charges Coalition, a group of nearly 40 organisations including the Royal Pharmaceutical Society, are campaigning to end prescription charges for people with long-term medical conditions. The continued rise in the charge for prescriptions forms a barrier year on year for working age people who rely on regular medication to manage long-term conditions. The charge applies to each item on the prescription, so if you have to take a number of medicines, as many with long-term conditions do, the cost can quickly mount up. Research shows that 1 in 3 of those with long-term conditions have not collected a prescription because of the cost. This can lead to poorer health, expensive hospital admissions and can affect productivity at work. We welcome the fact that the Prescription Pre-payment Certificate cost has been frozen, however many people with fluctuating and long term conditions have told us that this cost can still be prohibitive.

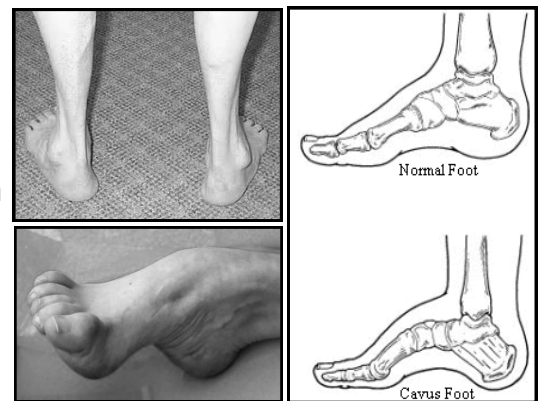
The Prescription Charges Coalition is pressing for people with long-term conditions in England to be exempt from prescription charges. They are disproportionately affected due to their need for ongoing medication, yet this is vital to keep them well and to prevent potentially life-threatening complications. Medicines are prescribed for a reason and a patient's ability to pay should not be part of the equation.

Living with Charcot Marie Tooth (CMT) Disease and then ME/CFS by Steven

Like ME and many other conditions out there it is important to remember that CMT is not a 'one-size-fits-all' condition. There are different variations of the disease and there are many different ways that it affects its sufferers. For the purpose of this article I will be describing what it is like to live with CMT type 1A, which incidentally is the most common form of CMT.

I was born with CMT but didn't know this until I was diagnosed at nineteen. Other than the fact that it took me a little longer to learn how to walk than the average baby and that I had supple legs we never realised there was anything wrong. I'd had a weakness in my ankles in particular from a young age that attempts had been made to correct with boot shoes that I had to wear all the time to support my ankles and try to prevent them from rolling over. Until the age of nine I was only checked over by a foot specialist as that was thought to be the only thing wrong. Furthermore, other than poor balance and a difficulty with running, there didn't seem to be any other issues. Although it wasn't noticeable at the time my mum says now looking back even at an early age I did find it difficult keeping up with friends and that I seemed a little bit more fatigued than your average child, but we put this extra fatigue down to the fact that I had Asthma.

Things were left alone until I reached the age of fourteen when, looking back, things started to change. At this point my ankles were starting the gradual 'rolling over' that to this day has given my legs the champagne bottle appearance. Also from this time the muscles in my legs started to waste, again lower leg initially. This meant that I was starting to have occasional pain in my legs and in particular sporting activities were becoming increasingly hard to keep up with as I found it more and more tiring. At this stage the only medical treatment I received was physiotherapy without any real idea as to what was going on. Again the medical professionals didn't know what to do with me and I was left alone yet again.



During my teenage years as I have mentioned I was always moaning that I was tired, even after waking up in the morning I was tired. Starting a school day, I was tired. The increasing strain to my ankles was also adding to the tiredness. Throughout secondary school I would say I didn't 'suffer' like I seemed to from collage onwards. Up until the age of sixteen, although extremely tiring, I was still walking into town (2.5 miles or so), standing around didn't seem to be a problem. Also at this point I hadn't started having trouble writing as the muscle wastage in my forearms was yet to truly kick off and my concentration levels weren't too bad. The only problem that I could never really overcome until the age of fifteen was learning how to ride a bike. Having such terrible balance as I do seems to make it almost impossible to just stay on a bike. At fifteen, thanks to some of my friends, I finally managed to pull it off but I still found it so much harder than they did and so much more tiring. Being able to ride my bike didn't last long unfortunately as during my college years I didn't have the opportunity to ride it and I seemed to have achieved the impossible and 'forgot' how to ride. To this day I cannot push off without falling off, with my balance problems and deformed ankles it just makes the task too difficult. It seems now looking back that everything went down the proverbial hill from college onwards. Everything started becoming that little bit harder and was making me that little bit more tired and stressed.

During this time my mum kept fighting with the medical professionals to try and make them see that there was something wrong going on as my legs in particular were going over more and more. Over the next two years I had x-rays and multiple tests on my feet and legs and ended up with a surgeon who wanted to do extensive surgery to both my lower legs. The problem with this was that it was going to be one at a time with both taking almost two years each and having to learn how to walk again on both legs. Over this time at college I was having an increasingly difficult time with walking, in particular walking to and from the bus station to the college and to and from college to town during the lunch hour. I would have to walk so quickly because of the short time over a large distance that my legs would be in a lot of pain which was of course tiring me out before I even did anything productive. The college days seemed to be a lot longer than school days and I really struggled with it in terms of tiredness and being stressed out because of it.

It was also during this time that I seemed to start having trouble with concentrating in lessons and being able to concentrate for long enough to complete my coursework. This was also adding to my stress levels. Over these two years it was also increasingly noticeable that I was having trouble with my hands and writing for any length of time and that my forearms were getting thinner and thinner.

When I was seventeen I secured a Christmas job at Superdrug and over the period of four to five weeks standing around on my legs was becoming an increasingly painful and tiring experience, so much so that I could not be as chirpy and happy as a position in a company like that requires. I would be working all day over a Saturday and a Sunday and I would be exhausted early on never mind at the end of the weekend. As my time at college was coming to an end I was referred to another foot specialist who initially wanted to carry on with the surgery. However, it was he who noticed there might be something else to contend with and referred me to a neurologist.

It was during my first year of university that I noticed that everything seemed a lot harder for me than for all of my friends. The course that I had chosen was also a really full on course that meant I was in pretty much nine till five and although things were to get worse I was struggling.

It was a battle to stay awake in every lecture and every lesson, having to concentrate like that wasn't doing me any good.

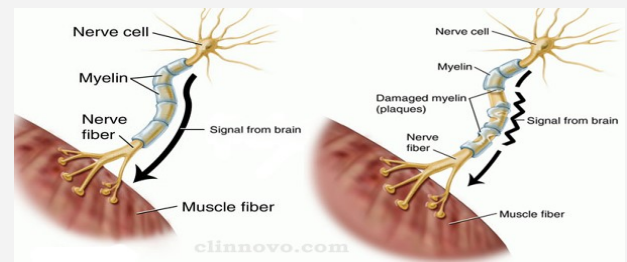
Luckily during my first year I wasn't living too far away from university and the walk to and from wasn't so bad but the walking into town on nights out and other things were really hard on my legs and it was getting to the stage that wherever I was going I was in pain. It was also during this time that I was having to have some extra tests both here in Doncaster and in Sheffield (where I was at university) to try and determine once and for all what was wrong.

Over the course of this year I never truly thought that this was going to be too much for me, that I wouldn't be able to cope with the pressures that university threw up every day and for the most part I did manage to cope. Over the year I went out and about less to try and lessen the amount of pain in my legs and to overcome the problems I was having with writing I would just use my laptop more. The only times where things would get a little hairy were when multiple essays were due in at the same time and when I would have to revise to multiple exams at the same time. The tiredness and lack of concentration were starting to take their toll.

During the summer between my first and second year when I was nineteen I was finally given the diagnosis of Charcot Marie Tooth Disease and although it finally gave me answers to a lot of questions it didn't

What is CMT ?

CMT is a genetic condition that damages peripheral nerves by myelin damage in a similar way to MS. Motor nerves are



responsible for passing on commands from the brain to the muscles and sensory nerves pass information to the brain about sensations, such as pain, heat, cold, touch, importantly for balance – where joints are in space. When these latter are damaged, people are said to have a neuropathy. Because of this nerve damage, people with CMT may find that some of their muscles become slowly weaker over the years, particularly in their feet and hands. Some find that feeling becomes duller, or numb, in the same areas. In the UK, around 25,000 people are thought to have CMT, making it the most common inherited neurological condition. Other key points about CMT are that the condition:

- It is hardly ever life-threatening, but often becomes slowly progressive over the years
- It comes in many forms, some of which are much more severe than others and can affect people very differently, even in the same family
- It can cause the muscles in the foot, lower leg, hand and forearm to become wasted and weak
- It can cause foot drop gait, foot bone abnormalities (e.g. high arches and hammer toes), problems with hand function, balance problems, occasional lower leg and forearm muscle cramping, and loss of some normal reflexes
- It may cause long-term pain and tiredness (fatigue) like with ME/CFS
- It can be passed on from parent to child: the precise way it is passed on to subsequent generations depends on the genes involved

