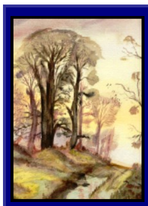
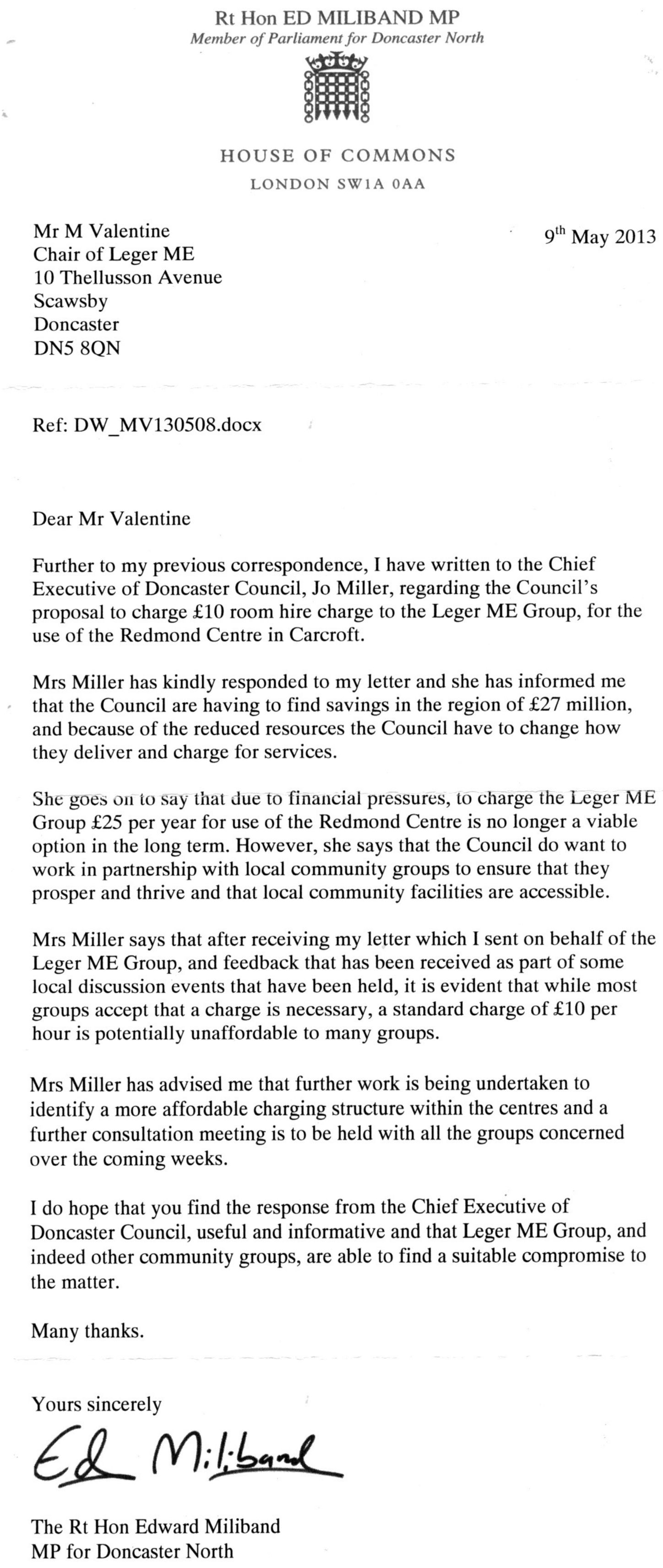


Price £ 2.50 (Free to members)

Pathways

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



Rt Hon ED MILIBAND MP
Member of Parliament for Doncaster North

HOUSE OF COMMONS
LONDON SW1A 0AA

Mr M Valentine
Chair of Leger ME
10 Thellusson Avenue
Scawsby
Doncaster
DN5 8QN

9th May 2013

Ref: DW_MV130508.docx

Dear Mr Valentine

Further to my previous correspondence, I have written to the Chief Executive of Doncaster Council, Jo Miller, regarding the Council's proposal to charge £10 room hire charge to the Leger ME Group, for the use of the Redmond Centre in Carcroft.

Mrs Miller has kindly responded to my letter and she has informed me that the Council are having to find savings in the region of £27 million, and because of the reduced resources the Council have to change how they deliver and charge for services.

She goes on to say that due to financial pressures, to charge the Leger ME Group £25 per year for use of the Redmond Centre is no longer a viable option in the long term. However, she says that the Council do want to work in partnership with local community groups to ensure that they prosper and thrive and that local community facilities are accessible.

Mrs Miller says that after receiving my letter which I sent on behalf of the Leger ME Group, and feedback that has been received as part of some local discussion events that have been held, it is evident that while most groups accept that a charge is necessary, a standard charge of £10 per hour is potentially unaffordable to many groups.

Mrs Miller has advised me that further work is being undertaken to identify a more affordable charging structure within the centres and a further consultation meeting is to be held with all the groups concerned over the coming weeks.

I do hope that you find the response from the Chief Executive of Doncaster Council, useful and informative and that Leger ME Group, and indeed other community groups, are able to find a suitable compromise to the matter.

Many thanks.

Yours sincerely

Ed Miliband

The Rt Hon Edward Miliband
MP for Doncaster North

Ed Milliband: More on the £10 per hour meeting charge

To date we have heard nothing further about the £10 per hour meeting room-charge threat. The letter to the left has been received as a follow up to the letter in Pathways 35. We are not certain who passed our concerns on to Ed, but we are grateful for his interest and intervention.

I, however, need to clarify on one issue. The £25 per year that Leger ME pays is to the Redmond Centre Community Group, and not to DMBC. The RCCG is an umbrella organisation that includes all the voluntary community groups that use the centre like ourselves. The RCCG raises funds for local good causes by organising various events and acts as a liaison between the user group and the Centre Manager. One way the RCCG helps community groups is by clubbing together and buying a public liability insurance policy from DMBC. We, like each member group, contribute £25 towards the cost of this policy. It a massive saving because it would cost each group like ourselves about £250 per annum for a public liability insurance if purchased individually.

Interestingly the RCCG have decided that this year's good cause is themselves—so the money raised will be ploughed back to the Redmond Centre User Groups. However I think it is inevitable that we will have to pay some increased room-hire charges.

Changing the subject. This edition of Pathways is about month late – purely because the office has been saturated with members' problems around welfare rights issues.

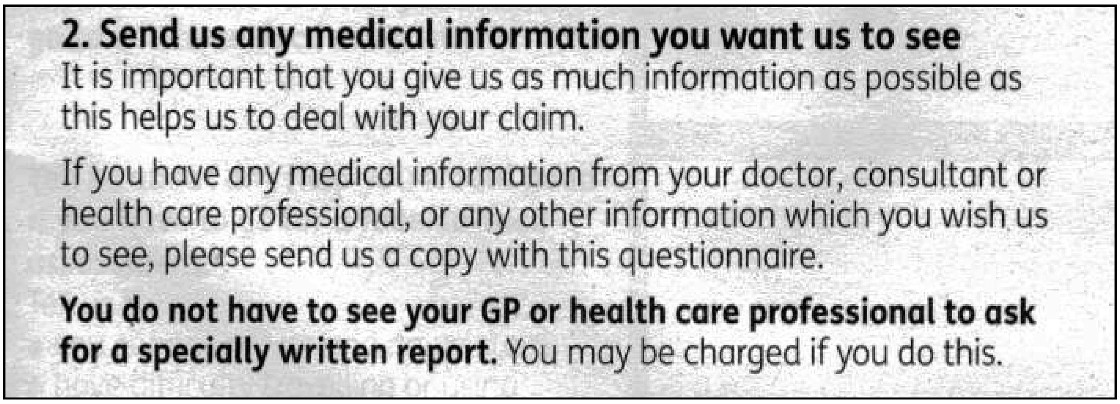
There is no doubt that the government intended to cut ESA & DLA. However the measures they introduced seem to have backfired financially. I also detect more of a laissez-faire attitude amongst DWP staff, and a more big brother approach by its contractors. *More inside*.

Gwen writes: Further to my ESA 50 fill out, and your request for me to obtain a medical record summary sheet, I've been to see my doctor today and she says that the DWP have told her that it is a waste of time, and if she sent it, they said they wouldn't bother to read it. During the conversation I brought up the word ATOS and she didn't know a thing about them. Anyway I've insisted that she does this and she is going to charge me £25. The other thing is that she has had quite a number of her patients with the same request she has declined. What's going on?

I'm fairly certain that your doctor has got this wrong or the practice has a policy of not co-operating with the DWP. Taking this at face value –I could say that your doctor is not acting in your interests and in fact may be causing you harm, and you should make a complaint about it or consider changing your doctor. However I think perhaps that she or the practice completely misunderstand the system.

A medical record summary sheet is really a brief statement of the status of your medical records. Apart from personal information it contains your current diagnosis/diagnoses, a summary of and tests of investigations, a record of recent appointments and repeat prescriptions. This information is available from most patient computer systems as a one or two page printout and can usually be obtained by anyone working in the surgery. As a courtesy I ask people to ask for it personally from their doctor. This document contains almost all the information required to fill out the early pages of DLA, ESA and PIP claim forms. The same information can be acquired indirectly, as I do in case reviews, from appointment cards and letters. It saves a lot of hassle on your part and our part. This is information you are entitled to under the data protection act subject to certain safeguards. We think that many doctors are reluctant to produce detailed medical reports for you personally because they get fees from the DWP on forms like ESA113 and DBD 370. These fees usually go the practice and not the individual.

Where I think your doctor has got the wrong end of the stick is that she does not understand the system. The DWP as a fund-holder pays ATOS (as a service provider) to process their forms and make assessments . It is the DWP that makes decisions about what they get in terms of information. Both the DWP & ATOS have their own databases and these are not linked in any way which often leads to confusion, misleading information and erroneous decisions to say the least. Such issues plague many of our members.

