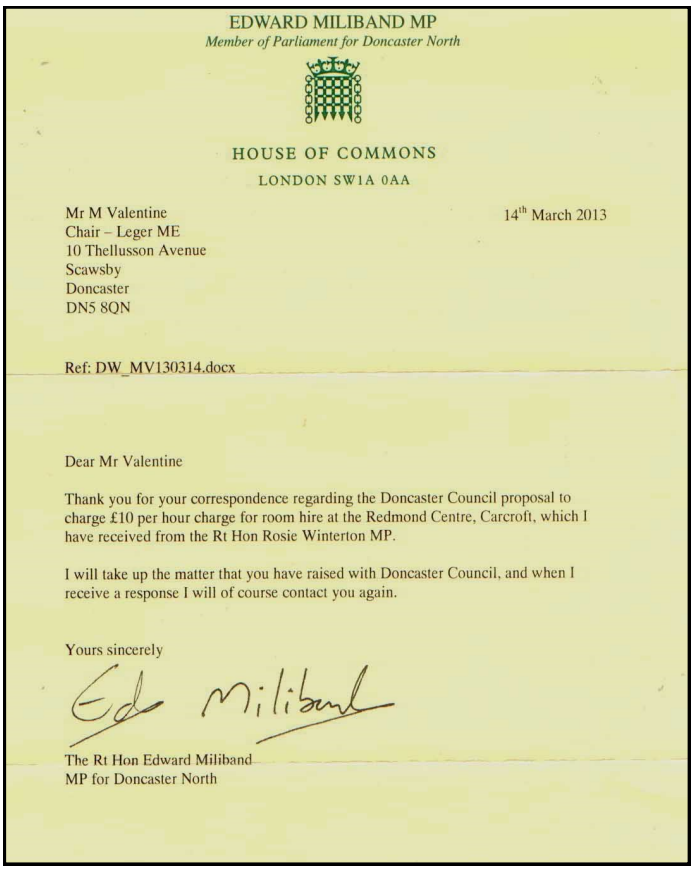
Price £ 2.50 (Free to members)

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.

Welcome to Pathways No.35.

Members who subscribe to our news bulletin service will be aware of the on-going dialogue regarding DMBC's decision to charge a flat £10 per hour for room hire at the Redmond Centre irrespective of the ability of the users to pay. There was a consultative meeting with all the other user groups and DMBC staff on the 14th March. The following comments were submitted to DMBC with the agreement of our members present.



EDWARD MILIBAND MP
Member of Parliament for Doncaster North

HOUSE OF COMMONS
LONDON SW1A 0AA

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

14th March 2013

Ref: DW_MV130314.docx

Dear Mr Valentine

Thank you for your correspondence regarding the Doncaster Council proposal to charge £10 per hour charge for room hire at the Redmond Centre, Carcroft, which I have received from the Rt Hon Rosie Winterton MP.

I will take up the matter that you have raised with Doncaster Council, and when I receive a response I will of course contact you again.

Yours sincerely

Ed Miliband

The Rt Hon Edward Miliband
MP for Doncaster North

1) What was quite clear from the meeting was that there are two categories of users firstly:

a) Local self-funded voluntary community groups based at the Redmond Centre who are members of the RCCG and who are self-funded or raise funds by their own efforts like ourselves.
b) Registered charities and other national organisations that use the centre, which have paid staff to implement their services. Such groups include 'Weightwatchers', SYCIL, CAB, NHS, WEA.

2) We strongly resent flat-rate charges of £10 that we view as unfair because they do not reflect the facilities provided e.g. the rate for Meeting Room 2 is the same as for the main room.

3) We think account should be taken of these groups' ability to pay usage charges, and a two tier policy similar to that of DCVS should be implemented.

4) We also think that the RCCG should negotiate on behalf of their members.

5) We are not happy about there being no internet connection available and not having access to the office photocopier which we would like to use to do our newsletters and other paperwork which we would be prepared to pay for at a reasonable cost.

6) In the economic climate, we see room hire charges as inevitable. While these charges may be appropriate for our monthly meetings with multiple attendees, the 1:1 personal mentoring services we provide would mean that we would have to pass the charge onto our member personally. These people who use this 1:1 service are mainly the more vulnerable with benefits or other financial hardship problems.

We have decided, reluctantly, to pay the room hire charges. As the result of a consultation of members, and those present on the 21st March, we have decided to raise the annual subscription to £15 P/A from April. Any new members who pay their subscription before April or members who renew their membership before April will pay the old rate.

You Write

Carole writes: I've Just been comparing energy bills over the last three months. Although I have used the same number of Kilowatt Hours (KWH), my energy bills have risen by 46% cost wise. With my bills electric has risen by 18% and gas by 16%. I have recently come off the British Gas Essentials Tariff when was offered to some people and been put on the basic tariff, and this has increased my bills by 12%. I've been looking around the price comparison websites, and the best I can do is save £40 per year by swopping suppliers. I've even considered home generation scheme like a windmill or solar panels. Any ideas ?