For Further information see
<http://cmt.org.uk/>

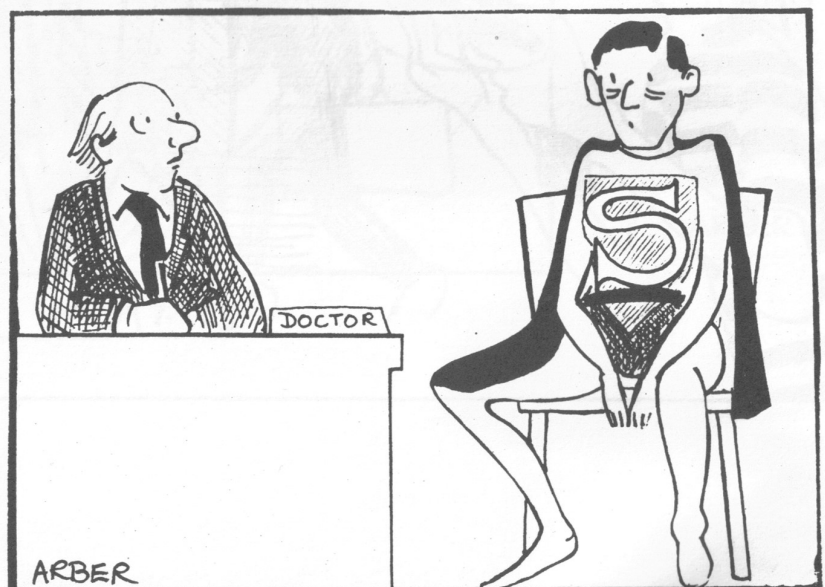
managed to stick it out for a couple of lessons I would be half asleep anyway and wouldn't have a clue what the lessons were about. And as for my concentration, forget it. Sitting at my desk trying to write something, anything, for an essay was almost impossible as was trying to revise for exams. Nothing would go in. It was not long after that Christmas that I had to make the difficult decision to leave university and come back home and it was an extremely difficult time. Thankfully now though life is good, or as good as can be expected and it's all about management. Management of my body and management of what I do.

So what's it like now with CMT. Well over the last five years there has been a noticeable change as the CMT continues to deform my legs and arms. Walking is difficult but not impossible, yet it does tire me out a lot. Also standing around for anything longer than five minutes is just out of the question it causes serious pain in my ankles, knees and the muscles around my lower legs. I also have some problems with my left knee and right ankle now that requires a bit of management but can easily flare up when walking or exercising. Another problem that seems to get worse year on year is how much the cold affects me, how much pain it causes and how much more tired it makes me. There are times when I will have to wear thermal clothes indoors even when the heating is on because I am that cold. And of course there is still the problem with my hands. I barely even write any more because anything longer than a few minutes and I'm in a lot of pain.

The thing that really changed my outlook on my life was finally being able to get my head around pacing. I know that it is a philosophy for ME but once I finally got my head around it, it made a difference across the board and I thank a friend of mine for finally getting through my thick head because if it wasn't for her I wouldn't be in the place that I am today.

In truth it is still incredibly frustrating day to day as for one dedicating yourself fully to pacing leaves you with a pretty boring day ahead of you, but you have to get your head around it and just not care. It's the best thing for me and my body. It was and can still be the hardest thing to turn down a friend because they've asked me to do something I can't any longer or because it was take too long and I would get exhausted and throw my routine all over the place. After a number of years of trying different things from insoles to foot orthosis I finally have a pair of ankle braces that help a lot with the rolling over of my ankles and they provide a decent amount of support without hurting my legs at the same time. From here on out it will have to be more of the same if I want to protect what I have. It is clear that my CMT is progressively degenerating year by year and that of course throws up different challenges and obstacles that I'll have to face and overcome whenever they arise and ultimately just be happy with what I've got because it could be a hell of a lot worse.

In September 2012 I received my diagnosis of CFS/ME from the old Sheffield ME clinic at Fairlawns. It came as a relief just to be able to say I had something else going on after months of being told by my GP that it was just depression. I find it difficult to quantify where the CMT begins and ends and where the ME takes over, if that is even the case or whether they both work in tandem. As I have mentioned earlier there is a noticeable difference in me after I picked up the virus when I was at university and how it has affected me since then. It is also fair to say that I am doing as well as can be expected at the moment, just as long as I don't overdo things (easier said than done). I've done my best over the last four years to remove much of the stress and frustration from my life as they are some of the worst things for ME and today although my life is in a routine and structured I have to take each day as it comes, and that's ok.



OVER THE LAST FEW WEEKS I'VE ONLY BEEN ABLE TO LEAP OVER SMALL BUILDINGS AND TRAVEL AT THE SPEED OF A SLOW BULLET.

Gardeners' Corner by Carolyn

I have always loved gardening and have always managed to leave a house and move on feeling that if I have achieved nothing else at least the garden left behind is in better shape than it was when I arrived. When ME came into my life things had to change and over the years I have found myself becoming increasingly more interested in pot planting with the use of bulbs. Having had success with a pot planted up with tete-a-tete daffodils along with small lily bulbs underpinning them to bloom later on, I am gaining in confidence enough to share an idea for a Summer flowering pot. I am very lucky these days as I now have a small patio and for this year my plan is to make this area more interesting by using pots and containers so here is an idea for a pot of summer flowering bulbs that once planted up will give you interest and colour for years to come with not a lot of cost and very little maintenance: -

Firstly, and very importantly, make sure the Spring Frosts have gone.

You will need at least an 8inch pot or container and preferably one that is up to 11inches. (The following is for an 11-inch pot)

Buy 7 ACIDANTHERA bulbs which will cost you about £4. Also buy 12 mixed BABIANA at £4 - £5.

Fill your pot with a good general purpose compost and then take some out for covering, and place in the taller growing Acidanthera bulbs to a depth of 5 inches. Add in the Babiana bulbs to a depth of 3-4 inches and cover them with the compost taken out. Water the pot and place it where you want it to bloom. If the weather is very dry, then don't forget to gently water the pot each week. The bulbs will flower each July – October. After flowering, take off the heads and let the green die down naturally back into the pot to put goodness back into the bulbs for next year.



Film Review: Dad's Army 2015

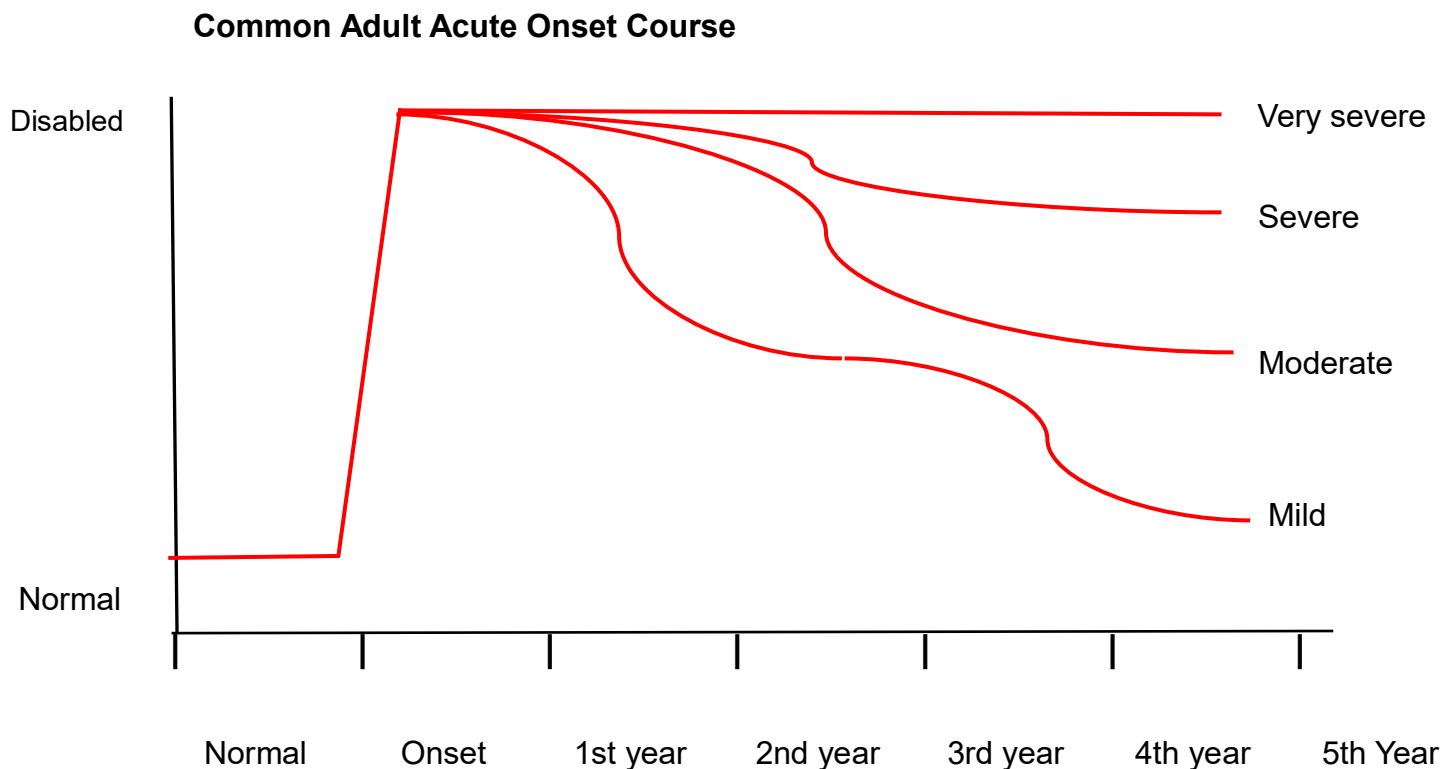
A few weeks ago, Dad's Army came to the Vue cinema in Doncaster. I had enjoyed the many reruns of the original BBC TV series. My curiosity was aroused when a feature on BBC TV's 'Look North' featured the filming for the film, at North Landing, Flamborough Head, Yorkshire. Most of us are aware of the setting and context of Dad's Army, so I decided to see that film when it came to Doncaster. I was however a little anxious that I may be disappointed that the main characters Captain Mainwaring (Arthur Lowe), Sergeant Wilson (John Le Mesurier), and Lance Corporal Jones (Clive Dunn) and now played by Toby Jones, Bill Nighy, and Tom Courtenay.