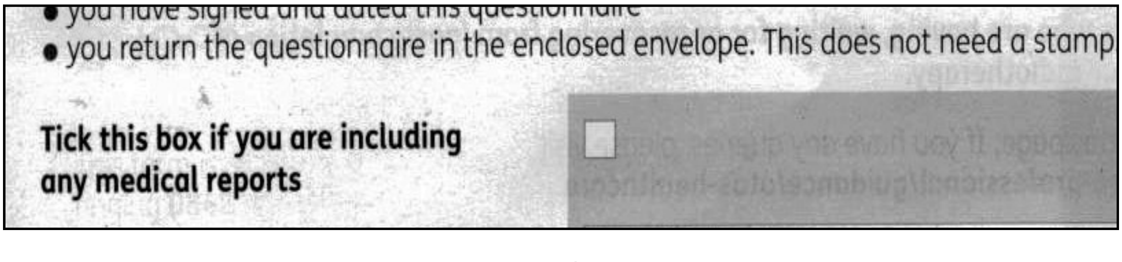


2. Send us any medical information you want us to see

It is important that you give us as much information as possible as this helps us to deal with your claim.

If you have any medical information from your doctor, consultant or health care professional, or any other information which you wish us to see, please send us a copy with this questionnaire.

You do not have to see your GP or health care professional to ask for a specially written report. You may be charged if you do this.



- you have signed and dated this questionnaire
- you return the questionnaire in the enclosed envelope. This does not need a stamp

Tick this box if you are including any medical reports ☐

My final comment is that on page 1 of the ESA 50 form on section 2 it says ''send us any information you want us to see", and on page 19 is a box asking for a list of additional documentary information. So, I certainly think that your doctor has it wrong. She may be confusing a letter frequently sent by the DWP to GPs saying that sick notes are no longer necessary when ESA is awarded.

Almost all the guidance I give is based on our 'inquests' for benefit refusals. Since we started to include medical record summary sheets, the number of benefit refusals has declined dramatically.

Susan Writes: I went to the dentist in February to have a crown fitted onto my lower back-most tooth. On the first visit the dentist gave me the usual injection, waited 2 minutes then proceeded to drill and put in a temporary crown.

One week and one day later I went back to have the work completed. Usual injection, 2 minute wait, but when she started work it was painful. She gave me a second injection and I went outside to wait for 10 minutes. We tried again, but still painful, so a third injection and another wait. When after the fourth injection and another 20 minute wait I was still not numb we were both worried! The dentist didn't understand how the anaesthesia could work one week but not the next. Even more worrying was how I could have four doses of anaesthesia and still feel as if I hadn't had any at all. In the end I told her to carry on. I would take as much pain as I could before signalling for her to stop; she would give me a minute to recover and then do a little bit more until I needed her to stop again. We were apologising to each other as we went. Eventually the work was completed. Needless to say, I now live in dread of having to undertake further dental work without the anaesthesia working.

The dentist stated that she was aware people with ME/CFS usually needed a little more anaesthesia, but couldn't understand how I could take the maximum dose she was able to give without it working at all. I am assuming the medication itself was OK and nothing was wrong with it. I have many questions. What could have happened to my body in the eight days between appointments? Will it happen again? Does the NHS have alternative drugs or methods of treating me?

I've had a word with a dental colleague I know and there is a detailed explanation about what happened which could have happened to anyone not just someone with ME/CFS.

On your first appointment the dentist would have remove decayed and disease material from your tooth, and then shaped the resulting cavity or stump to take filling material and capped the tooth off. The temporary crown would be to then cemented on. The back molar teeth in the lower jaw have three roots, all complete with their nerve supply and capable of feeling pain. To anaesthetise the tooth your dentist will have two choices, firstly of inject a dose of local anaesthetic at the apex of each tooth root, known as infiltration. This would involve at least three injections targeted at each apex. X-ray's may have been taken to check the anatomy of the roots because at the back they may be bent and may go outside the area of the tooth. The second option and the most likely choice of the dentist would have been to do a regional nerve block on the lower jaw branch of the trigeminal nerve. The local anaesthetic would be injected into the nerve bundle behind the back tooth that serves all the teeth on that side. The anaesthesia in that case would affect the whole half of the lower jaw, and would have been deep. The dose of anaesthetic would have been large. That is why you had no problems with first appointment.

Some molar teeth have roots which have deviate outside the footprint of the tooth which are difficult to anaesthetise locally

At the second appointment the dentist would 'take off' the temporary crown, check the tooth and then cement the crown on. This could be done without an anaesthetic because the removal of the crown would be from filling and non-living material with no nerve supply. However, many dentists choose to use a local anaesthetic to be on the safe side, particularly if there is a likelihood of abnormal pain sensitivity for example with ME/CFS. However the anaesthetic dose used in much smaller and is usually targeted at the root apex using the local infiltration technique rather than the whole region anaesthetic block. So firstly the level of anaesthetic would not be as deep and secondly it would be local to the tooth.

Once you started to feel unexpected pain, this would make you panic, anxiety would kick in and you would anticipate pain every time your dentist did something. Mentally this would turn up your pain sensitivity– and you would feel pain more. Successive injections would have been speculative to try to achieve anaesthesia. There can be a fourfold difference in dose needed to anaesthetise and calm one patient as opposed to another in sheer panic. The dentist would have been stressed as well, and how he or she handled this could have affected your perceptions of pain.

Why you got that pain in the first place has several possibilities, and could be a combination of all... Given the first dose anaesthetic would have been light the pain could have come from an adjacent tooth not anaesthetised, or from an apex of an affected tooth outside the infiltration area. The second possibility is that the touching of a metal crown to a different metal e.g. dental instrument or other filling in your mouth created a miniature battery and stimulated a distant nerve. This is a well-known electrolytic affect, and is sometimes experienced by people with dissimilar metal fillings which accidently come into contact with aluminium foil, e.g. from a bite of a wrapped chocolate bar or cutlery. The local anaesthetic used commonly is lidcaine (xylocaine). It comes with or without adrenalin. The adrenalin is a vasoconstrictor to the jaw and reduces local blood flow thus making the anaesthetic be deeper and last longer. It could be a stimulant, and increase pain perception if used. If someone has a condition that would be affected by adrenalin e.g. heart condition or diabetes, the adrenalin- free version is used. Dentists generally use the adrenalin-free version for people with ME/CFS.

Your problem was basically a 'one off' and it really should not put you off any future essential dental work. The use of a general anaesthetic for your procedure would be medically unjustified because of massive risks associated with general anaesthetics. I've heard of trials of a Tens type of machine being used in dental procedures. However if I were in your situation, prior to any future appointments I would take a couple of strong painkiller tablets - e.g. paracetamol & codeine a couple of hours before, and have a word with your dentist about the choice of local anaesthetics beforehand.

Bernadette writes: I'm sorry that I've not been in contact with the group, but in October 2010 I was diagnosed with breast cancer. I've had a mastectomy. chemo & radiotherapy. Just before my operation my mother died and I've had a series of family bereavements. I've had good treatment at the hospital and have an excellent oncologist who I see every six months. I've ended up with lymphedema and I have to see the nurse every three months. I have missed your newsletters. However my main problems as ever are ME/CFS-related. What I'm finding very difficult is the exercises from the clinic to help control my lymphedema.

As you will possibly guess, the chemotherapy I had caused my hair to fall out, and gave me increased fatigue. I have a friend treated at the same time as me, and we have followed similar paths. She found it very difficult to cope with the fatigue and was surprised that I could cope with it as well as I did. The fatigue from chemotherapy is exactly the same as that with ME/CFS, but because I have previous experience with pacing and handling ME/CFS relapses, I could handle it better that my friend who found it very difficult. While very often I would attribute my health problems to ME/CFS, now I have to report everything to my doctors. They have offered me a bone-density scan and I have now to take raloxifen for five years. What could I now be doing to treat for the ME/CFS?

Breast cancer is the most common cancer suffered by members of Leger ME. Overall a woman in the general population has about a 1 in 8 chance of getting breast cancer. The proportion of people with ME/CFS is about the same. In the news recently you will have heard about the BRCA 1/2 gene mutations—it is worth asking your oncologist if this was your case, as it will have implications for your children and other family members.

Sounds like you have had the full range of treatments available. The first thing most people will want to know is if the cancer has been cured. It is really only if you are clear after five years that it can be considered cured.

Cancer can re-occur, and there are no guarantees. The raloxifen is a preventative treatment just in case. It is a more recent updated derivative of tamoxifen which has been used for many years.

As far as your future management for ME/CFS goes: Firstly, do rigorously have your oncology check-ups and ask your doctor to check your bloods, blood pressure etc. to ensure that later life health problems, which are usually easily treated if they occur, are caught in the early stages. Raloxifen is an anti-oestrogen, and it is certainly is worth having your bone density for checked for osteoporosis. While you should stop taking food supplements when undergoing cancer treatment, you should consider an A-Z multivitamin and a fish/ vegetable EPA/GLA oil supplement after your treatments have finished because group-wise we know these help ME/ CFS. Regarding your hair falling out, it should grow back. One group member had grey hair prior to her breast cancer chemotherapy. Once the chemo had finished, it grew back—dark ginger, her normal colour before she went grey.

The Holiday Mind

(From inspiration seen on a boat in the Norfolk Broads)

THIS month Pathways readers will be having their holidays.
We want them to have real holidays.
From the viewpoint of psychology a holiday is more than a mere search for pleasure and amusement:
More than a relief from the routine of daily work:
More than a renewal of bodily heath.

A real holiday is the achievement of a completely care-free mind.
Unless you can realise that, your holiday will not do you very much good.
You go away to get a change of air, a change of scenery, a change of life.

Don't take a scrap of your everyday life with you.
Forget there is such a thing as memory.
Cultivate forgetfulness!
Too many people take excess luggage with them in the shape of business and home worries.
Believe us, they pay heavily for it.

Once you step into the train forget you ever had any work to do.
Forget those unpaid bills;
Don’t give a single thought to the worries and difficulties of the week after next.
Give politics a rest.

Forget there is such a thing as a newspaper.
Most of us live too much in the future: a few live too much in the past.
Just for once live entirely in the present.
Get back to the days when you were young,
When you were content to let others do the worrying for you.

Holiday time is the one time in the year when mental slackness is a virtue
Delicate machinery is given a holiday periodically, for even steel gets tired,
Give the infinitely delicate machinery of your mind a holiday.
Just for once don’t think,
Just BE.

That **IS** the true Holiday Mind.