Dealing with list last first. Forget a home generation scheme as you need at least £5000-£7000 up front, and the you would break even maybe after 10 years or you are tied into a long term contract. I've had a look at BG's tariffs which are as follows.

Tariff	Comments	Mode	Payment method	Cancellation fee	Average monthly cost	Gas	Electric
Clear & Simple	Our most popular energy tariff with discounts for Direct Debit and Dual Fuel customers.	Variable	Direct Debit Cash / Cheque Pay As You Go	None	£106	£67	£40
Online Variable (May 2014)	Cheapest available British Gas tariff with online account management.	Variable	Direct Debit Cash / Cheque	£30 per fuel	£102	£64	£39
Price Promise (April 2015)	Guarantee that your energy prices will not rise until 30 April 2015.	Fixed	Direct Debit Cash / Cheque	£50 per fuel	£116	£73	£44
Price Promise (July 2014)	Guarantee that your energy prices will not rise until 31 July 2014.	Fixed	Direct Debit Cash / Cheque	£35 per fuel	£113	£71	£43

The cheapest tariff is the 'Online variable'. You don't get bills so everything has to be online i.e. internet based. You could speculate and go for a price promise tariff—but it is a gamble depending if energy prices go up or down. You could change supplier, but as you say, there will not be a massive annual cost-saving. Everyone I've talked to says that you should buy your gas and electricity from the same supplier. The next thing is to try to reduce your energy consumption with insulation, low energy light bulbs etc. Perhaps the best advice I've heard is to invest in warm clothes!

Carol writes: **"**I'm on DLA, I've just made enquiries with the DWP about PIP (Personal Independence Payment replacing DLA) which may be useful for other members.
A). If I report any changes to my health after 7 October 2013, then I will be asked to claim PIP.
B). If my existing DLA is due to end on or after 7 October 2013, then the renewal will be PIP.
C). Everyone else in receipt of DLA will not be contacted until 2015 or later, unless there is a change in health or my DLA award expires."

Tony writes: "I'm the publicity officer of the ME Association. It's time to add your GP surgery details to our 'Telling GPs the Truth about ME' campaign, which will be ready to roll out during ME Awareness Week in May. If you want your GP to receive a copy of our clinical guidance booklet "ME/CFS/PVFS: an Exploration of the Key Clinical Issues" – and 900 people so far have told us that they do – please send details of your surgery to our Publicity Manager,
email: tony_mea@btinternet.com or text: 07516 656 537.

A well-supported Christmas fundraising Appeal bought in over £9,000 which will let us tackle this GP education project with gusto. At a rough guess, this will buy up to 4,000 copies of the booklet. A fully revised edition of the booklet is being prepared for the campaign. The authors are MEA medical adviser, Dr Charles Shepherd, and consultant neurologist Dr Abhijit Chaudhuri, who works at the Queens Hospital, Romford, Essex. So, please, if you think your GP needs educating about ME/CFS or Post Viral Fatigue Syndrome, let us know using the contact details above."

Sandra Writes: "I am wondering if you can help me. i am struggling to drive at the moment with pain. My carer, who is also my daughter, is wanting to learn to drive and as you know money is very tight. Do you know if there is anyone who can help us with funding for this. I have looked into it myself but i can't find anything or anyone that I can ask. I would be very grateful if you can help us.

Why not ask Motability ? Over the past 35 years, Motability has helped over three million people get mobile by exchanging their mobility allowance to lease a car. However with the introduction of PIP, it will be very difficult for people with ME/CFS to go via this route, so I suggest while you can, as you are already driving a Motability car, that the first option would be to contact them. There are however limitations. Drivers under 25 are restricted to cars with an ABI Insurance Group of 16 or lower and with a power output of 115 brakehorse power (BHP) or less. In addition, only one named driver under 21 is permitted – this could be the disabled customer, or another driver living at the same address.

For disabled people without a driving licence, you can learn to drive in your Motability car as long as:
•You have a provisional licence
•You are listed as a permitted driver on the Certificate of Motor Insurance
•You are accompanied by a driver who is over 21 and has held their licence for at least three years
What is not clear is if this applies to Carers.
There is extra support on offer to drivers aged 16-24 (whether yourself or a named driver) through Pass Plus. This is a free six-hour course provided by the AA, specifically designed to help young drivers to drive more safely. Successfully completing the course in addition to passing your test can reduce the insurance excess for young drivers anyway—so is a bonus for the future.

Bill writes: "With having to wait for the monthly meeting I've have submitted my DLA form late, and now I've received a letter from the DWP asking why? What do I do?