Once the film got started and the new characters were introduced, the new actors just fell into their characters with ease. In this version of the show the woman's ATS take a new major role. Additionally, Catherine Zeta Jones plays a shady lady who shows up in Walmington-on-Sea claiming to be a journalist writing a feature about the Home Guard for The Lady magazine, but seems to be taking a close interest in the D-Day plans in which the platoon has somehow become farcically involved. Needless to say although fooled at first, one by one the platoon realises the true reason her visit. Although I laughed quite loudly at many of the antics of the home guard, it was noticeable that the younger members of the audience didn't share my enjoyment as much. Watch out for flying tanks, and real German soldiers. In the end we see Mrs Mainwaring and the women of the ATS (absent from the TV series and brought into the film by artistic licence) help the platoon save the day for England.

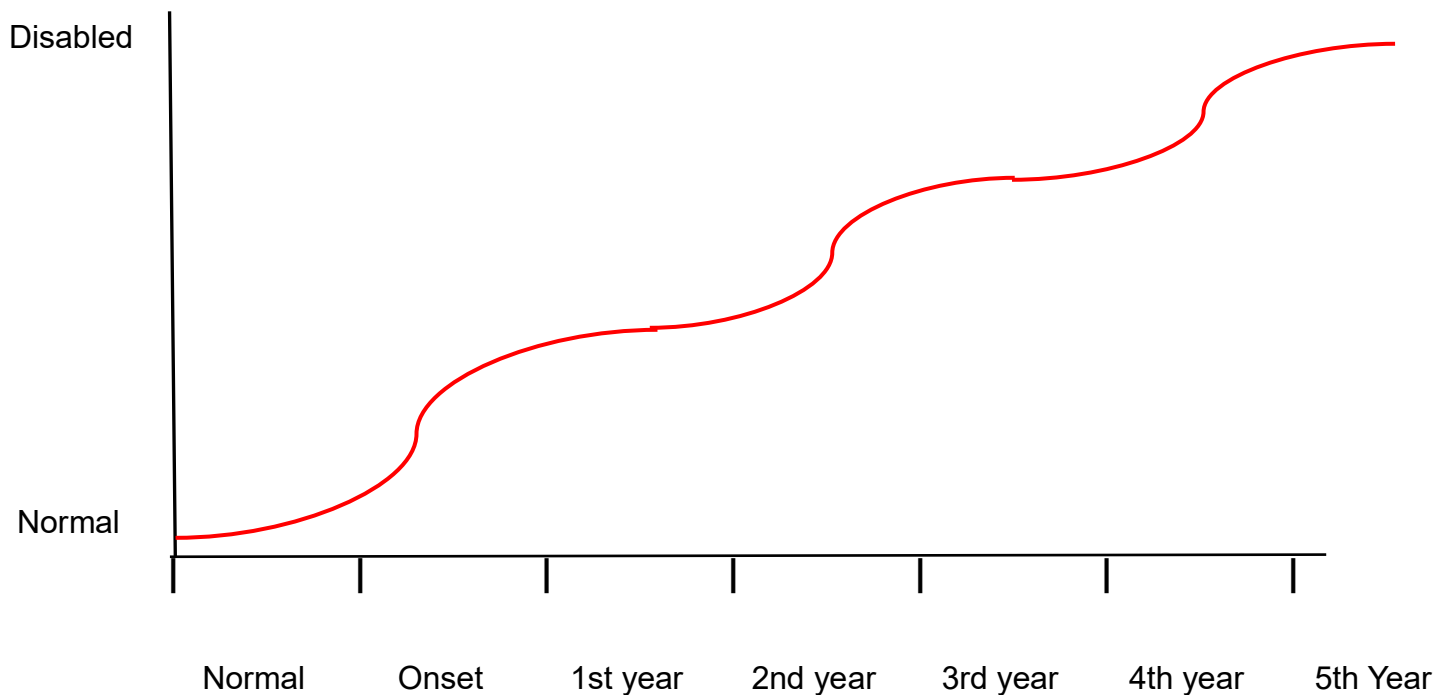
ME/CFS Typical Condition Course.

Very often I'm asked "How long will it last"? I have no definite answer, and really the situation is the same with the ME/CFS clinics, who also have no definite answer. I've researched the matter, and really the only information I have is from our own experience. A simple way to express this is shown in Dr David Bell Books, "The disease of a thousand names". The most common pattern I see is the pattern known as 'Adult Acute onset'. I've expressed this as a disability versus time graph: -



Typically, patients report vague series of subclinical symptoms which are usually dismissed as being tired, 'needing a holiday' or needing time out. Then at some point the disease is triggered by a stress event. For example, a patient experiences an infection typically viral e.g. flu, tummy bug or some other infection. This would normally be treated and expected to resolve just as a one off event. What then happens is that there is an apparent resolution of the infection. Following this there would be expected as few weeks of 'post viral debility' where patient report feeling a little 'under the weather'. This very often then resolves and that is the end of the matter. However, in perhaps 1 in 1000 cases the fatigue syndrome is triggered. Within the space of few days there is an acute increase in the disease process where disability massive increases. Many patients recall a prolonged period of being on the settee all day, just being very fatigued. This acute onset stage then carried for many months. After a year many patients report feeling no better. During the second year the symptoms pattern changes and there is a gradual improvement of the patient, which for many cases continues into the 3rd and following years. Just how long the chronic phase lasts can be under a year for children, but for middle aged adults, the final level of recovery is not really clear until the 4th or 5th year. The level of recovery can be expressed as a percentage of original health. Mild cases recover to well over 60% of original health, Moderate to 30-40% and severe to 20%. Very severe cases see no improvement over many years, and are typically 1-2% of all cases. Severe cases are usually around 20-25% of cases. About half are moderate and around 20-25% of cases are mild. With the severe and very severe courses work is impossible. In moderate cases limited work is possible, perhaps in the order of four hours a week with environmental adjustments. Mild cases can mostly cope with part-time work. The actual measurement of disability depends on one of the many systems used, and these graphs are only illustrative. The trigger can be another stress factor, e.g. vaccination, accident, childbirth, operation. It is thought that this stress event somehow triggers a permanent change in the immune system in such a way that it does not reset. Biochemistry suggests this mechanism. Many patients who experience this course are abnormally allergic with abnormal sensitivity patterns. There are atopic family histories, with asthma eczema and other autoimmune disease being often reported.

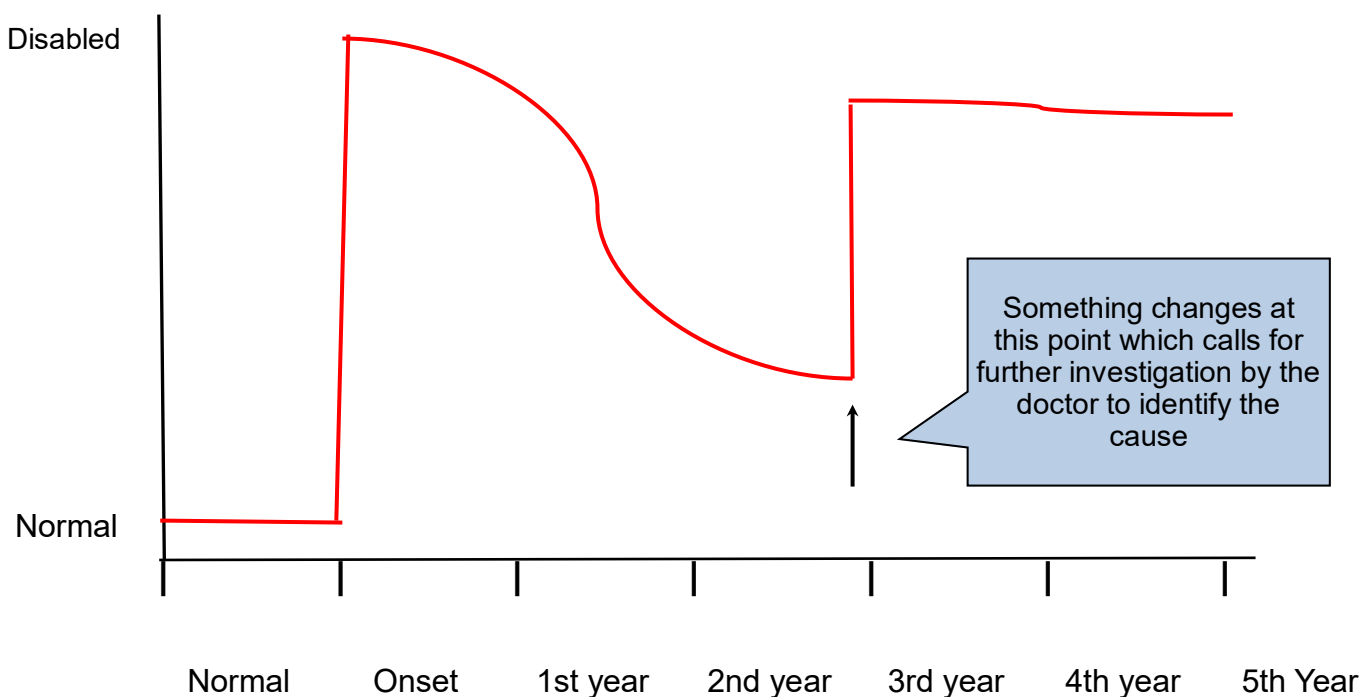
Insidious Onset Progressive Example



The next most common onset pattern patients report is known as insidious onset. Here there is no detectable trigger event. The patient just slides into ME/CFS over a period of time. This course can be thought of as progressive. This applies to around 10% of group members. In my experience over the course of many years there is little improvement, and this pattern is associated with a poor prognosis. These patients very often can't relate to a triggering event, and very often I can't really work out what is happening. There are very often problems of acceptance with these cases. A similar pattern is seen in primary progressive multiple sclerosis.