Recipe corner

Chicken and Broccoli Pasta Bake

Cooking time: Ready in about 40 mins.
Serves: 4

Ingredients

350g pasta shells or quills
200g broccoli,
cut into very small florets
and the stems thinly sliced
2tbsp olive oil
350g boneless, skinless chicken breasts,
thinly sliced
175g chestnut mushrooms, quartered
4tbsp sundried tomato paste
(just leave out if you don't like tomato
– it still works!)
80g pkt soft cheese with garlic and herbs,
(such as Boursin)
284ml carton single cream
100ml or so, semi-skimmed or skimmed milk
(optional – see note in Method)

For the Topping

Bunch of spring onions, finely sliced
85g mature cheddar, grated
1 garlic close, finely chopped
50g flaked almonds

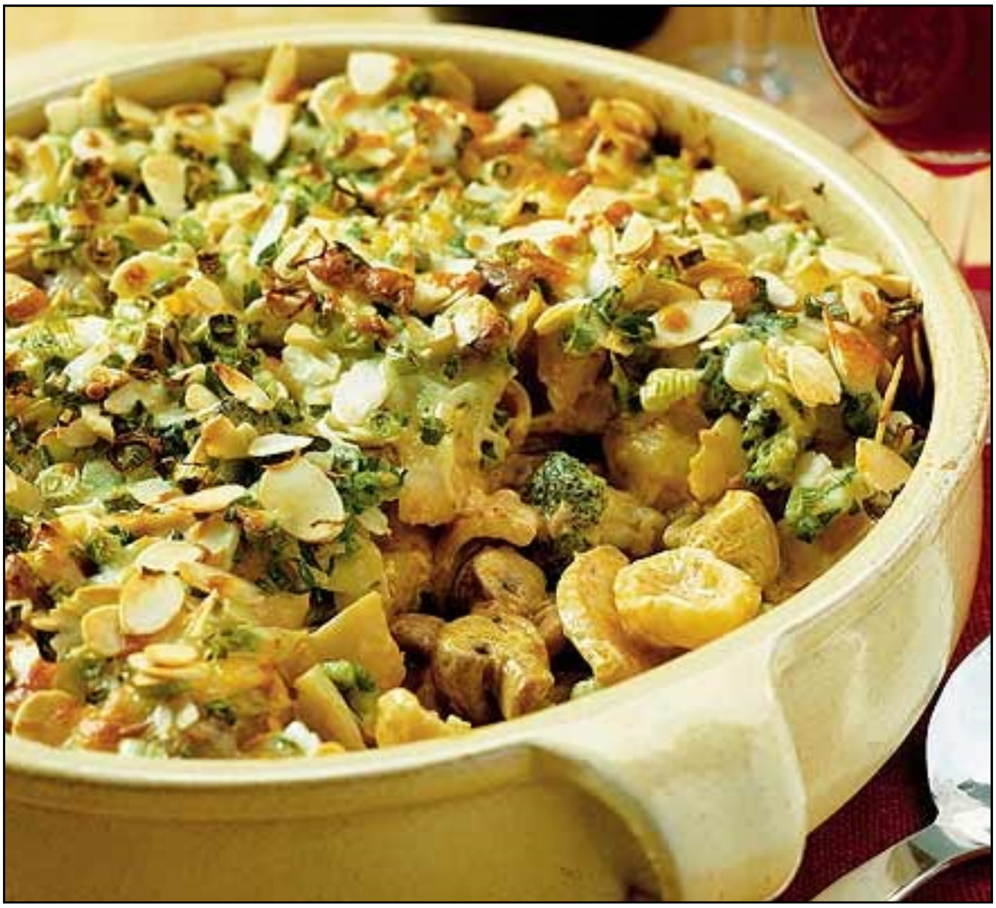
Method

Preheat the oven to 190C/gas5/fan170C
Bring a large pan of salted water to the boil. Put in the pasta, stir well and return to the boil. Cook for 6 minutes, then add the broccoli and cook for 5-6 minutes more until the pasta is just cooked. Drain well, then return to the pan.

Heat the oil in a wide pan, add the chicken pieces and fry until lightly browned. Tip in the mushrooms and stir fry for 1 minute, then stir in the tomato paste, cheese and cream. Gently simmer, stirring, until the cheese has melted to thicken the sauce. Season with salt and pepper.

Pour over the pasta, stirring gently until coated, then tip into a shallow ovenproof dish (about 1.7litre capacity) and level the top. (Note: if you feel it might tend to dry out in the cooking then add 100ml or so of semi or fully skimmed milk at this stage)

Mix the spring onions, cheddar, garlic and almonds for the topping and sprinkle over the pasta. Bake for 20 minutes until golden.



Note:

For a healthy alternative use low fat cream or crème fraiche instead of the cream
Use 'light' boursin cheese
Use 'lighter' cheddar cheese
or
try the veggie version using Quorn pieces.

If you would make it again, try using cubed ham and green beans

Why you should Exercise Caution & Discretion when using Social Media.

If you think that you can just say anything on Social Media, you are mistaken. Free speech does not mean free rein. Anyone using Social Media should be aware of the legal pitfalls, and know how to avoid them. With the internet explosion the law is just catching up — but if someone uses Social Media the legal implications of defaming someone online are serious. People lose their inhibitions on Facebook and Twitter and often post whatever comes to mind. As a result, an increasing amount of legal action from allegations of online bullying and harassment is increasing.

Defamation is a civil offence rather than a criminal one. This can be slander, where the defamatory statement is spoken, or libel, where it is written, broadcast or otherwise published. Most courts have ruled that Social Media-derived defamation is libel, although chat on an online bulletin board is more like slander. According to the law, by simply posting the statement on Twitter or Facebook, or re-tweeting or sharing it, it is considered as publication. Any adverse or implicative comments suggestive comments could lead to consequences like a job being lost or someone being taken to court for defamation. The Defamation Bill, which is expected to become law at the end of 2013, will require litigants in England and Wales to show that defamatory statements have caused “substantial harm” to their reputation, up from the current threshold of simply “harm”. Negative comments spread rapidly and are seen by more people, for example someone may complain to friends and family about something which is essentially a private matter—out once it is published on Social Media is becomes public. There are many examples of workers being sacked when inappropriate comments are made on Social Media;

Social Media myth-busting

Question: If I post something using an account anonymously or I do not identify myself can I get away with it?
NO. The High Court In 2007 ordered the operator of a football club fan webpage to disclose the identities of those posting defamatory remarks anonymously. Although the operators claimed it would be breach of the Data Protection Act to disclose the personal information & identity the court decided that the courts decided that the disclosure ‘was proportionate, as there was no other way to identify who had made defamatory statements.

Question: Am I not free to say what I want as long as it is my truly held opinion?
No if you are to use the “fair/honest comment” defence, it must be of public interest, and recognisable as a comment rather than an implication of fact, and be based on something that is true. The comment must also be honest. If things are over stated or exaggerated then expect problems.

Question: Am I not disclosing information to a closed user group when I use Social Media?
Although many social networks have improved privacy settings, most users do not know how to set them up properly. Many people do not also understand who is getting their information. There are a lot of people out there who check Social Media - the DWP, employers, the press and other media, insurance companies and very often criminals.

While Social Media are great to keep in touch with friends, network and even help promote your business. However, it is worth remembering the following advice before you post something online:

- Do not post unkind things online.
- Do not post threats online. Under the Communications Act 2003, it is illegal to send menacing electronic communications.
- Do not post offensive comments online. The Malicious Communications Act 1988 has been used to prosecute someone who made fun of dead children on Facebook and YouTube.
- Employers should have tightly-drafted policies or codes of conduct.
- Do not disclose personal information e.g. anything that could be of use about money or bank accounts
- By law, it is illegal to disclose identities of certain classes of individual’s e.g. rape victims and children accused of certain crimes.

A Problem with some Commonly Used Medicines.

A couple of weeks ago, James Gallagher, the Health and science reporter for BBC News wrote a feature ‘Drug 'overused' despite heart risk: ‘Painkillers linked to heart risk’

Two common painkillers, ibuprofen and diclofenac, can slightly increase the risk of heart problems if taken in high doses for a long time, data suggests. People with severe arthritis often take the drugs, which also calm inflammation, to go about daily life. The researchers said some patients would deem the risk acceptable, but they should be given the choice.

A study, published in the Lancet, showed the drugs posed even greater risks for smokers and the overweight. The risks have been reported before, but a team of researchers at the University of Oxford analysed the issue in unprecedented detail in order to help patients make an informed choice.

The group investigated more than 353,000 patient records from 639 separate clinical trials to assess the impact of non-steroidal anti-inflammatory drugs. They looked at high-dose prescriptions levels, rather than over-the-counter pain relief, of 150mg diclofenac or 2,400mg ibuprofen each day. They showed that for every 1,000 people taking the drugs there would be three additional heart attacks, four more cases of heart failure and one death as well cases of stomach bleeding - every year, as a result of taking the drugs.

So the number of heart attacks would increase from eight per 1,000 people per year normally, to 11 per 1,000 people per year with the drugs. Although 3 per thousand sounds like it is quite a low risk, the judgement has to be made by patients. Gallagher said this should not concern people taking a short course of these drugs, for example for headaches. The problem is that it is cumulative to those already at risk of heart problems. It is well known that high blood pressure, cholesterol and smoking all increase the risk of heart problems. There is emerging evidence that this applies to ME/CFS patients. There are ways to reduce the risk. This could include statins for some patients. A drug called rofecoxib (Vioxx) was voluntarily taken off the market by its manufacturer in 2004 after similar concerns were raised.

There are more than 17 million prescriptions of non-steroidal anti-inflammatory drugs in the UK each year. Two thirds are either ibuprofen or diclofenac. A third drug, naproxen, had lower risks of heart complications in the study and some doctors are prescribing this to higher-risk patients.

Vioxx

Rofecoxib is a non-steroidal anti-inflammatory drug (NSAID) that has now been withdrawn over safety concerns. It was to treat osteoarthritis, acute pain conditions, and dysmenorrhoea. It was marketed under the brand name Vioxx. Rofecoxib gained widespread acceptance among physicians treating patients with arthritis and other conditions causing chronic or acute pain. However in September 2004, it was withdrawn because of concerns about increased risk of heart attack and stroke associated with long-term, high-dosage use.

NSAID drugs do a similar job to aspirin by stopping the blood from clotting although this also increases the odds of a stomach bleed. When a NSAID is prescribed is it usually given with a medicine to reduce stomach acid. Even diclofenac gel & topical ointments can cause thinning of the stomach lining —so caution when using external NSAID is needed

These medicines were a "lifeline" for millions of people with painful health problems because they are effective in relieving pain. However because of their potential side-effects, in particular the increased risk of cardiovascular complications which has been known for a number of years, there is an urgent need to find alternatives that are as effective, but safer.