No panic Bill, you are a fully paid up member of Leger ME so we are here to help you. This is a problem we frequently come across, In these cases we will send a letter something like the following to the DWP on your behalf:

Bill is one of our clients.

According to our records he received that form on 9th November 2012. The form was issued by Gwen at the Doncaster Jobcentre Plus who is assisting Bill with his Limited Capability of Work programme. As a matter of Leger ME policy we do not fill out these forms until we are satisfied that all the necessary evidence and support documents are available. We have considerable experience in dealing with the DWP system and, considering his case and history, I thought it prudent to wait until there was enough evidence available make an application worthwhile.

This evidence did not really materialise until late January due to NHS waiting lists and other administrative delays. We only hold welfare rights sessions during the third week of the month. I last saw Bill on the 21st February at one of these sessions to complete the paperwork. With you receiving the completed application form on the 8th March the timeline seems about right.

Could we make is crystal clear that due to government cutbacks and the changes in the benefits system, we are overwhelmed with cases. One thing I am not prepared to do is compromise an application simply because it is inconvenient administratively for yourselves. The people who apply for DLA as a rule are usually very ill and have limited ability which you DO NOT seem to take into account. I would view any further queries of this nature as unnecessary harassment of our member.

Medical Committee for Medical Products for Human Use refuses to license medicines for fibromyalgia. *(PJ 23/30 March2013)*

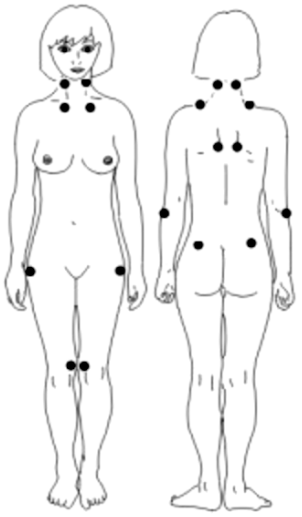
It's not very often I see features about health problems that concern us. However, in this weeks Pharmaceutical Journal there is a feature about *Current treatment options for fibromyalgia*. The feature covers basic fibromyalgia concepts and treatment, was written by Richard Larkin, a senior clinical pharmacist at City Hospitals Sunderland NHS Foundation Trust and covers pregabalin, duloxetine and milnaciprin.

The refusal to license these three medicines is based on the grounds of efficacy (or how well they work). The available evidence suggests that only one in seven patients will get a 30% reduction in pain level. However these medicines are licensed in the USA by the Federal Drugs Administration. This is not unexpected because many doctors view fibromyalgia with the same scepticism as was the case with ME/CFS. As a consequence, as with ME/CFS, there are currently no licensed medicines to treat fibromyalgia in UK. Locally, GP's and the hospital clinics do use duloxetine and pregabalin with mixed results so this headline does not really affect people around our area.

Pregabalin is a pro-drug that has to be metabolized to the more familiar gabapentin before is it effective. It is a synthetic opiate drug, related to the more familiar codeine and morphine. In practice most of the people I see say that they have to take such a high dose that sedation and weight gain are a problem, although for a few it is very effective.

Duloxetine is related to fluoxetine (Prozac). It is a SNRI-type medicine currently licensed for diabetic neuropathic pain, which is the same sort of pain that people with fibromyalgia suffer from—hence an implication that it may be useful. I've known several people try it without any spectacular success.

Milnacipran is a similar type of drug not available in the UK at present**.**



• = sites of tender points used to diagnose fibromyalgia

Fibromyalgia

The word fibromyalgia means pain (algia) coming from the muscles (my) and fibrous tissues (fibro) such as tendons and ligaments. Most people with fibromyalgia also have other problems as well, hence fibromyalgia is sometimes called known as fibromyalgia syndrome (FMS). It is a chronic (persistent) condition. Fibromyalgia does not affect the joints, and so is not like arthritis. Fibromyalgia is a condition characterised by chronic, widespread pain, which is often severe, and increased pain sensitivity. Patients often report a range of symptoms, usually including poor quality unrefreshing sleep and cognitive disturbances like those observed in ME/CFS..

Research has shown that people with fibromyalgia have certain subtle changes in some chemicals in the brain and nervous system. For example, there seems to be a minor change in the level of certain brain chemicals called neurotransmitters. These are the chemicals responsible for transmitting messages between nerves and between brain cells. People with fibromyalgia tend to have an increased amount of a chemical called substance P in the fluid that bathes the brain and spinal cord (the cerebrospinal fluid (CSF)). Although it is strongly suspected that FMS is due to a disturbance in the central nervous system regulation of pain, further research in this direct may help discover the exact process leading to the condition and treatments.