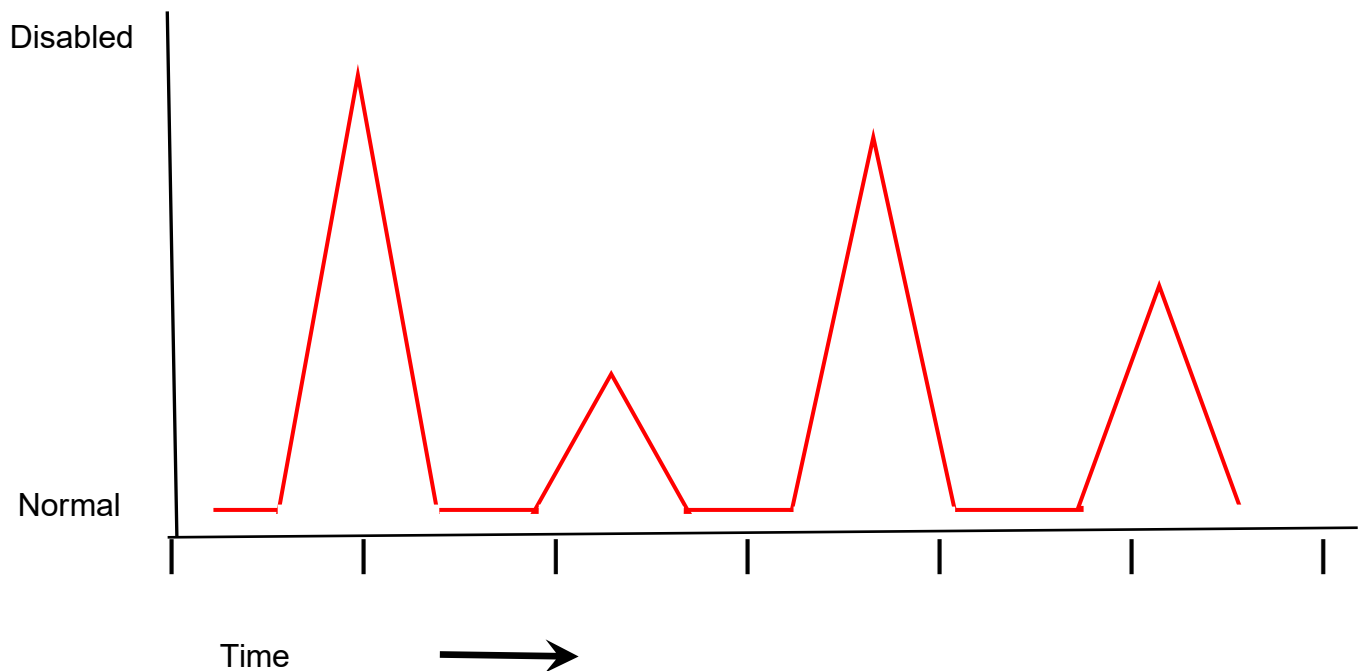
Here is a third course which we sometimes see which is best described as Atypical. Here there is a step change in the person's disability from the expected pattern. Almost always this implies another disease process. Commonly it is the onset of type 2 diabetes, but could be anything.

Atypical Course Example

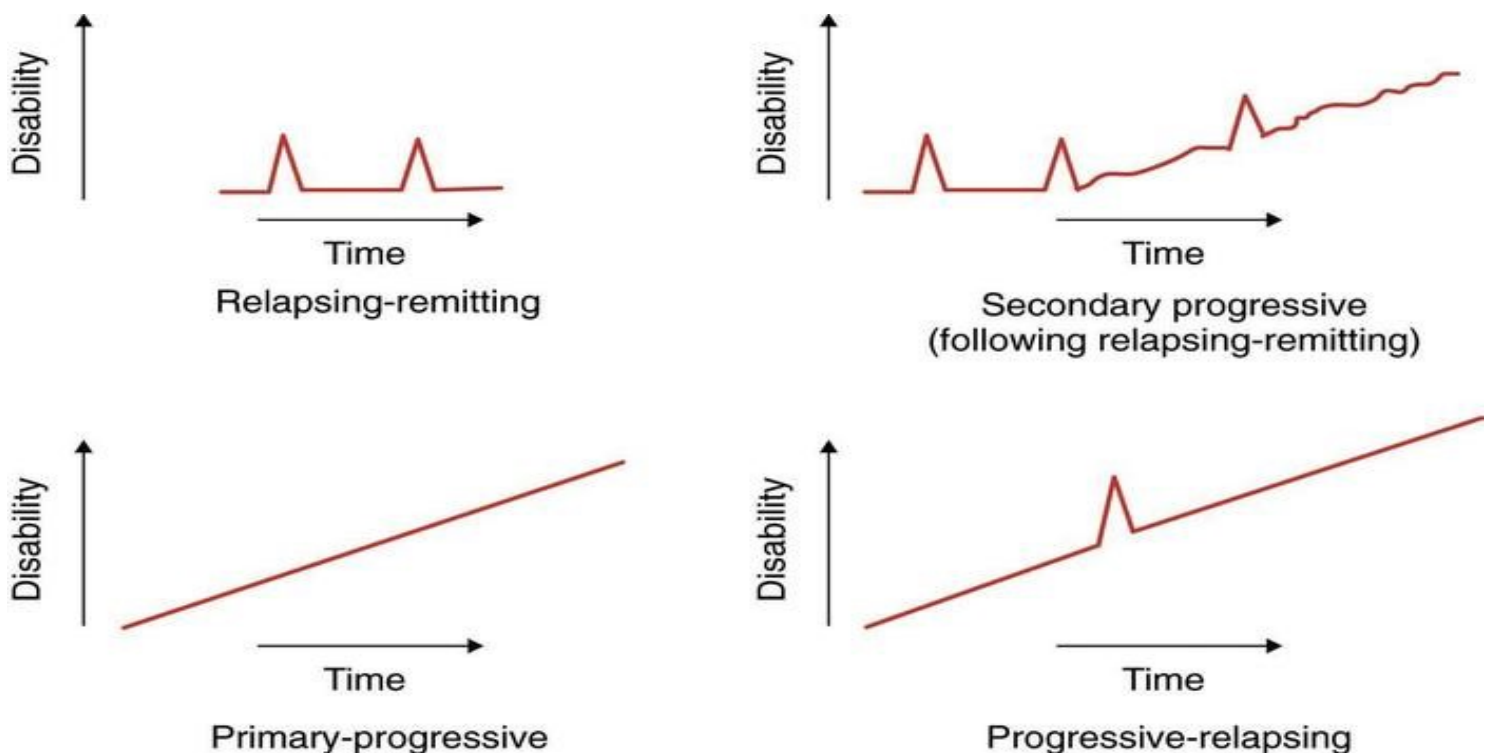


There is another pattern that I sometimes see—and that is a relapsing remitting course. Here the disease process occurs in variable episodes of intensity with periods of normality in between. These periods are not regular and may vary between a few weeks and many years. This tends to happen in patterns with a definite immune dysfunction, I tend to think of this as the typical pattern repeated many times. There is some definite trigger, which for example could be exposure to something, and maybe, if that something could be identified, it could be avoided.