Make the Most of Your Money *from Sheffield ME Group Newsletter Spring 2013*

Big thanks to one of the Sheffield MEG members for this fabulous article.

The first step is to assess your situation. Brace yourself to face the facts. Locate all your money papers and passwords for online banking and bills, as you'll need to complete a full breakdown of your income and expenditure. It's quite tiring, so break up the task into sections, no need to do it all at once. The Citizens Advice Centre can make referrals to CASHflow, an online budgeting tool, which is a new approach to the way advice agencies like a CAB help people with debt problems help themselves. http://cashflow.uk.net .
You can down load similar ready-made excel templates from Money Saving Expert, which has lots of detailed sections to catch all the scattered little expenditures that really add up http://www.moneysavingexpert.com/banking/Budget -planning/

Next, armed with the information gathered in your budget you can prioritise your bills or debts.
It is vital to respond to bills according to financial priority, not who sends the nastiest letters.

Deal with financial demands according to risk, e.g. bills which are secured on your home and fuel bills etc. are a priority. Try the Shelter guide to Priority and Non-Priority Debts http://england.shelter.org.uk Get advice about dealing with debt/priority and non-priority debts. If you have debts, seek help from a CAB or similar advice organisation. Minimise expenditure. This doesn't mean being horridly frugal, but being a canny shopper can make a huge difference.

Consider cancelling non-essential purchases and services such as window-cleaning or car washing, sky subscriptions or perhaps have them less often. Build up a stock of healthy snack food and wash out drinks bottles so you can always take a snack and water when you go out. Then you'll never have to buy them at premium prices if you get low energy. The worst that can happen is that you don't need them and bring them home to use another day.

Price check assiduously but also remember to weigh up the cost of energy expenditure traipsing around different shops to get the cheapest prices. Make a compromise that works for you. Some people with ME/CFS find it best to do supermarket shopping online and save their energy. You may not see as many end-of-aisle special offers but that is offset by not succumbing to special offers which you don't really need. It's always worthwhile trying to plan ahead of what you might be eating and add to this the items you have run out of. By making a shopping list, action list for when you go out, this can help you keep focused on the necessities and stop you impulse-buying or walking up and down aisles.

Non-Geographical Alternative Telephone Numbers. You can often find a free-phone number for businesses by searching www.saynoto0870.com/ Numbers starting 09 will cost a lot of money.

Pet Food & Pet Meds It definitely pays to bulk-buy and order on line. Plus it's convenient to have the heavy sacks of pet food delivered. One good supplier is http://www.gjwtitmuss.co.uk

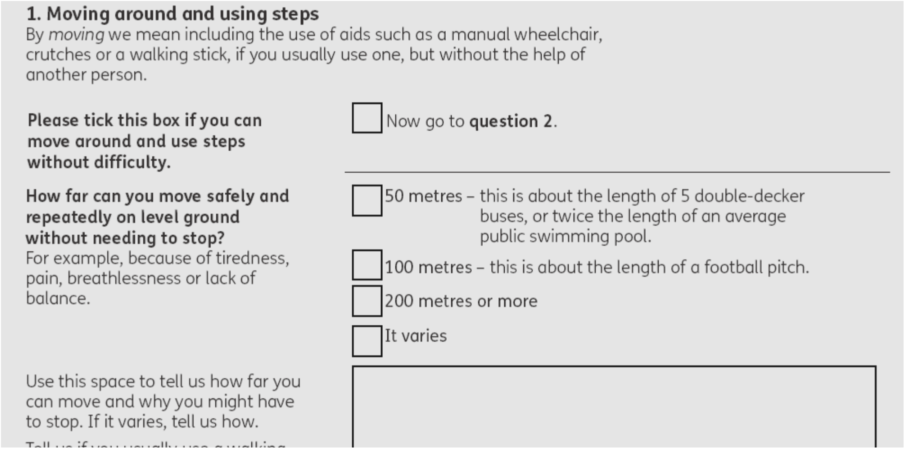
Printer inks Look out for compatible inks, in some cases these cost £7 compared to £49 for official inks. Discuss special occasion spending with family and friends. They may be relieved to call it off or set a price limit. Instead of going for large flashy gifts, small fun presents can mean a lot too. Some people make arrangements to go to the theatre or an event later in the year rather than swap soap and socks for Christmas. It helps spread out energy-expenditure and means you can have outings to look forward to. Do check out Turn2us, a charitable service which helps people access the money available to them - through welfare benefits, grants and other help.

Consider selling unwanted items on Ebay or Gumtree. Look up the prices of completed items first, so you can make an assessment if it's worth your effort. Some items have a surprisingly high resale value. An audio book CD set was around gathering dust and originally cost £19.99 but now it is counted as a rare item and it sold for £82! But don’t forget to pay your Ebay selling fees!

Check your balance on loyalty cards: You may find that you have more to spend than expected. One person found they had £172 on Nectar points, which can in very useful. Boots points can be used for Christmas presents, which I used to treat myself for free. Tesco Clubcard points can be converted to restaurant vouchers which can help to take a few people out for coffee and cake; or they also offer annual memberships to many different clubs, even magazines, again can be used as great gifts for Birthdays or Christmas.

The PIP/ESA Anti Mobility Trap

(Continued from Pathways 35)



1. Moving around and using steps
By *moving* we mean including the use of aids such as a manual wheelchair, crutches or a walking stick, if you usually use one, but without the help of another person.

Please tick this box if you can move around and use steps without difficulty. ☐ Now go to **question 2**.

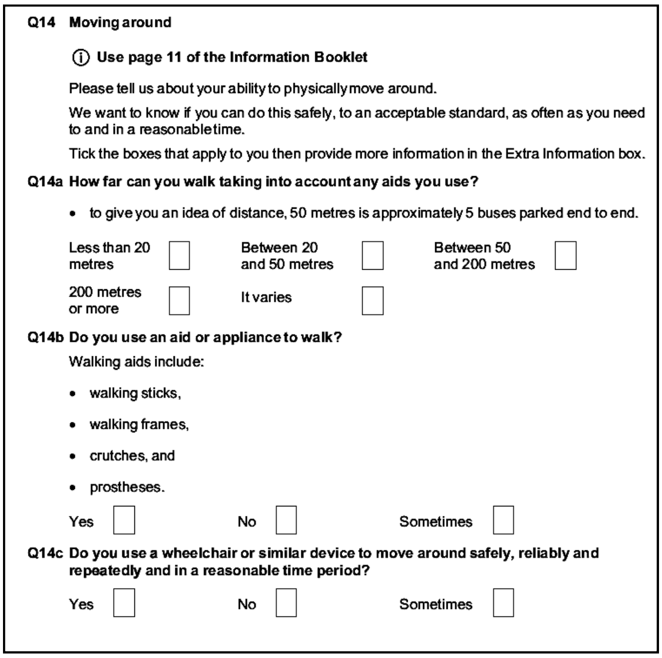
How far can you move safely and repeatedly on level ground without needing to stop?
For example, because of tiredness, pain, breathlessness or lack of balance.

☐ 50 metres – this is about the length of 5 double-decker buses, or twice the length of an average public swimming pool.
☐ 100 metres – this is about the length of a football pitch.
☐ 200 metres or more
☐ It varies

Use this space to tell us how far you can move and why you might have to stop. If it varies, tell us how.

Over the years when conducting inquests into DLA refusals, one thing has become quite clear. The DWP look at past records going back several years—and many applications are rejected to the surprise of the applicants, even though the original application and medical evidence is there.
I believe prevention is better than cure and as far as possible, when group members put in applications for DLA we check for the traps.

There is a potential issue with the new version of the ESA 50 v3 form. My view is that the latest version of the ESA 50 form has two boxes missing for moving around. The lowest option you are given is 50 metres. If you cannot get around or it is 20 metres you only have this option. If you tick the 50 metre box and the DWP accept this then you get the 15 points and the benefit. However, should you apply for Personal Independence Payment (PIP), you have told the DWP you can move 50 metres in the ESA 50 v 3 form— and by implication it means that you are able to move around more than 20 metres and so you will not qualify for the higher mobility payment.



Q14 Moving around

ⓘ **Use page 11 of the Information Booklet**

Please tell us about your ability to physically move around.

We want to know if you can do this safely, to an acceptable standard, as often as you need to and in a reasonable time.

Tick the boxes that apply to you then provide more information in the Extra Information box.

Q14a How far can you walk taking into account any aids you use?

- to give you an idea of distance, 50 metres is approximately 5 buses parked end to end.

Less than 20 metres ☐ Between 20 and 50 metres ☐ Between 50 and 200 metres ☐
200 metres or more ☐ It varies ☐

Q14b Do you use an aid or appliance to walk?

Walking aids include:

- walking sticks,
- walking frames,
- crutches, and
- prostheses.

Yes ☐ No ☐ Sometimes ☐

Q14c Do you use a wheelchair or similar device to move around safely, reliably and repeatedly and in a reasonable time period?

Yes ☐ No ☐ Sometimes ☐

The following is the published points tariff for PIP MOBILITY ACTIVITIES

1. Planning and following journeys
a. Can plan and follow the route of a journey unaided. 0 points.
b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. 4 points.
c. Cannot plan the route of a journey. 8 points.
d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. 10 points.
e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. 10 points.
f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. 12 points.

2. Moving around.
a. Can stand and then move more than 200 metres, either aided or unaided. 0 points.
b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. 4 points.
c. Can stand and then move unaided more than 20 metres but no more than 50 metres. 8 points.
d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. 10 points.
e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. 12 points.
f. Cannot, either aided or unaided, –
(i) stand; or
(ii) move more than 1 metre. 12 points.

Here is a page from a draft questionnaire which has been circulated within the DWP circles for claiming PIP.
From the above there is a critical distance of 20 metres which the ESA50 v3 does not allow you to choose. To get an award of the mobility component you need to score:
8 points for the standard rate (equivalent to low rate mobility) and: 12 points for the enhanced rate (equivalent to high rate mobility which most LME members get).