The normal clinical use of the above drugs would be for anxiety/depressive disorders. The fact that they are not licensed should not be taken as an indication that they are ineffective. Amitriptyline is an old well established antidepressant not licensed for pain control, but it is prescribed by many doctors at a low dose simply because it works in practice. There are other useful medicines cocodamol, (opiates with or without paracetamol), other tricyclic antidepressants, and drugs known as presynaptic alpha2-delta calcium channel blockers have been prescribed with some benefit to patients.

Changes to Welfare Rights

From Benefits & Work

Personal Independent Payment PIP Introduction timetable

The timetable for moving working age disability living allowance (DLA) claimants onto personal independence payment (PIP) has been put back by two years, until after the next election, for people with indefinite or lifetime awards of DLA. *(I wonder why?).*

From April 2013: The new timetable will begin with a pilot from 8th April 2013 for new claims to PIP in the North West and part of the North East of England. Postcodes affected are:
CA, CH (except CH5, CH6, CH7 and CH8), LA (except LA27, LA28, LA62 and LA63), CW, FY, L, PR, WA, WN, BL, DH, DL (except DL6, DL7, DL8, DL9, DL10 and DL11), M, NE, SR, and TS (except TS9).

From June 2013, all new claims from anyone aged 16-64 will be for PIP instead of DLA throughout the whole of Great Britain. The only exception will be renewal claims from a fixed term DLA award which is due to expire before the end of February 2014, where the renewal claim will still be for DLA rather than PIP.

From October 2013. following DLA recipients will begin to have to claim PIP:
Children turning 16 will have to claim PIP when their existing fixed term award is coming to an end. People reporting changes of circumstances which might affect their rate of payment, such as an improvement or deterioration in their condition, but not issues like going into a care home or hospital or changing address. People with a fixed-term DLA award which expires from the end of February 2014. Anyone who chooses to make an application for PIP, including people who have a fixed-term or indefinite award of DLA.

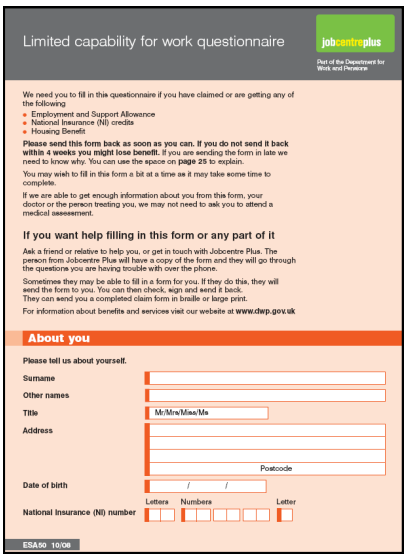
From October 2015, everyone still getting DLA will have to make a claim for PIP. Claimants will be selected randomly rather than by area or age, although the DWP say that they will "invite claims as early as possible from recipients who have turned 65 after 8 April 2013, when PIP was first introduced."

The DWP does not now expect to complete the reassessment of all existing DLA claimants for PIP until March 2018.

THE PIP rules are more severe than DLA so if you are considering applying for DLA, do no now while the old rules still apply.

Changes to the ESA 50 forms

A new version of the ESA 50 form is now being issued. Apart from revamping and slightly different questions, the only significant addition is an 18th section which is about feeding. Unless you cannot feed yourself it is of no significance. Employment and Support Allowance Claim Form Guides to the new claim form and new regulations - 28 January 2013 - are now available. They are available as a download to fully paid up Leger ME members, on request.


Limited capability for work questionnaire

jobcentreplus

Part of the Department for Work and Pensions

We need you to fill in this questionnaire if you have claimed or are getting any of the following

- Employment and Support Allowance
- National Insurance (NI) credits
- Housing Benefit

Please send this form back as soon as you can. If you do not send it back within 4 weeks you might lose benefit. If you are sending the form in late we need to know why. You can use the space on **page 25** to explain.

You may wish to fill in this form a bit at a time as it may take some time to complete.

If we are able to get enough information about you from this form, your doctor or the person treating you, we may not need to ask you to attend a medical assessment.

If you want help filling in this form or any part of it

Ask a friend or relative to help you, or get in touch with Jobcentre Plus. The person from Jobcentre Plus will have a copy of the form and they will go through the questions you are having trouble with over the phone.

Sometimes they may be able to fill in a form for you. If they do this, they will send the form to you. You can then check, sign and send it back.
They can send you a completed claim form in braille or large print.

For information about benefits and services visit our website at **www.dwp.gov.uk**

About you

Please tell us about yourself.