Relapsing Remitting Course



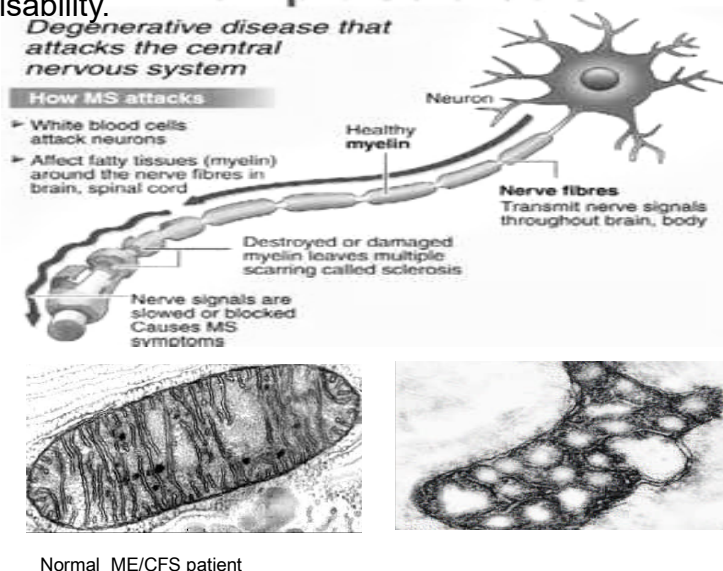
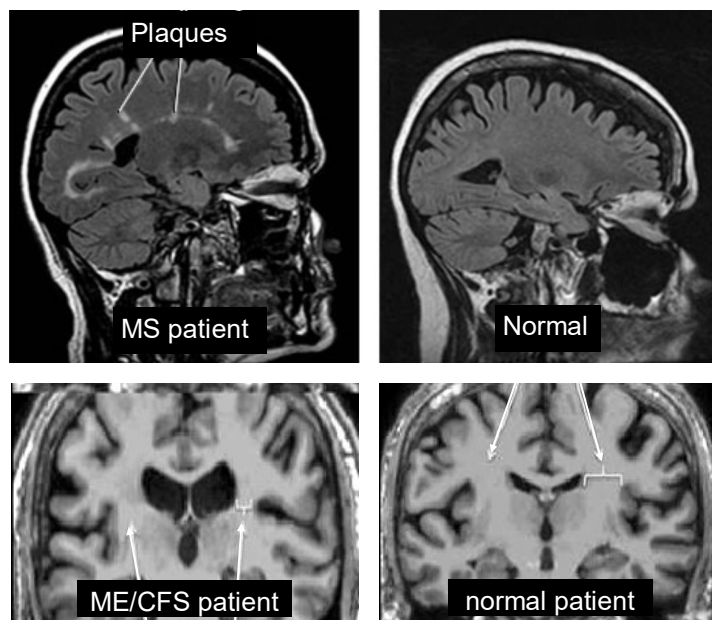
This pattern is often seen in Benign Multiple Sclerosis. In the case of BMS it can be related to inflammatory lesions within the brain or spinal cord. I often wonder if these cases are some misdiagnosed ME or vice versa. Certainly the absence of detectable brain abnormalities would favour ME rather than MS. For comparison, I've included typical patterns from multiple sclerosis. In MS there is a gradual progression with peaks which usually relate to neurological inflammatory plaques. These patterns could also be followed in rheumatoid arthritis where similar inflammatory episodes occur and in Myasthenia Gravis where antibodies attack the motor end plates of muscles.



Comparing Service for ME and MS in Sheffield

In past editions of Pathways, I've compared various chronic conditions, including Multiple Sclerosis (MS), against ME/CFS. The purpose of this series of features was to give credibility to ME/CFS and to show that there are many common themes and differences. I recently attended a meeting about the MS services in Sheffield. I thought it would be a good idea to compare that directly to the Sheffield ME/CFS Clinic's Services. I would like to thank my colleague Benjamin for his contributions.

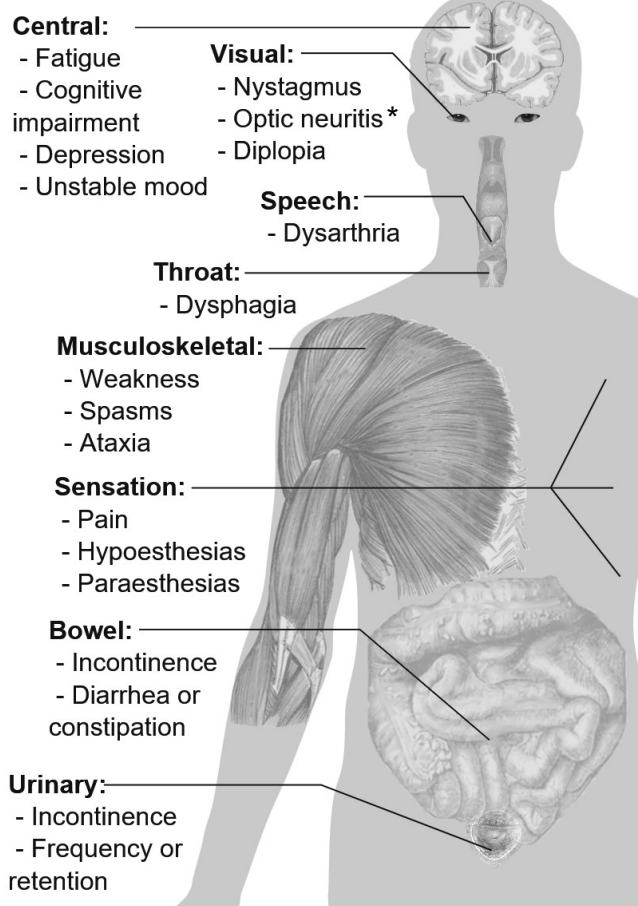
Firstly, looking at the two conditions. MS is an inflammatory disorder of the brain and spinal cord in which focal lymphocytic infiltration leads to damage of myelin and axons. Early in the course of the disease there are periods of neurological dysfunction that usually recover. However, in the long term there is disease progression where there is extensive and chronic neurodegeneration, the clinical correlate of which is progressive accumulation of disability.



While conventional MRI scans show definite abnormalities with MS, with ME/CFS the differences are a little more difficult to show, but they are there. The amount of white matter within the brain is measurably reduced. This corresponds to the nerve axons (wiring within the brain). Also there are measurable mitochondrial abnormalities within cells. Mitochondria are the power stations of the cells, and there are many of them in each cell. They need sophisticated high-magnification electron microscopes to actually see them. Mitochondria are found in all body cells.

There was recently a programme about MS on TV. Quite a number of *Pathways* readers asked me what the differences were in symptoms. In fact, some readers were beginning to believe they have MS. There are a very small number of people have a dual diagnosis of ME & MS.

The image to the right is a summary of MS symptoms, all of which are common to ME/CFS with the exception of optic neuritis (marked with *). In MS it can happen quite suddenly, with someone painfully losing their eyesight on one side. This one difference between ME/CFS and MS requires urgent investigation and treatment to try and avoid the possibility of total permanent sight loss.



With MS the symptoms seen can be related to the anatomical part of the nervous system affected by plaques. Sometimes, on MRI scans, plaques can be seen with no symptoms. It is though there is a certain amount of redundancy within certain brain areas which don't do anything functionally, with ME/CFS there is no similar mapping. It is true that some people are affected on one side or only certain groups of muscles are affected. It is thought that this effect is in the peripheral nervous system or the muscles themselves.

Both conditions are immune-mediated by different mechanisms. With MS, some disease-modifying treatments have been available since 1995, whereas with ME/CFS there is nothing comparable that I know of. The problem is that these treatments are limited to the relapsing remitting variant of MS and there is no treatment for the progressive type. Here is a summary of the MS treatments available on the NHS in Sheffield.

Nervous system area affected by MS plaques	Symptoms
Cerebrum	Cognitive impairment Mood disorders
Optic nerve	Unilateral painful visual loss
Cerebellum	Tremor Poor balance
Brainstem	Diplopia, oscillopsia Vertigo Swallowing problems Impaired speech
Spinal cord	Weakness Stiffness / spasms Bladder dysfunction Erectile dysfunction
Other	Pain Fatigue

Drug	How given	Monitoring (required)
IFN β -1b (Betaferon)	Subcutaneous injected under skin on alternate days	Full blood count and liver functions tests
IFN β -1b (Extavia)	Subcutaneous injected under skin on alternate days	Full blood count and liver functions tests
IFN β -1a (Rebif)	Subcutaneous injected under skin twice weekly	Full blood count and liver functions tests
IFN β -1a (Avonex)	Intramuscular injection weekly	Full blood count and liver functions tests
PegIFN β -1a (Plegridy)	Intramuscular injection fortnightly	Full blood count and liver functions tests
GA (Copaxone)	Subcutaneous injected under skin once or twice weekly	
Teriflunomide (Aubagio)	Oral tablet or capsule daily	Liver functions tests
Dimethyl fumarate (Tecfidera)	Oral tablet or capsule twice daily	Full blood count and liver functions tests, Kidney tests, baseline MRI scan
Fingolimod (Gilenya)	Oral tablet or capsule daily	Full blood count and liver functions tests. Check for heart slowing on first dose
Natalizumab (Tysabri)	Intravenous injection given by drip	MRI imaging to see if effective
Alemtuzumab (Lemtrada)	Intravenous injection given by drip	Full blood count, thyroid, and kidney function tests.

There is nothing similar for ME/CFS in Sheffield. I understand that there is research into treating ME/CFS with biological agents (ending with 'zumab') being carried out in other countries.

Specific differences in strategies between ME/CFS and ME in Sheffield

Relapses: With MS, when relapses occur, they happen very quickly. One treatment option is to give a massive dose of a steroid like methyl prednisolone over a very short time. Typically, this is 500mg. Steroids are anti-inflammatory and immunosuppressive, and drastically reduce the length and intensity of the relapse, but do not improve the extent of recovery. Some years ago a similar strategy was tried with ME/CFS and it didn't work.