So by ticking the 50 metre box - although you could get the ESA, the implication is you could give the DWP fodder to stop you getting the PIP for the mobility activities'

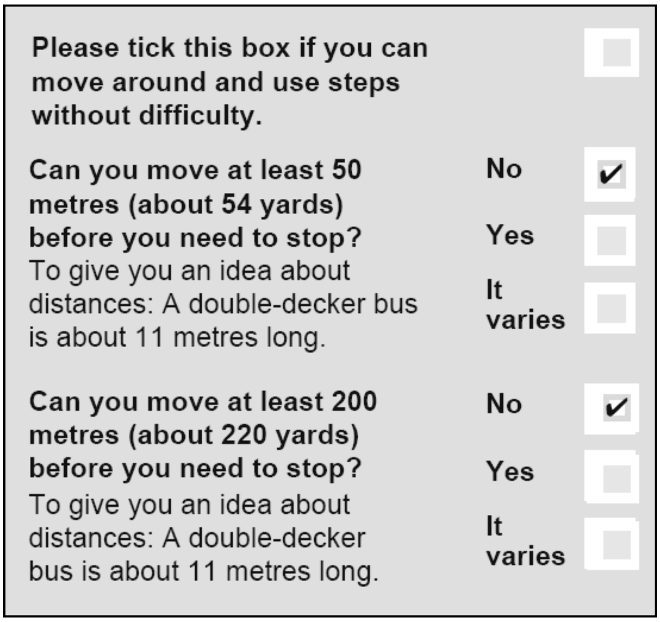
So what can we do about it? Here are the some options:

- Cross out the 50 metres and write in 20 metres or add another 20 metre box or other manual change. This possibly would be ignored by the DWP.
- Place a sticker over the offending questions from an earlier version of the form (*see right*). This would be possibly the more acceptable with very little change to the meaning of the form.
- Leave the question blank and put a note on saying ‘See additional information’ attached. Might be acceptable, but attachments seem to very often get lost in the system.
- Add pages from the PIP claim form. This will give the DWP a better idea—but as with the above attachments seem to very often get lost in the system.

Benefits & Work posted the following on their website on the 28th June under PIP NEWS.

The DWP has launched a six week consultation on Personal Independence Payment, looking solely at the enhanced mobility component. The move comes after protestors launched a Judicial Review of the DWP's failure to consult on changing the qualifying distance from 50 metres down to 20 metres. Benefits and Work is urging members to take part in the consultation, even though there is a strong likelihood the DWP will ignore its findings. We believe it is important that the DWP are forced to admit that the changes to PIP have nothing to do with improving the methods of assessing disability and everything to do with cutting costs. In addition, we think it is vital that support is given to the brave campaigners who have forced the DWP to make this embarrassing concession. In addition, the Judicial Review is likely to be stayed whilst the consultation takes place, but may be restarted once it is over.

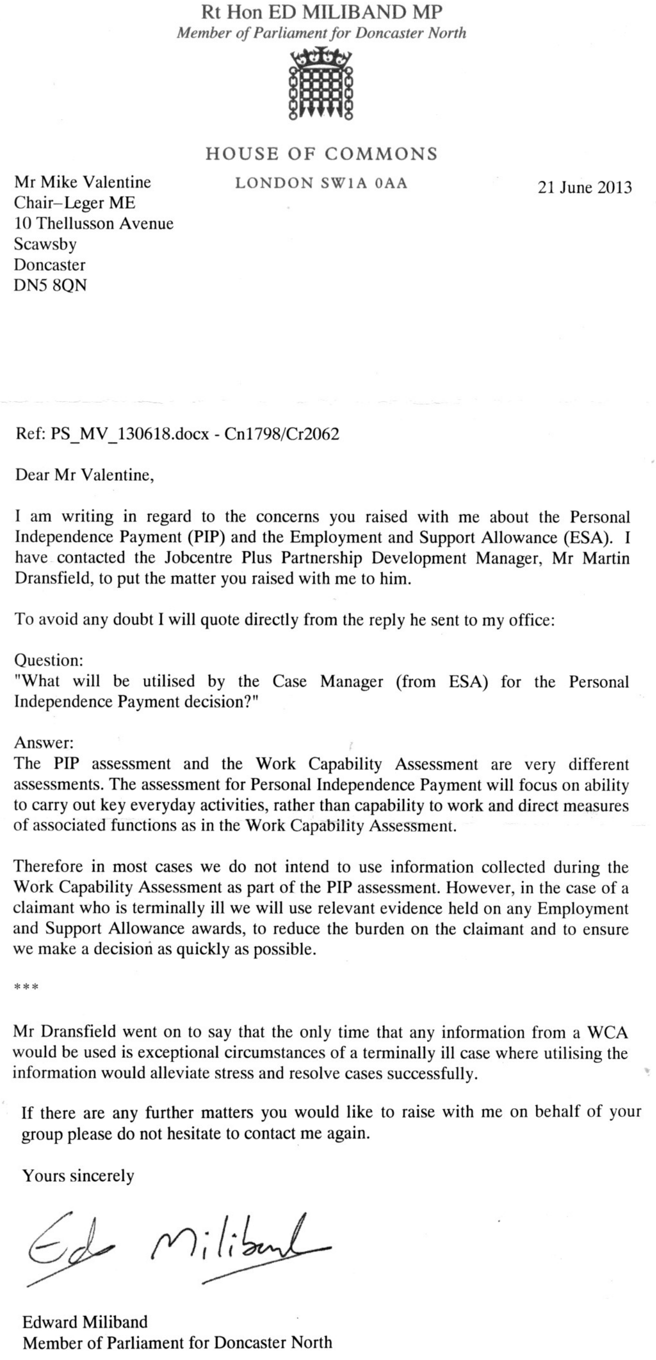
Also recently this issue was featured on our email news round. Unexpectedly the letter to the right was received from local Doncaster MP Ed Milliband. I must admit that from my experience with Leger ME members and DLA, I’m very sceptical about what Mr Dansfield says about the ESA and PIP being independent and not linked. Will this be respected by those civil servants who do the actual administration? We will write to Ed should any evidence emerge to the contrary.



Please tick this box if you can move around and use steps without difficulty. ☐

Can you move at least 50 metres (about 54 yards) before you need to stop?
To give you an idea about distances: A double-decker bus is about 11 metres long.
No ☑
Yes ☐
It varies ☐

Can you move at least 200 metres (about 220 yards) before you need to stop?
To give you an idea about distances: A double-decker bus is about 11 metres long.
No ☑
Yes ☐
It varies ☐



Rt Hon ED MILIBAND MP
Member of Parliament for Doncaster North

HOUSE OF COMMONS
LONDON SW1A 0AA

21 June 2013

Mr Mike Valentine
Chair–Leger ME
10 Thellusson Avenue
Scawsby
Doncaster
DN5 8QN

Ref: PS_MV_130618.docx - Cn1798/Cr2062

Dear Mr Valentine,

I am writing in regard to the concerns you raised with me about the Personal Independence Payment (PIP) and the Employment and Support Allowance (ESA). I have contacted the Jobcentre Plus Partnership Development Manager, Mr Martin Dransfield, to put the matter you raised with me to him.

To avoid any doubt I will quote directly from the reply he sent to my office:

Question:
"What will be utilised by the Case Manager (from ESA) for the Personal Independence Payment decision?"

Answer:
The PIP assessment and the Work Capability Assessment are very different assessments. The assessment for Personal Independence Payment will focus on ability to carry out key everyday activities, rather than capability to work and direct measures of associated functions as in the Work Capability Assessment.

Therefore in most cases we do not intend to use information collected during the Work Capability Assessment as part of the PIP assessment. However, in the case of a claimant who is terminally ill we will use relevant evidence held on any Employment and Support Allowance awards, to reduce the burden on the claimant and to ensure we make a decision as quickly as possible.

***

Mr Dransfield went on to say that the only time that any information from a WCA would be used is exceptional circumstances of a terminally ill case where utilising the information would alleviate stress and resolve cases successfully.

If there are any further matters you would like to raise with me on behalf of your group please do not hesitate to contact me again.

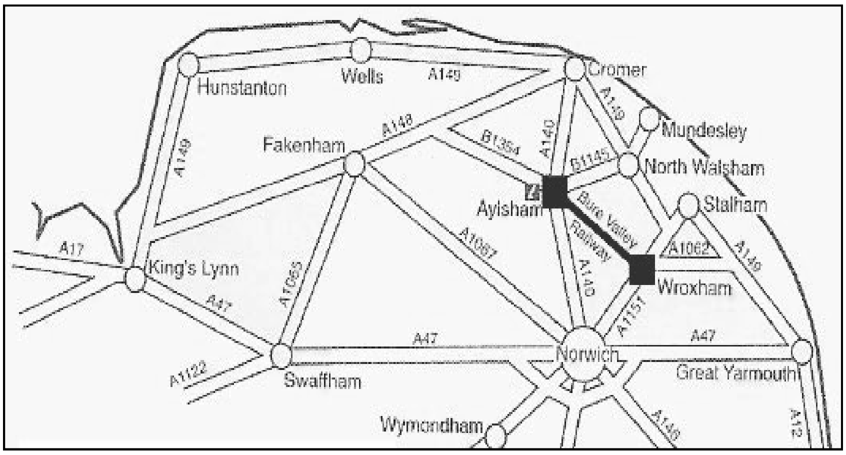
Yours sincerely

Ed Miliband

Edward Miliband
Member of Parliament for Doncaster North

Out and About in North Norfolk: The Bure Valley Railway

The Bure Valley Railway is a 15 in gauge heritage railway in Norfolk, within The Broads National Park. The railway runs from Wroxham to Aylsham (9 miles or 14½ kilometres) and is Norfolk's longest narrow gauge line. It uses both steam and diesel locomotives. There are intermediate halts at Brampton, Buxton and Coltishall. There are 17 bridges, including a 105 (32m) long girder bridge over the River Bure in Buxton with Lammas as well as Aylsham Bypass Tunnel under the A140 at Aylsham. They offer services to the enthusiast, traveller and tourist in all seasons of the year.