Surname

Other names

Title Mr/Mrs/Miss/Ms

Address

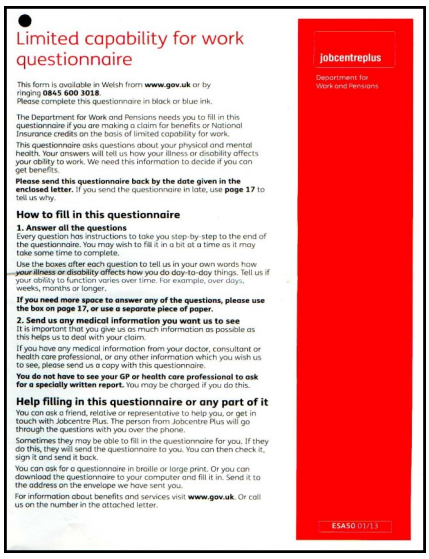
Postcode

Date of birth / /

National Insurance (NI) number Letters Numbers Letter

ESA50 10/08

Old version


Limited capability for work questionnaire

jobcentreplus

Department for Work and Pensions

This form is available in Welsh from **www.gov.uk** or by ringing **0845 600 3018**
Please complete this questionnaire in black or blue ink.

The Department for Work and Pensions needs you to fill in this questionnaire if you are making a claim for benefits or National Insurance credits on the basis of limited capability for work.

This questionnaire asks questions about your physical and mental health. Your answers will tell us how your illness or disability affects your ability to work. We need this information to decide if you can get benefits.

Please send this questionnaire back by the date given in the enclosed letter. If you send the questionnaire in late, use **page 17** to tell us why.

How to fill in this questionnaire

1. Answer all the questions
Every question has instructions to take you step-by-step to the end of the questionnaire. You may wish to fill it in a bit at a time as it may take some time to complete.
Use the boxes after each question to tell us in your own words how your illness or disability affects how you do day-to-day things. Tell us if your ability to function varies over time. For example, over days, weeks, months or longer.
If you need more space to answer any of the questions, please use the box on page 17, or use a separate piece of paper.
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.

Help filling in this questionnaire or any part of it
You can ask a friend, relative or representative to help you, or get in touch with Jobcentre Plus. The person from Jobcentre Plus will go through the questions with you over the phone.
Sometimes they may be able to fill in the questionnaire for you. If they do this, they will send the questionnaire to you. You can then check it, sign it and send it back.
You can ask for a questionnaire in braille or large print. Or you can download the questionnaire to your computer and fill it in. Send it to the address on the envelope we have sent you.
For information about benefits and services visit **www.gov.uk**. Or call us on the number in the attached letter.

ESA50 01/13

New version

Anger at Prime Minister's misleading defence of 'bedroom tax'

From Benefits & Work 11/3/13

The Prime Minister has caused anger among many disabled people by giving MPs a misleading account of his government's new "bedroom tax". David Cameron claimed at this week's Prime Minister's questions that "people with severely disabled children" and "people who need round-the-clock care" would be exempt from the new housing benefit regulations. Although some families with children with high support needs will be exempt from the regulations – which come into force on 1st April and affect those in social housing – this exemption will be at the discretion of their local authority. And the exemption is only the result of a court success last year by disabled people and their families, a victory the Department for Work and Pensions (DWP) wants the Supreme Court to overturn.

Cameron also failed to point out that only disabled people who need a spare room for an overnight paid care worker will be exempt from the bedroom tax, while those who rely on partners or other family carers for their support will still lose out. His comments caused anger among disabled people on Twitter, with many furious to hear of more misleading information from the government on the impact of its welfare reforms. A DWP spokeswoman told Disability News Service that local authorities "have the discretion to exempt families with a disabled child" but that family carers "would not be exempt".

The new regulations will see housing benefit reduced by 14 per cent if a household is found to have an unoccupied bedroom, and by 25 per cent if they have two or more unoccupied bedrooms. Children under 16 of the same gender – and all children under 10 – will be expected to share a bedroom. Cameron's comments came as his government faces a possible judicial review over the impact of the bedroom tax on disabled people, after claims were lodged on behalf of 10 individuals and families. Lawyers acting for the claimants argue that the changes will have a far greater impact on disabled people than non-disabled people.

They say the regulations breach the Equality Act and the Human Rights Act, as well as the UN Convention on the Rights of Persons with Disabilities. The high court will decide by the end of this month whether there will be a full, four-day judicial review, which would take place in May. Cameron's comments also came as National Housing Federation (NHF) figures showed that 230,000 disability living allowance (DLA) claimants would lose an average of £728 per year in housing benefit as a result of the new regulations. Even if all the extra £30 million funding allocated by the government to help foster carers and disabled people in adapted properties was given to DLA claimants hit by the tax, they would each receive just £2.51 per week, compared with an average £14 a week loss.

A lawyer representing five of the families seeking the judicial review – who all have disabled children who need separate bedrooms for impairment-related reasons – said the regulations would have a "catastrophic impact" on thousands of disabled children and adults. Anne McMurdie, who represents another three of the claimants – a disabled man with a mental health condition, the father of a disabled child who shares caring duties with the child's mother, and a disabled woman cared for by a parent in a significantly-adapted property – said the court case raised "issues of the greatest significance".