Low Vitamin D levels: The geographical distribution of MS cases increases the further north from the equator people live. Vitamin D deficiency also follows a similar pattern. This poses the question of a relationship with MS. I understand that there is no proven causal relationship between the two. Where vitamin D deficiency occurs it is thought of as a random finding and is treated. With ME/CFS, many people have a definite problem with Vitamin D deficiency. If it is a problem, treatment sometimes results in reduced fatigue and less pain, but as in MS, no causal link has been identified. Vitamin D deficiency is most likely to be related to lifestyle and restricted exposure to sunlight. Some patients prefer to buy their own supplement. It may be that other chronic conditions would respond to vitamin D supplementation especially if sufferers are unable to access sunlight.

Fatigue management: This is the last item in this comparison of CFS/ME with MS. With MS it is treated as a symptom rather than the major problem as it is with ME/CFS. Fatigue is one of the most common symptoms in MS, and as with ME/CFS a check is made for reversible causes, e.g. medicine side effects, depression, anaemia or thyroid disease. In MS, treatment is slightly different from ME/CFS. The doctor looks at rest, healthy eating, exercise and sleep hygiene, all of which are standard ME/CFS strategies. If this process fails, they consider drugs.

1) Amantadine, although it is unlicensed for this use, is within the NICE clinical guidance for MS.

For ME/CFS, a report from the USA by Dr. Bell found that 40% could not tolerate the drug (mostly due to jitteriness and anxiousness) and 40% reported from moderately improved to excellent results. Amantadine seemed to be most effective in treating moderately ill patients. Dr. De Meirleir reports Amantadine relieves fatigue in some ME/CFS patients. Dr. Bell reports that the standard dose of 100 mg twice daily causes jitteriness and exacerbates symptoms in ME/CFS. He starts at 25 mg and works his way up to 50 mg daily. However, side effects were reported. Amantadine is said to be generally well tolerated (but seems to be less so in ME/CFS overall). Side effects can include dizziness, trouble sleeping and nausea. Rare side effects include shortness of breath, swelling of hands and feet, nervousness, anxiety, difficulty in concentrating, and exacerbations of pre-existing seizure disorders and psychiatric symptoms. Very rare cases of suicide attempts have been reported in people without psychiatric symptoms taking short-term courses of Amantadine for the flu.

2) Modafinil (again unlicensed) is used against fatigue in MS. No medical intervention like this is available from the Sheffield ME/CFS clinic nor is any within the NICE ME/CFS guidelines.

Modafinil is a drug that is currently being used in the symptomatic relief of excessive sleepiness associated with narcolepsy, obstructive sleep apnoea/hypoapnoea syndrome and moderate to severe shift work sleep disorder in adult patients. The problems are that serious skin rashes requiring hospitalisation and discontinuation of treatment have been reported in adults and children in association with use of modafinil within one to five weeks of initiation of treatment. Modafinil should be discontinued at the first sign of a rash and not restarted. Adverse psychiatric events including psychosis, mania, delusions, hallucinations, suicidal ideas and aggression have also been reported. If psychiatric symptoms occur, modafinil should be discontinued and not restarted. Caution should be exercised in administering modafinil to patients with a history of psychosis, depression or mania. Modafinil has also been assessed as a possible form of treatment for ME/CFS and two papers have been published in relation to this (Turkington et al 2004; Randall et al 2005). Given this new information it would not be sensible for people with ME/CFS to take part in clinical trials if they have a history of drug-induced skin rashes or psychiatric illness.

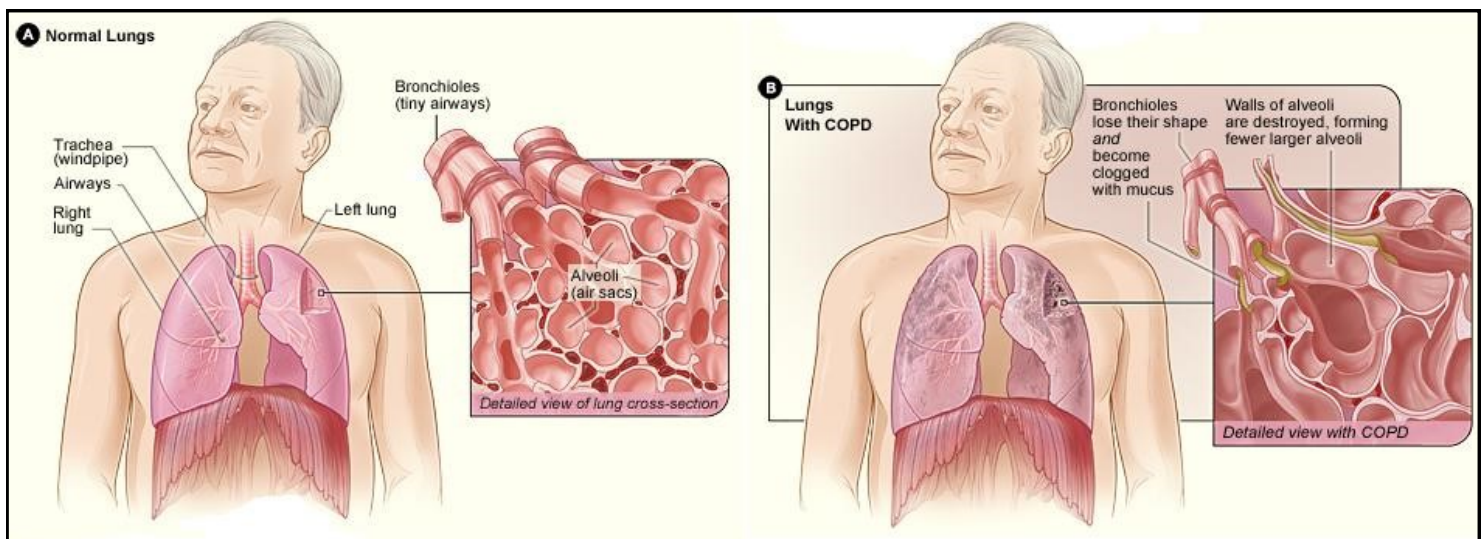
What stands out like a sore thumb is the complete absence of the ME/CFS management cornerstones of cognitive behaviour therapy, graded exercise therapy and pacing from MS fatigue-management strategies.

Smoking and ME/CFS

If you have ME/CFS and smoke, by stopping smoking you can massively improve your health.

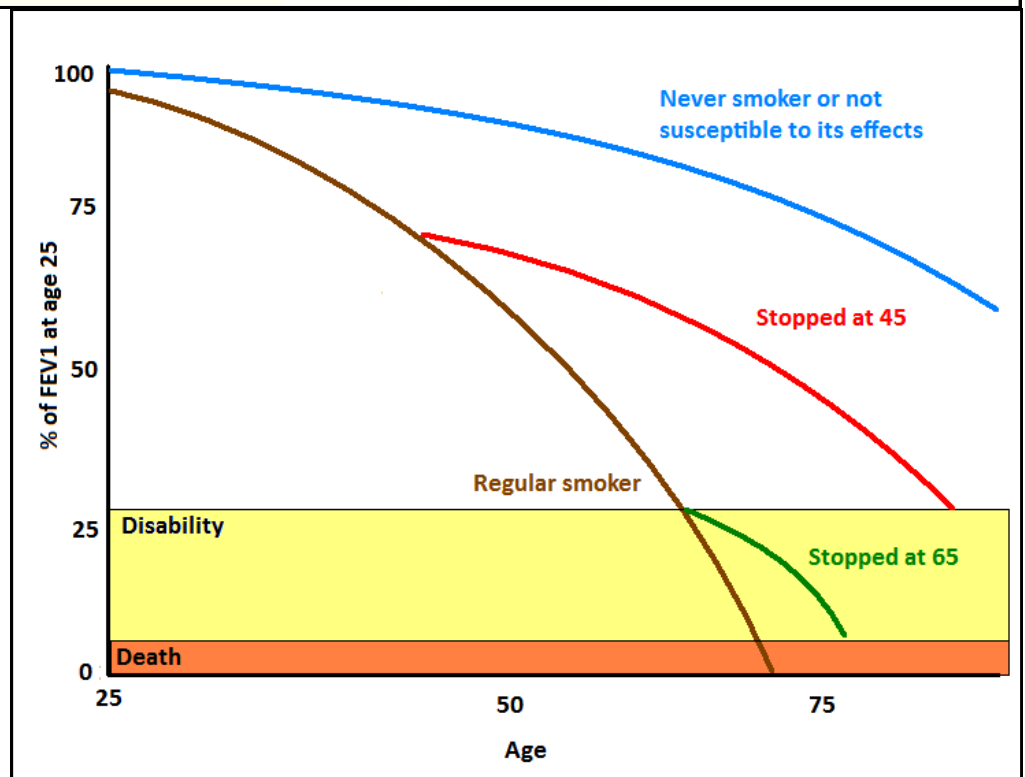
Many years ago, shortly after qualifying, I drew the short straw for the Oxygen Round in Barnsley. The coalfields of South Yorkshire were one of the blackest blackspots for respiratory disease — the legacy of coal and smoking. Now many years after the South Yorkshire coal mines have almost gone there is still the legacy of a major health blackspot in the Conisbrough & Mexborough area. My job was to take oxygen cylinders to patients in their homes. They were of two sorts, firstly those with lung damage due to lung diseases e.g. Chronic Obstructive Pulmonary Disease and cancer. The second group were the more clinically interesting cases, mainly asthmatics and those with heart failure. I witnessed many patients in their homes gravely ill, unable to leave the house and needing oxygen. Almost all were smokers and it was very distressing to see patients gasping for oxygen and then lighting a cigarette. Matches and other naked lights themselves are also a danger. Going back to school, a classic science experiment is to put a glowing splint into a jar of oxygen, and see it burst into flame. At the local hospital where I'm a volunteer, smoking is banned with good cause. There are many patients on oxygen who still feel the need to smoke. Fires from cigarettes are a major cause of damage within a hospital.