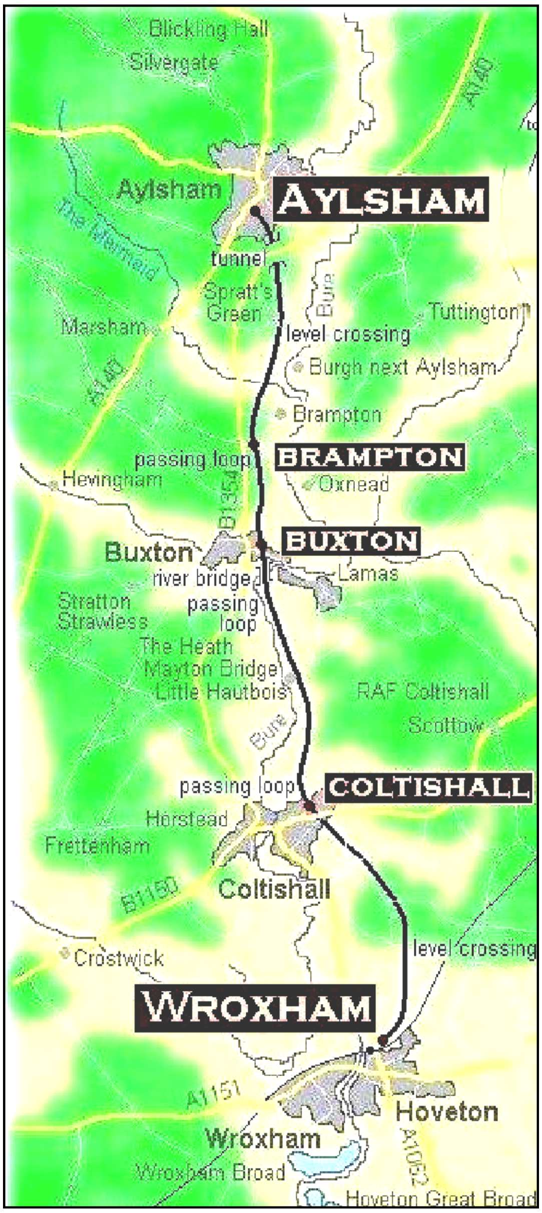


The Bure Valley Railway was built on the track bed of part of the former Great Eastern Railway line between Wroxham and Dereham. It originally opened on New Year's Day in 1880. The steam and diesel trains pass through scenery which is as varied, interesting and beautiful as any to be found on any railway journey in England. Between Aylsham and Wroxham there are three intermediate stations at Brampton, Buxton and Coltishall, all of which have their own characteristics and, if time permits, can form part of a fascinating day exploring the Bure Valley by rail and foot or bicycle. The original standard gauge line was double track—however the railway is narrow gauge and only occupies part of the original track bed. The other half of the track bed is trackside path which follows the route. It is suitable for walkers and bicycles; being a former railway it is flat with no steep hills or gradients.

The main station of the line is situated in the middle of the market town of Aylsham. Although it is now a terminus, you can easily imagine where a bridge once took the line under the road and beyond. The station buildings here were built in 1989 to a traditional railway design and house a busy railway shop, café and a tourist information centre. The Bure Valley Railway's workshops are also based at Aylsham and are often open to the public.

Disability Issues Information & Access

Do they take advanced bookings for Wheelchair users?	The railway will always endeavour to carry wheelchairs and their users. Whilst a booking is not always essential, it does help if you know when you are thinking of travelling, to phone before hand to make sure that no other wheelchair passengers are already booked. To check availability please call +44 (0) 1263 733858
Do they have Coach or Car parking?	At both Aylsham and Wroxham stations there are large coach and car parking facilities. These are FREE to those visiting the railway. Aylsham also has designated disabled spaces right by the entrance to Aylsham station. There are also very small car parks at Buxton and Coltishall, mainly for those who wish to use the footpath only.
I have an electric scooter, rather than a wheelchair, can I still bring it?	Small electric scooters or wheelchairs can be accommodated within our accessible carriages provided they are not too large, or heavy and can be easily manoeuvred on-board a rail carriage without the help of railway staff to lift them into position. If travelling on the combined Train and Boat package, then please seek advise at time of booking, certain boats cannot accept electric scooters, or may need seats to be removed from the deck, prior to boarding.



When we visited Aylsham station, there were two engines.

The left hand one was shunted in and out of the station to give different people the experience of driving an engine.

The right hand engine had pulled a train from the end of the line at Wroxham. The route itself is quite scenic giving good views of the surrounding countryside, the fields and villages.

The river Bure is only visible from the train for part of the route.

As this railway is narrow gauge, it tends to be a bit of a bone-shaker—so if you do visit find yourself an upholstered seat or take a cushion.

Dental Care & ME/CFS: Common questions answered.

Adapted from Perspectives ‘All in the drill by Dr. Richard Cantillon BDS

What is the best way to look after my teeth? You should visit your dentist at the frequency you are advised; brush your teeth twice a day using fluoride toothpaste; use dental floss/tape or inter-dental brushes once or twice a day; reduce your frequency of exposure to sugar-containing food and drink to not more than three or four times a day.

When and how should I clean my teeth? You should brush last thing at night and one other time, usually first thing in the morning. This should be with a manual brush with a small head and rounded end filaments, a compact angled arrangement of long and short filaments and a comfortable handle, or a powered toothbrush with an oscillating/rotating head. It should take about two minutes to brush your teeth and you are advised to spit out excess toothpaste rather than rinse.

What kind of toothpaste should I use? Consider using toothpaste with triclosan and co-polymer or zinc citrate. This will keep plaque levels down. Also, think about using a higher fluoride concentration (5000ppm), if prescribed by your dentist. This would be appropriate if you have a high decay rate/risk, which he/she will be able to assess. *(Some members have reports increase on fatigue when fluoride-containing toothpaste is used. Ed)*

Sometimes I feel too ill to get out of bed. What can I do to clean my teeth? If you are having a difficult day and feel unable to get out of bed, please don't neglect your teeth. It may be possible to ask a member of your family or your carer to help or failing that, to use a chlorhexidine mouth- wash (0.2 - 0.12%) twice a day. It is important to follow any instructions given to you by your dentist or hygienist. This would be sufficient for a short period of time.

I thought that mouthwashes were used to freshen breath, How can they help my teeth? Mouthwashes can be used to freshen the breath. However, more importantly, they are useful in a role to prevent cavities, e.g. by containing fluoride, and to prevent gum disease e.g. by containing antibacterials. Gum disease and dental decay are the most common causes of bad breath (halitosis). There are also mouth-washes designed specifically to deal with halitosis. As with any unexplained symptoms, it is best to seek professional advice if they persist for longer than a couple of weeks.

What else should I think about to help care for my teeth? It is useful to bear in mind that people with ME/CFS who take medication (e.g. anti-depressants) or natural remedies for anxiety may suffer from a dry mouth. This in turn will increase the risk of tooth decay and gum disease. Take frequent sips of water and consider chewing sugar-free gum to increase the flow of saliva. Artificial saliva can be prescribed and is sometimes useful. In the case of a dry mouth, high fluoride toothpastes (2800/5000ppm) might be advisable. In addition, the use of a fluoride mouthwash at a time other than when you brush your teeth is helpful. This can be daily (0.05%) or weekly (0.2%) and should be rinsed for about one minute before spitting out. Your dentist or hygienist can also apply topical fluoride varnish to your teeth when appropriate.

Will diet also help? A healthy balanced diet is good for everyone - especially a diet that includes complex carbohydrates and avoids too much caffeine. Try to avoid sugar as much as possible and drink water rather than sugary drinks where you can. Decay-causing foods are usually more heavily processed and manufactured, e.g. confectionery, cakes and biscuits, buns, pastries, fruit pies, sugared cereals, jams, honey, ice cream, fruit in syrup, fresh fruit juices, soft drinks, and dried fruits. The two most important elements of a healthy diet are eating the right amount of food depending on your activity levels and eating a healthy balanced diet contains foods from all the major food groups including lots of fruit and vegetables; starchy staple foods such as wholemeal bread and wholegrain cereals; some protein-rich foods such as lean meat, fish, eggs and lentils; and some dairy foods, preferably of the lower fat variety. Try not to eat snacks but - if you must - try to avoid the examples given above. Your teeth can also be damaged if they are exposed to acid in your diet, e.g. acidic fruit and fruit juice, carbonated drinks, wine, sports drinks, pickles, vitamin C tablets. This can be managed by limiting acidic intakes to meal-times and not brushing immediately after an intake.

My dentist doesn't understand ME and that I am not really well enough to undertake very much treatment without feeling poorly. What can I say to him? It is important with any health care professional that you develop a sufficiently good relationship so that you are able to discuss your concerns and problems with regard to treatment and your health management. Most dentists will be sympathetic to your needs if you explain your problems to them. If they don't have sufficient information and understanding, then simply let them have copies of the booklets and leaflets you have obtained and details of relevant websites. Dentists take their continuing education very seriously.

What else does my dentist need to know? Always tell your dentist about your general health, previous dental history, any allergies you might have and most importantly, any medications you might be taking. You are most likely to be asked for regular updates already, when you attend for routine visits.

I react very badly to local anaesthetics, what can I do? Do not let your concerns about anaesthetics prevent you from having essential dental treatment. Anaesthetics are to make your visits more comfortable, not less! Unfortunately, some people with ME do not react well to local anaesthetics. It might be helpful for some ME sufferers to have an adrenaline-free anaesthetic with fewer additives. Your dentist will be familiar with all the ap-propriate drugs to be used under these circumstances. Make sure they are aware of your previous experiences, especially if you have had problems.

I suffer from severe ME and am mainly bedbound. This means that I cannot visit the dentist. Would the dentist visit me? It might be possible for you to arrange a home visit through your current dentist. Unfortunately, however, NHS funding is not available for many dentists to provide this service, and it might be necessary to ask for this through your local health care provider. This will require research locally. You might find a dentist who will do this under private contract or, if you are lucky and have been a long-standing patient, as a good-will service. There will be a limit to treatments available at home.

I have heard that, if I have my mercury fillings removed, this may help my ME. Is this true?
For many years there have been concerns about the safety of mercury fillings (dental amalgam). This concern relates to the possibility that toxic metal could be slowly absorbed into the body. Mercury toxicity has sometimes been linked to certain medical conditions including ME/CFS. However, in the opinion of The ME Association and the British Dental Association, there is no consistent evidence to support this view. At the moment it is not advised to elect to have sound amalgam fillings removed. However, if you need to have a defective filling removed, e.g. one that's fractured or leaking, it would be perfectly reasonable to consider alternative materials e.g. composite resin, porcelain, gold.

What about antibiotics for tooth abscesses or severe tooth/mouth infections? It may be necessary, on occasion, for the dentist to recommend a course of antibiotics if you are showing systemic symptoms, e.g. feeling ill, increased temperature, swollen lymph glands. It is unlikely that this will be recommended unless absolutely essential. Sensitivity to drugs is common in people with ME/CFS but, where there is a serious infection, it is best to take antibiotics rather than risk the infection causing more health problems for you. Some people with ME/CFS do react badly to antibiotics. If you have had a bad reaction or an allergy to an antibiotic in the past, please be sure that you have told your dentist.