McMurdie, from Public Law Solicitors (PLS) in Birmingham, said the government had failed to address properly the "true impact" on disabled people, or the "true costs" of the new regulations. She said the long-term impact was likely to include the costs of rehousing, extra respite care, people being forced to move into residential accommodation, and adaptations in people's new homes.

She said: "Inevitably, disabled people will fall into debt and some will lose their homes or be forced into accommodation which does not meet their needs." She added: "The case may well

have wide implications for future welfare policy-making – just how much the burden of cuts can fall disproportionately on disabled people." The final two claimants, Jacqueline Carmichael and Richard Rourke, came forward as a result of work by the *We Are Spartacus* online network of disabled campaigners.

Carmichael lives in a two-bedroom housing-association flat with her husband, her full-time carer, and has to sleep in a fixed position in a hospital bed with an electronic pressure mattress. Her husband cannot share her bed for safety reasons, and there is no room for a second bed, so he sleeps in the second bedroom. The Carmichaels say they cannot afford the 14 per cent benefit reduction which will be imposed from 1 April.

Rourke, a wheelchair-user, lives in a three-bedroom bungalow, with substantial adaptations. He has a disabled daughter, also a wheelchair-user, who is studying at university but returns home for summer vacations, other holiday periods, and often at weekends. The third bedroom is a tiny box-room used to store mobility and care equipment. Rourke cannot move home because there is no wheelchair-accessible, two-bedroom social housing available. If forced to move, he risks losing access to his support network, say his lawyers.

New DLA reform confusion after senior civil servant 'contradicts McVey'

From Benefits & Work 11/3/13

The government has again been accused of sending out misleading and confusing information about its disability living allowance (DLA) cuts and reforms, after a senior civil servant apparently contradicted the Minister for Disabled People. Disabled people's organisations (DPOs) at a Department for Work and Pensions (DWP) event had been anxious for clarity on eligibility for the new personal independence payment (PIP), which will gradually replace working-age DLA from April this year. But contradictory comments from Esther McVey, the Conservative Minister for Disabled People, who spoke at the event, and one of her own senior civil servants, have only added to the confusion.

In December, McVey shocked disabled activists and DLA claimants by announcing that the key walking distance criteria for PIP had been reduced from 50 metres to 20 metres. The following month, she bowed to intense campaigning pressure and agreed that PIP claimants should only be assessed on what they could do "safely, reliably, repeatedly and in a reasonable time period". This should have meant that some people who could walk a little more than 20 metres could still claim the enhanced rate of PIP, and so still qualify for a Motability vehicle, and McVey confirmed this at last week's *PIP Delivery Update and Claimant Journey Teach-in*.
But her comments were later apparently contradicted by a senior civil servant, when he agreed with a benefits expert from Disability Rights UK (DRUK) that current regulations only allow for this group of disabled people to receive the standard rate of PIP. DRUK has now written to the Minister, urging her to make the PIP position "legally clear".

The letter, from DRUK chief executive Liz Sayce, says: "While we, along with other DPOs, welcome your clarification, the present wording of the Social Security (Personal Independence Payment) Regulations 2013 provides for those disabled people who cannot stand and move up to 50 metres safely, reliably, repeatedly or in a reasonable time period to be awarded only the standard (lowest) PIP mobility rate. "This was acknowledged and confirmed to us by a senior DWP officer at the end of yesterday's meeting."

Sue Bott, DRUK's 'Director of Development', said she feared the Government intended that people who could walk a little more than 20 metres – even if they could not do it "safely, reliably, repeatedly and in a reasonable time period" – would only receive the lower PIP mobility rate. She said the situation facing disabled people preparing for the move to PIP was now "very unclear" and a "lawyer's paradise" that would end up having to be tested in the courts. She said

she was “a little bit suspicious” about the government’s motivation in stirring up confusion, and added: “It feels like trying to implement a cut by the back door.” She said: “The problem with something that is obscure is that it is very easy then for people to not get what they are entitled to. “You can imagine how the likes of Atos [the controversial IT company which will be carrying out many of the PIP assessments] will interpret this descriptor. “As usual, it will be left to people knowing their rights and having the energy to pursue an appeal to get what they ought to be entitled to.” She added: “The [PIP] system was supposed to be simple, but it has turned out to be anything but.”