The biggest cause of COPD in our area is smoking. There are other causes e.g. genetic, other lung diseases, occupational and substance sensitivity. Whatever the cause, the following happens: -

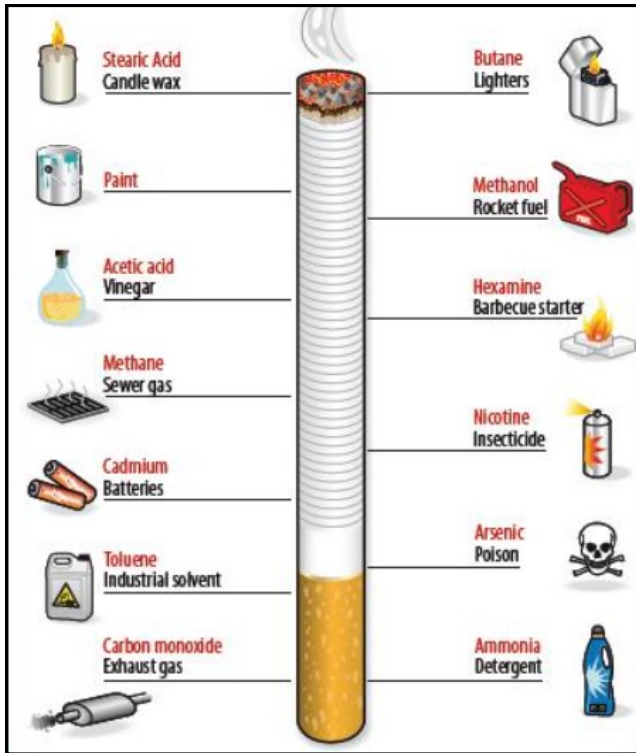


Naturally lung function decreases as we get older. FEV1 is used to measure lung function. To the right the blue line shows a healthy aging curve. The brown shows a regular smoker who would become very disabled in their mid-sixties. However, if they stopped smoking at 45 the smoking legacy would catch up with someone in the late 90s. Even if someone who is disabled gives up in their mid-sixties, it will add another five years to their lives.

COPD is progressive. Treatments only relieve symptoms or slow down health deterioration, they do not cure.



The chemicals present in cigarettes can cause disease in every part of the body.



Other smoking-related matters.

E cigarettes and Vaping. These are regarded within the health community as being less dangerous than cigarettes. They are promoted as reducing harm. The main issue is the fluids used—and many of the ingredients are not proven safe. Most health professionals I know view them as being just as dangerous as smoking cigarettes.

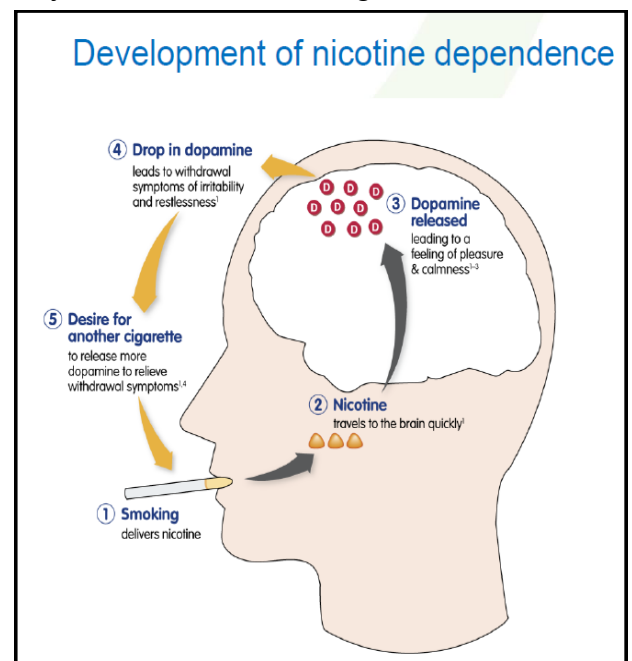
Herbal cigarettes, cannabis and other illegal drugs. These are considered just as dangerous as tobacco smoke. Really anything with a naked flame emitting fumes is dangerous. For cannabis, the increase in health risk is 4-10 times that of cigarettes depending on the information source..

Secondary exposure to Smoke. There is good evidence that being near someone who smokes receives as much as 50% of the airborne fumes as the smokers. This is why smoking is banned in many public places.

Strategies to help smoking cessation. Over the years many devices and strategies have been marketed to help people stop smoking. Current thinking is that smoking gives people pleasure and calmness by releasing dopamine in the brain. Once level drops, withdrawal symptoms of irritability are experienced—so this leads to a desire for more cigarettes to relieve withdrawal symptoms.

Nicotine Replacement Therapy (NRT) is intended to break the cycle. There are six types of NRT; patches, gum, lozenge, micro-tab, nasal spray and inhalator with no evidence to show one form being more effective than another. NICE has approved the following therapies for those who are planning on quitting; Nicotine Replacement Therapy (NRT) and the drug therapies bupropion (Zyban) and varenicline (Champix).

There is a smoking Cessation service available at the Redmond Centre.



North of Doncaster. *Personal comment from Trevor Wainwright***Three Festivals, three anthologies and three cars Part 2: *The journey continues.***

I made good time to Lamesa, the usual breakfast and comfort stops, do a bit of composing, then on my way again. The sun came out, the sky was completely blue, spring flowers in bloom at the side of the highway, very quiet, a great drive. Driving steadily into the town, with St George's flags on my car, waving to some of the townsfolk who waved back; it felt great to be back. Arriving at Connie's and being met with hugs, she showed me the anthology, I found my poems but there was something I missed. I wouldn't find out until the following day, but I'd got my second anthology, and was ready for my second festival but first it was get to KEPT and a live promo, welcomed back like an old friend. I did the promo then it was head for Darla's (Connie's sister) and a great Texas welcome. To describe her house would be to say it was like a mini Southfork from Dallas. We began to eat and talk then a big cloud appeared on the horizon. Thunder began to roll across the plain. The wind started picking up, bringing in a Lamesa dust storm. It took the lighting out so we sat out of the wind on the porch outside sharing our songs and rhyme, as night drew in.

Friday morning breakfast at Connie's and so the 15th Forest Fest began, with me leading the way to KEPT, again the St Georges flags proudly flying. Once there Thom said, "it's your show Trev, you're the man" leaving me to open the show and do the introductions, Connie was the last one to read, then it was to the first of the Aged Persons Homes where I read *The Saluting Boy*, this resulted in me meeting a former soldier who had served in the Pacific fighting the Japanese. It was an honour to shake his hand, the tour continued then at the final venue, an aged person's day centre. Thom told me what I should have known, that my poem *Caring* had taken second place in the Peggy Zulika Lynch Competition, blind-judged by students who knew nothing about poetry. It went down well when I read it.

The afternoon saw me Thom and Bob at a children's centre, performing for them and encouraging them to write. They did and they were good. The final two events of the day were Steve Brooks and Evelyn Roper doing their annual Buddy Holly tribute on the projection house roof at the Sky View Drive In, and a poetry slam at Lamesa Country Club. Six of us decided to enter. Connie and I went out on the first round. Thom got to the final but lost to a new guy called Caleb from Lubbock. However, he did have one claim to fame, he was the only one among us to score a zero from one of the judges, something that would haunt him later. The first day had gone great, at last my tour was coming together. Things would only get better I thought, driving back to the motel.

Saturday was party day beginning with workshops. It was also great to be working with David Lester Young who dresses as Benjamin Franklin (the man on the \$100 dollar bill). He was stopping at Connie's; her computer had a virus and he sorted it, Cowboy Poet John Levacy again ran a great workshop, me inspired to write a poem based on the Cowboy Code. After lunch we let the afternoon unfold at its own pace, beginning with a ladies event while the rest of us chilled, me in Forrest Park listening to Connie's son Dusty strumming on a guitar, then we gathered for a jam session in the park to bless the trees, this was enhance by the bringing out of the parachute of hope, on which I left a message on 16 April 2011, my debut there, the message read, "Trev Cas' Lad" my stage name at the time. "One chance is all you've got, give it your best shot." Afterwards it was the Pinata, a star shaped object filled with candy hung from a tree. People take it in turns to be blindfolded and hit it with a stick until it bursts and everyone gets a share, this brought forth much amusement and delight when it finally burst. The final event began with the showing of the Forrest Fest 15th Birthday Cake, blue and pink icing with both chocolate and plain sponge in the middle. Daniel made a presentation to Connie for all her work and the final event got underway, the show went on, performer after performer. I would read poems that I had written on my tour in addition to my regular featured ones, then that was it, the last act then clear the hall, and so to bed, but with great memories of a great well planned event.