I suffer a lot with mouth ulcers, what can I do? Mouth ulcers are very common and usually heal within a couple of weeks. There are many possible causes and they are rarely serious. As with any condition if you are worried, or the ulcers persist for longer than three weeks, it is important to seek professional advice. Usually, treatment is aimed at giving relief of symptoms by prescribing mouth-washes like hot salt water or chlorhexidine or topical corticosteroids. Your dentist will refer you for a second opinion if there is any doubt over the diagnosis or the management of the condition, e.g. oral cancer, coeliac disease. Blood tests may be necessary to obtain the diagnosis. In general terms, if you observe any changes to the lining of your mouth it is important that you seek advice. Dentists are trained to pick up early signs of oral cancer and oral signs of systemic disease. They will carry out an examination of the mouth lining every time you attend for an examination.

And Finally Look after your teeth and gums, eat a healthy balanced diet, don't smoke and visit your dentist and hygienist regularly.

Summer Food Safety: Ten Tips to avoid Summer Hazards

Summer eating can be enjoyable with fresh seasonal produce, outdoor eating and entertaining for special occasions or family gatherings. Unfortunately, food poisoning is more common in summer than at any other time of year.

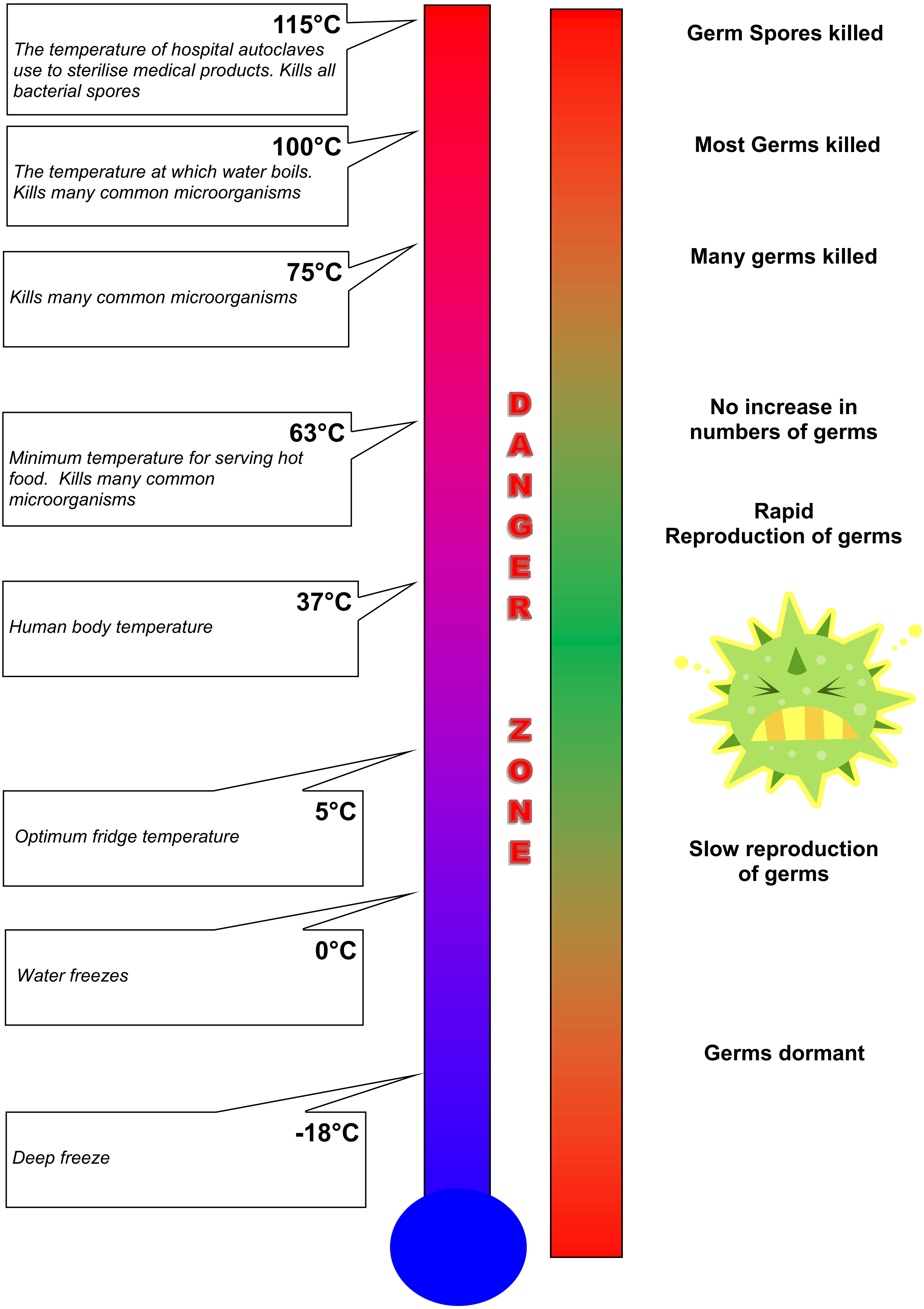
Bacteria in food multiply faster in hot, humid weather. Most home kitchens aren't designed for the safe handling of large quantities of food. Preparing and eating food outdoors – in the garden, when camping or at picnics and barbecues can also be difficult, where refrigeration and places to wash hands are not readily available.

Food poisoning can cause vomiting and diarrhoea and may be quite serious for children, older people and people with conditions that weaken their immune systems. Prevent food poisoning from spoiling your summer fun. Follow these simple steps to keep food fresh and safe this summer.

1. **Set your thermostat**.
   Make sure the fridge temperature is below 5°C and keep your freezer at minus 15 °C to minus 18 °C. Stock your cooler well with ice packs or clean ice. Keep salads fresh and meat safe in the cooler or fridge at 5°C or less until cooking or serving.
2. **Get food home quickly**.
   Take chilled, frozen or hot food straight home in insulated containers.
3. **Keep hot food hot**.
   If you don't want to cool food straight away, keep hot food at 60 °C or hotter. Reheat foods thoroughly so they're steaming (above 75 °C) or boiling.
4. **Don't leave hot foods to completely cool before refrigerating.**
   Put hot food in the fridge or freezer as soon as the steam stops rising. Cool it rapidly first by dipping the container in ice or a cold-water bath. Divide food into smaller, shallower containers so it cools more quickly in the fridge.
5. **Keep raw meat, chicken and seafood chilled and away from cooked food**.
   When a bacterium from raw meat gets onto cooked food, this can cause food poisoning. Keep raw meat below other foods in the fridge and don't let raw meat juices drip onto other food. Use different chopping boards for raw and cooked food, or wash them between uses. Wash your hands thoroughly after touching raw meat.
6. **Thaw frozen food thoroughly.**
   Unless food is manufactured to be cooked from frozen (check pack instructions), make sure it's thawed right through before cooking.
7. **Don't overfill your fridge**. Having enough room for air circulation inside the fridge is important for effective cooling. A good tip if you're catering for a crowd is to keep drinks on ice or in an insulated cooler and reserve the space in your fridge for food.
8. **Store leftovers safely**.
   Store any leftovers in the fridge and eat within three to five days. If you don't plan to eat them within this time, freeze them straight away.
9. **Know when to throw away**.
   Don't eat food that's been left out of the fridge for more than four hours – especially poultry, meat, seafood, cooked rice and cooked pasta.
10. **Avoid handling food when you're not feeling well**.
    If you have diarrhoea, vomiting, sore throat with fever, fever or jaundice, or infectious skin conditions, avoid handling food and see a doctor if symptoms persist.

E. Coli 0157 is a bug that causes massive epidemics of food poisoning. It doesn't take a massive dose of bugs to cause an epidemic in fact in theory one cell is enough. One of the biggest food poisoning outbreaks in the USA was caused when a very small piece of a raw beef burger was eaten.
One bacterial cell can be two in 20 minutes, and then each of these can double every twenty minutes so it is only a matter of several hours before an epidemic is rife.

Keeping food at temperature too high or low for germs to grow is the key to food safety



115°C
The temperature of hospital autoclaves use to sterilise medical products. Kills all bacterial spores

100°C
The temperature at which water boils. Kills many common microorganisms

75°C
Kills many common microorganisms

63°C
Minimum temperature for serving hot food. Kills many common microorganisms

37°C
Human body temperature

5°C
Optimum fridge temperature

0°C
Water freezes

-18°C
Deep freeze

DANGER ZONE

Germ Spores killed

Most Germs killed

Many germs killed

No increase in numbers of germs

Rapid Reproduction of germs

Slow reproduction of germs

Germs dormant

Is ME/CFS different in older people?

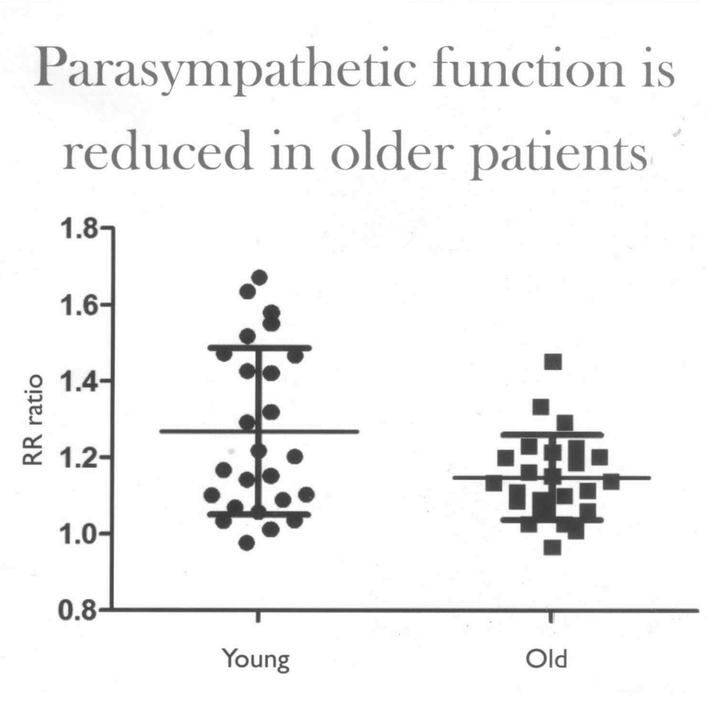
From ME Research UK—'Breakthrough' Spring 2013

"The effects of age and illness combine to create even more severe autonomic dysfunction "

It is estimated that around 9,300 people develop ME/CFS every year in the UK, and that around 200,000 are living with the illness at any one time. We also know that most become ill between the ages of 30 and 50, but does age itself make a difference? For instance, do people who are older when they first become unwell have a different type of disease than people who first become ill at a younger age? The issue is important scientifically because there is now quite good evidence to suggest that abnormalities of the autonomic nervous and vascular systems underpin at least some of the symptoms of ME/CFS. These abnormalities are, however, also a complication of the ageing process itself, so it is certainly possible that older people who develop ME/CFS are at additional risk of these complications, over and above the effect *cf* ageing itself.