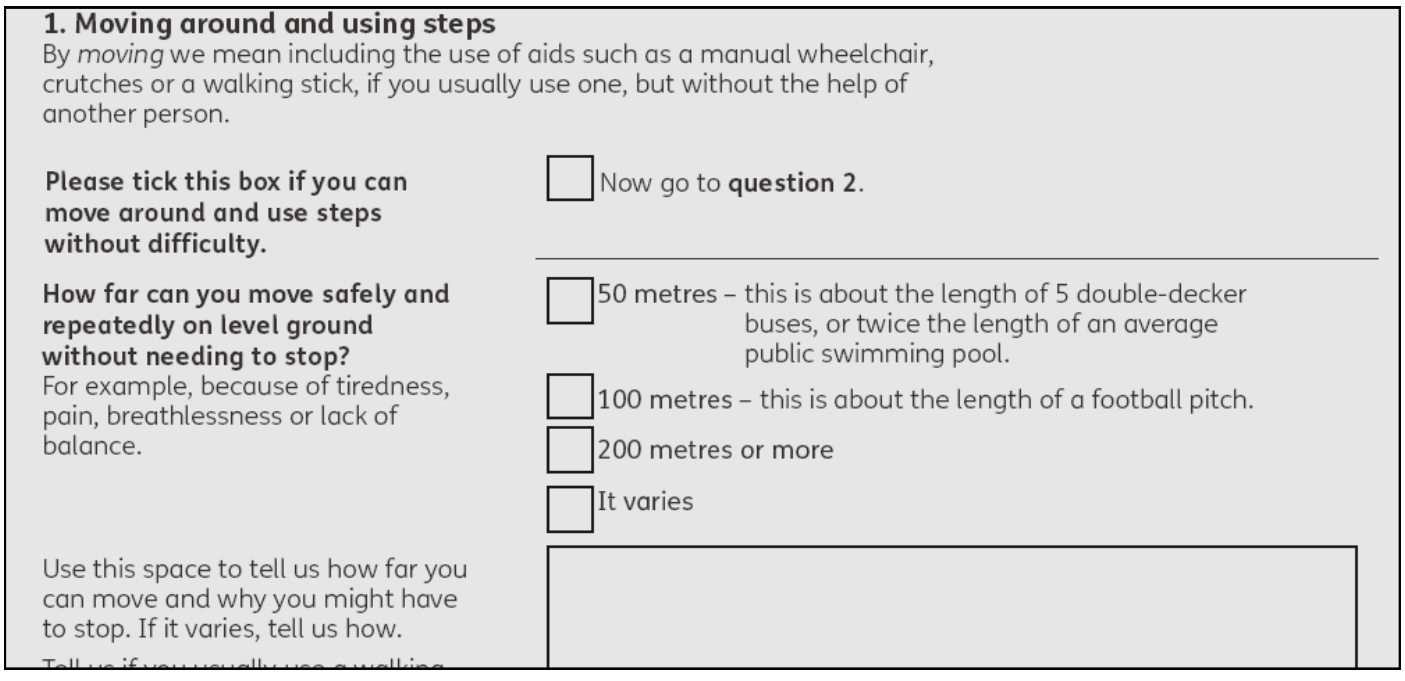
A DWP spokeswoman insisted that there was no confusion, and that “individuals who cannot stand and then move 20 metres will receive the enhanced rate of the mobility component”. She said that if a claimant could “move distances between 20 metres and 50 metres but cannot do so safely, to an acceptable standard, repeatedly and in a reasonable time period, they would also receive the enhanced rate”. She added: “The Minister made this clear, as have our officials.” She said that McVey would be responding to DRUK’s letter in due course. It is just the latest example of confusion and apparently misleading information from DWP over its DLA reforms. Last month, Disability News Service reported that the Government’s own telephone helpline advisers had been passing DLA claimants with lifetime or indefinite awards out-of-date information about when they would face reassessments.

Potential Implications for future PIP claimants who are also claiming ESA

Over the years when conducting's 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 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 PIP, you have told the DWP you can move 50 metres— and by implication it means that you are able to move around more 20 metres and so you will not qualify for the higher mobility payment. At present there is not enough information around to advise members what to do.



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.

Tell us if you usually use a walking

News from Fairlawns.

The South Yorkshire & North Derbyshire Chronic Fatigue Syndrome/ME Service.

Here is a feature from the Sheffield Star By Richard Blackledge first . published on 12/11/12 about Cheryl Harper from Penistone who suffers from ME/CFS and I frequently see at LPIG meetings.

HEALTHY LIVING: ME can feel like a life sentence but now I don't see myself as ill

CHERYL Harper's old life will be familiar to the daily experience of many working mums – juggling long hours in her job with bringing up children, exercising and a busy social calendar.

But for Cheryl, the hectic pace took its toll, until she finally reached breaking point and was struck down with ME, leaving her exhausted and housebound. The 38-year-old, from Penistone, Barnsley, became one of around 250,000 people in Britain affected by the condition, which causes severe and debilitating fatigue.