Sunday morning and back to Austin, composing as I was driving, starting the afternoon with an event at a second hand bookstore called Recycled Reads. It was to be a mixture of poetry and prose, poets were given three minutes, prose readers were given longer, one having to be stopped after 15 minutes. Later it was Kick Butt, my turn to read and I mentioned that David, Thom and I had been at Lamesa, and mentioned their new nicknames; Mr \$100 and Thom Zero, then completed my spot to great applause. Both were introduced with them later, David giving me the first bump in respect. Thom received a zero sign from Mark, one of the more eccentric poets.

Monday night and I was back at Riley's Bar telling Joe I had already decided what I was going to read, including some new work. Later though, listening to the band play a song from the 1960's and a poem written about it, I was telling him I was changing things, he referred to me as a minuteman poet., later introducing me as such adding "He may well recite a poem he wrote a minute ago". I replied with the quip, "actually it was a minute and a half". Again the evening went well and a surprise after the performance, one of the audience was a guy from Doncaster who was working in Austin, I was the last thing he expected to see.

Wednesday, and I was once more on the road, this time to San Antonio, to book into the motel and find the new venue, along with a visit to the local library to catch up on things back home. I came out of the library to it pouring with rain, but it was warm, the last time I had felt warm rain was May 1994 during my first overseas aid mission to Croatia during the Bosnian conflict. Then it was get to the venue, finding out that San Antonio at rush hour is somewhat like suicide alley, eyes in the back of your head came to mind. Taking it steady I arrived with plenty of time and gave a great performance again beginning with the Saluting Boy and ending with Along the Texas Coastline with new poems in between, coming away with more donations for AWR.

I made another early start on Thursday. Daniel had said if you can get to East Weslaco High lunch is on me. Never one to turn down a free meal I did, it felt great to be back, as I walked to the college. I would be giving an extra afternoon performance, in addition to the planned one for Friday. Lunch over, I began reading and saying how I worked to pay for my trip and how everybody had a part to play in college, stressing the importance of the Janitors in keeping it clean.

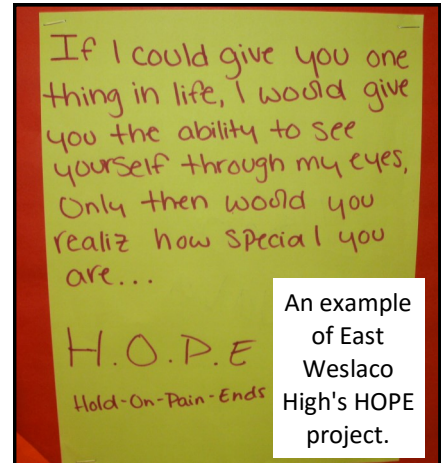
That evening saw the opening of my third festival where I received my third anthology and had driven there in my third car. Yes, it had all come together and would stay together as all who featured in the anthology read their work despite the humidity, insects biting and thunder bringing the threat of a storm. New friends had been made. One, a Professor of English, had a look at my entry in the anthology and handed me it back with a \$5 dollar bill in it. I asked if I would mind if I gave it to AWR, he said he would be honoured. We finished just as it began to rain. It was time to go, me to my hotel, paid for by the local Chamber of Commerce, a perk of being the Visiting Guest International Poet, when it broke into a full thunderstorm, the benefit of which I realised the following morning when I was getting into a cool car to drive to my second stint at East Weslaco High, again the Saluting Boy went down well.

That night it was the annual slam. I was the only one not to read from a script, made my poem up on the spot, and finished my spot with 5 seconds to spare; never the less I still came last but as usual enjoyed the experience. Saturday—a good breakfast and on the road again this time to workshops and open mics, the first being at South Padre Island. Driving over the bridge to the Island it felt like I was coming home, both workshop and open mic going well, the others couldn't believe how prolific I was as poem after poem was composed. Then it was to Harlingen for a lunch time recital at a local grill again going down well, one of the nicest parts was the food there. The final—Pechanga—again a great night good food and company, a chance once again to share experiences. Again, I read The Texas Coastline. After the event one of the poets asked if next year I would come to his school in a deprived area, saying he would be honoured. I said if it could be arranged the honour would be mine.

After another early start a long drive, more poems composed on the way. It was back to Austin ready for my final performance at Kick Butt. I was walking across the car park there when one of the hosts known as Hot Tamale saw me and said "Trev you're still here". I said "Yes, driven up from McAllen this morning after the Valley Fest". She too had also driven from the South, from Laredo. Again a great night again sharing our stories then it was time to make my way back to the motel and pack. That night there was a thunderstorm. I'd never known one like it, the whole motel seemed to shake. My thoughts were about the flight home. I needn't have worried. The flight was not till late afternoon. I woke later and the sun was shining, the thunder storm had left the air smelling fresh, I had mixed feelings as I loaded the car but looked forward to being with my family again, and sharing my poetry with others of like mind on my return. The plane took off on time I was still writing and would continue to do so even writing seven haikus on the final run in, more on the last flight and the final poem after I got home bringing my total of tour poems since 2011 to 733, making me until proven otherwise the UK's most prolific travelling poet.



Leo Pena Placita Park Mission.
The towel represents the disciples
washing the feet of Jesus



At East Weslaco High showing my
living cheaply skills



The three anthologies

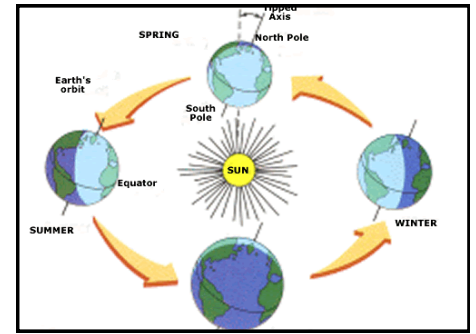


Nearly home, welcome to Heathrow

Spring Seasonal Traditions

Why is Easter not always on a fixed day?

Everyone knows that Christmas day is on the 25th December, but Easter is not. Ever wondered why? Going back to schooldays and lessons, we were taught about the Passover, and its relevance to the Jews. We also learned about the events of The Crucifixion—and how it related to the Christian faith. It was an English monk, the Venerable Bede in the dark ages, who came up with a nice way of remembering when Easter falls - it's the first Sunday after the first full moon after the spring equinox. As we were taught in school the Earth's orbit around the sun is almost circular. The axis of rotation is offset at 23 degrees, and remains fixed in space. The consequence of this is the short days in winter and the long days in summer. The spring equinox occurs where both day and night are twelve hours long –this usually being between the 21st and 22nd March. The moon orbits the Earth, in 28 days, but is not synchronised to the Earth's orbit. If you do your calculation the earliest Easter can be is 22nd March, and the latest it can fall is 25th April. So really the dates for Easter are determined by two independent astronomical events. There is a third dimension—this is the different Christian churches who have slightly different interpretations, as have the Jews and Muslims.



Historically the moveable date for Easter caused many inconveniences. In the UK, The Easter Act 1928 is an Act of the Parliament of the United Kingdom first passed in 1928, but not implemented. The purpose of the Act is to provide a fixed date for Easter rather than the current moveable feast. The effect would be to establish Easter Sunday as the Sunday following the second Saturday in April, resulting in Easter Sunday being between 9th April and 15th April. The Act is so phrased as to require the agreement of both the House of Commons and the House of Lords before the Government may issue a Commencement Order. It also requires the opinion of all relevant churches be taken into account, although it does not require their consent. Although the subject is raised occasionally in Parliament, this agreement has not been achieved. You do hear about this from time to time. In January 2016, Archbishop of Canterbury Justin Welby announced that he had been in discussions with the Catholic, Coptic and Orthodox leaders over a fixed date for Easter, and that he hoped it would happen within the next five to ten years. Welby has suggested that Easter be fixed on either second or third Sunday of April relative to the Gregorian calendar. This proposal remains to be approved, especially by Eastern churches.

Easter Eggs

Easter eggs, also called Paschal eggs are decorated eggs that are often given to celebrate Easter or springtime. As such, Easter eggs are common during the season of Eastertide (Easter season). The oldest tradition is to use dyed and painted chicken eggs, but a modern custom is to substitute chocolate eggs, or plastic eggs filled with confectionery such as chocolate. Although eggs, in general, were a traditional symbol of fertility and rebirth.



For Christians, for the celebration of Eastertide, Easter eggs symbolize the empty tomb of Jesus, from which Christians believe Jesus resurrected. In addition, one ancient tradition was the staining of Easter eggs with the colour red "in memory of the blood of Christ", shed as at the time of his crucifixion. This custom of the Easter egg can be traced to early Christians of Mesopotamia, and from there it spread into Russia and Siberia through the Orthodox Churches, and later into through Europe through the Catholic and Protestant Churches

Pancake Day.

the Easter egg tradition may also have merged into the celebration of the end of the privations of Lent in the West. Historically, it was traditional to use up all of the household's eggs before Lent began. Eggs were originally forbidden during Lent as well as on other traditional fast days in Western Christianity (this tradition still continues among the Eastern Christian Churches). Likewise, in Eastern Christianity, meat, eggs, and dairy are all prohibited during the Lenten fast. This established the tradition of Pancake Day being celebrated on Shrove Tuesday. This day, the Tuesday before Ash Wednesday when Lent begins, is also known as Mardi Gras, a French phrase which translates as "Fat Tuesday" to mark the last consumption of eggs and dairy before Lent begins.