An ME Research UK-funded study has been examining this aspect, and the results (published in the European Journal of Clinical Investigation, 20 13) make interesting reading. For this investigation, patients aged over 50 years were matched, on a case-by-case basis, by sex and duration of illness to a group of younger patients. This matching was particularly important to disentangle the effects of ageing from the effects of illness duration, which itself critically affects the type and severity of symptoms experienced by patients. Of the 179 consecutive patients who had attended the Northern Regional CFS Clinical Service in Newcastle between November 2008 and June 2011, 52 (29%) were over 50 years old. Twenty-five of these patients (aged between 51 and 70 years; who had been ill for 93 months on average) were matched case-by-case to 25 patients (aged between 16 and 29 years; ill for 91 months on average). In addition to a full clinical assessment, the volunteers underwent assessment of symptoms, and autonomic nervous system function was tested by measuring heart rate variability as well as the sensitivity and effectiveness of the baroreflex mechanism, which is involved in blood pressure control. Overall, there was no difference between the younger and older patients as regards pain, cognitive function, sleepiness or anxiety. However, older subjects had more fatigue, more depression, and a poorer overall quality of life.

The most intriguing differences between the two groups were found in the measurements of autonomic nervous system function. Compared with the younger patients, the older group had significantly increased 'low frequency' but reduced 'high frequency' heart rate variability. This suggests an imbalance between the two complementary parts of the autonomic nervous system, the sympathetic ('quick response') and parasympathetic ('rest-and-digest') divisions. Additional support for the relative impairment of parasympathetic function was seen in the RR ratio (an indicator of the inter-beat interval of the heart) which was significantly reduced in the older subjects (see the figure to right). Resting heart rate was significantly lower in older patients, who also had an impaired ability to maintain blood pressure. One of the most interesting findings concerned the left ventricular ejection time (the time interval from the opening to the closing of the aortic valve in the heart), which was significantly longer in older than in younger patients (286 versus 275 ms). In both groups, however, left ventricular ejection times were much shorter than the 374 ms measured in healthy people by a previous study. This supports other findings from Newcastle University of a reduced left ventricular performance and impaired cardiac function in ME/CFS patients. '



Now, some of these observed effects are certainly due to the ageing process itself because autonomic nervous system function, including heart rate variability, is known to deteriorate with age. However, since autonomic dysfunction is a consistent finding in people with ME/CFS of any age, it may be that the effects of age and illness combine to create even more severe autonomic nervous system dysfunction in older patients. It is even possible that the underlying disease process differs between older and younger patients.

Overall, the results show that there are distinct physiological and clinical differences between older and younger people with ME/CFS, even though they have had the illness for the same length of time. Not only do older patients have more fatigue and depression, and a poorer quality of life, but they also have a significantly greater burden of autonomic dysfunction. The importance of these findings lies in the fact that a sizeable proportion of people with ME/CFS present with symptoms for the first time aged over 30, and a significant proportion are aged over 60. It is important to be aware that the combination of underlying ME/CFS disease mechanisms and the normal physiological effects of ageing may result in a greater disease impact (particularly on the cardiovascular system) in these people who are older when they become ill.

Bringing the evidence together .*Funding a systems approach to modelling symptom data*

Since 2006 researchers at Newcastle University have collected a large volume of clinical. autonomic and symptom data from patients recruited to studies funded by ME Research UK and its partners, the John Richardson Research Group and the Irish ME Trust. Full sets of data are available for over 200 patients to date and the very large amount of data available (plus information collected from every patient attending the Newcastle ME/CFS Clinical Service) represents a very valuable longitudinal resource of clinical and biological information on people with the illness. While their scientific papers published to date have reported key headline findings. Prof. Newton and colleagues recognise that mining this rich dataset has the potential to reveal even more about the illness, including the relationships between demographic, clinical and biological parameters.

The power of modern computing and in particular a scientific approach called 'systems biology' allows the development of multi-dimensional models of how a large number of different measurements link with each other. Such models might allow the identification of processes causing disease and, crucially, allow formal estimation to be made of how changes in one or more symptom might be expected to impact on the overall burden of disease. Of course, these models can never replace studies involving patients, but they can allow prediction of which patient studies are most important and indicate the direction of future research and treatment.

An example of such a systems approach to a complex clinical problem is the work on the cell biology of ageing, by Prof. Kirkwood and colleagues at Newcastle University (Not Rev Mol Cell Bioi, 2003). Their modelling of the interactions between multiple molecular mechanisms believed to contribute to the ageing of cells led to a novel prediction of the interaction between mitochondrial dysfunction, oxidative stress and chromosomal erosion in human cells something that was subsequently confirmed experimentally.

The aim of this new ME Research UK-funded investigation, headed by Prof. Newton but involving other colleagues in cross-discipline collaboration is to apply similar computational and mathematical tools to the rich data set on ME/CFS patients which now exists at Newcastle University.

There are four elements to the study: identification and phenotyping of the study cohorts; development of the ME/CFS symptom model; testing of the ME/CFS symptom model; and indicative application of the model in ME/CFS to explore the possible effects of treatments for fatigue or other symptoms ('in silico trials' to identify potentially valuable interventions for 'in vivo' testing). The work may yield novel insights and hypotheses that can be tested subsequently in clinical or biomarker studies.

North of Doncaster *Personal comment by Trevor Wainwirght.*

(From http://www.scienceomega.com/article/1053/tackling-chronic-fatigue-syndrome-from-the-top-down)

Tackling chronic fatigue syndrome from the top down. A top-down approach has helped to advance research within the field of chronic fatigue syndrome, explained by the CFS Research Foundation’s Anne Faulkner. For more than a quarter of a century, CFS/ME has stimulated vigorous debate amongst members of the medical research community. From the outset those working to promote investigation into this illness have been involved in an uphill struggle. Surprisingly, one of the most significant obstacles originated from sections of the medical community that were reluctant to recognise CFS/ME as a genuine illness. Moreover, pejorative terms such as ‘yuppie flu’ did little to improve the condition’s credibility within a broader societal context. All the while, substantial numbers of people continued to suffer from the debilitating effects of CFS/ME. Attempts to learn more about its causes have been hampered by a widespread misconception that the associated symptoms are trivial. In 1993, the CFS Research Foundation was established with the aim of improving our understanding of CFS/ME. The organisation’s founders were committed to tackling what they saw as an illness that had been widely neglected by doctors and scientists alike. Two decades later, the fight against this illness is still being waged, but significant progress has resulted from the involvement of individuals at the very top of the scientific community. CFS/ME can cause devastating exhaustion, both for muscles and for the mind, Painful joints, painful muscles, migraines, a lack of sleep, gastrointestinal upsets, a loss of short-term memory and difficulty concentrating: all of these symptoms are associated with this illness."

Chronic pain. 75% of individuals with CFS/ME endure chronic and widespread pain. Conventional painkillers are often ineffective in relieving the illness’s symptoms. When you take into account additional aggravating factors such as exhaustion and loss of concentration, it is easy to see how CFS/ME can result in suffering without the prospect of relief. Unfortunately, little is known about why pain associated with this illness causes such a problem for those affected. There is some evidence to suggest the brains of CFS/ME patients handle pain differently from those of healthy individuals. Indeed, some experts believe that people with this illness have a hypersensitivity to pain. I asked Faulkner about the research currently being conducted to uncover more about the causes of CFS/ME. Gene research is always going to be one of our main priorities. We have to drill down to the basics of this illness. However, we also have to acknowledge that advances in this area are not easily won: understanding the genetic mechanisms of CFS/ME is a long-term objective. In light of this, we are working to help the patients who are suffering now. To this end, we are about to undertake a three-year research project involving scientists from London teaching hospitals. We are going to address the problem of pain. This particular situation is getting better all the time, but I do think that significant numbers of people still think that CFS/ME is mere ‘tiredness’. When this view is allowed to prevail, people begin to say: ‘I get tired too, but I don’t make such a fuss about it’. Even so, society is slowly beginning to recognise that this is a painful, devastatingly crippling illness. A quarter of patients with CFS/ME are either housebound or bed bound; that is a huge number of people. I think that some sections of the public are beginning to wake up to the fact that this illness needs to be taken more seriously."

Social consequences. The extent of these problems will depend on your location and the people with whom you are mixing. For example, patients frequently have difficulty getting their employers to understand exactly what they are going through. Unfortunately, similar problems can also emerge within family units. There have been cases in which women have had CFS/ME, and their husbands have been told that they need to ‘pull themselves together’. This has often been the advice of the family doctor. Naturally, this sort of medical advice can have a dreadful impact on a marriage. In turn, if a person’s children don’t really understand what their mother or father is going through, they are unlikely to help out as much as they should. When we created the foundation in the early 1990s, CFS/ME was an illness which was misunderstood by almost everybody; Doctors were – on the whole – hopeless. They simply told people that there was nothing wrong with them and to pull themselves together. Furthermore, scientists tended to shy away from the illness because unfortunately, some of the related patient support groups were fairly aggressive. The research community was wary of CFS/ME because it received so much angst from patients. During the course of the last two decades, we have done our best to turn this situation around. CFS/ME is now more widely recognised as a devastating and debilitating illness that can have tragic consequences for those affected."

Top-down approach Two decades ago, the quality of most of the research conducted within the field of CFS/ME was poor. We knew that we needed to enlist the help of scientists who were pre-eminent in their fields – not necessarily within the field of CFS/ME, but in biology, neurology, and so on. Over the years, four Fellows of the Royal Society have sat on the Research Committee of the CFS Research Foundation. It doesn’t get much better than that. For example, when GPs suggest that CFS/ME is not a genuine illness, we point out that their opinions differ from those of Royal Society Fellows. Involvement at this level has trickled down through the scientific community and has helped CFS/ME to gather some of the attention that it deserves.