She has since been supported by Sheffield's specialist Chronic Fatigue Syndrome/ME service at the Fairlawns medical centre on Middlewood Road, where she was given help learning how to change her routine and balance the energy she uses each day. Cheryl, a mum-of-two, first became ill eight years ago, and the onset of her ME was shockingly sudden, occurring as she drove home from a day at work as the manager of an insurance firm.

"I was like any other busy working mum, I was always on the go, went to the gym and myself and my husband enjoyed a good social life," she said. "But one day in mid-2004 I was driving home from work and I could feel myself getting more and more tired and so I went to bed as soon as I got in.

"When I woke up the next morning I couldn't get out of bed, my arms wouldn't lift up and I was aching all over. My husband thought I had flu, but with the excruciating head pain I thought I had a brain tumour." She then endured a distressing two-year ordeal, struggling to understand her problems while doctors tried to provide a diagnosis. "It struck me down out of the blue and I was off work for six months feeling constantly exhausted," Cheryl said. "I would wake up and not feel refreshed at all and I didn't leave the house in that period because I was just too ill." Cheryl became increasingly dependent on her husband, Damon, dad to her daughter Lauren and younger son Xander.

She was eventually prescribed medication by her GP, who diagnosed depression, but the treatment failed to relieve her growing list of symptoms - unrelenting fatigue, nerve pain, sensitivity to light and sound and lack of concentration, all typical of ME.

Cheryl returned to work, but at the end of 2005 once again found herself resigned to being too ill to leave the house for another six months. After further appointments with psychiatrists, a pain clinic in Mexborough and tropical disease specialists, Cheryl was finally told she had ME and referred to Fairlawns.

“The service was fairly new so I was one of their first patients,” she said. “I just felt relieved to be there.” She was offered either group or individual therapy sessions, and introduced to the concept of ‘pacing’, which helps ME sufferers find ways to balance how they use their energy, ensuring they use the same amount each day.

“I chose group sessions so I could meet people in similar situations. As CFS/ME is an invisible illness, you can feel very much on your own, so it was great to hear that it does actually exist and listen to other people’s experiences,” Cheryl said.

“I have to carefully plan my daily routine out to make sure I don’t use up all my energy in one activity that will give me a ‘boom’ one day and in turn will ‘bust’ for the next few days and leave me with no energy.”

Cheryl now paces all her activities, and eats small nutritious snacks throughout the day at two-hour intervals, instead of large meals. “The condition has completely changed my life. Now I can’t burn the candle at both ends, I have to regulate everything, including my sleep time.”

Cheryl is well enough to work three days a week, but still needs treatment for nerve pain in her hands and acupuncture to deal with aches.

She said she thought the ME service was ‘fantastic’, adding: “It’s the only lifeline in the area and has been a massive support to me. I have no idea what brought my condition on, but I think I made things worse as I overdid it through working long hours, not eating properly and over-exercising.

“I don’t know if I will relapse again. I did initially go through a grief period for what life was like before, as the condition can feel like a life sentence at the start - but now this is my life, and I don’t see myself as ill.”

Myalgic encephalomyelitis (ME) fact file

- ME stands for Myalgic encephalomyelitis. Myalgic means muscle aches or pains, while encephalomyelitis means inflammation of the brain and spinal cord.
- Symptoms include muscular aches, joint pains, disturbed sleep, poor concentration and headaches.
- There is no test for the condition, and there are also issues about the illness’s name – the term chronic fatigue syndrome is favoured by doctors, but many sufferers prefer the term ME.
- Possible causes include genetic factors, viral infections, stress, depression and traumatic events, such as bereavement.
- CFS/ME affects around one in 300 people in the UK, and there are an estimated 2,000 sufferers in Sheffield. The condition is three times more common in women than men, and people in their early 20s to mid-40s are most susceptible.

For more information about the specialist service call 0114 2292937, or the Sheffield ME Group on 0114 253-6700..

OUT AND ABOUT 3 *by Anne Fisher*

I hope you were able to visit some of the places in the last feature (OUT AND ABOUT 2). Here are a few more you may like to try, I can not guarantee that all these places are suitable for everyone so please use your own judgment if you try them.

OPEN COUNTRYSIDE. Manifold Valley, South Derbyshire – Wetton mill to Waterhouses (the track does start at Hulme End but passes through a tunnel on a single track road which is rather dangerous however you can park in unofficial spaces by the side of the road after the tunnel). There is a cafe and toilets at Wetton Mill and Lee House. The path is an old railway track and is very flat and tarmacked, this gives a very comfortable ride apart from the occasional wooden bumpy bridge. It is very popular with cyclists and families. The actual path is about 9 miles long but don't forget you have to get back so remember your battery life if using a scooter. The wildlife and views in this area are wonderful and worth visiting but it is rather isolated.

NATURE RESERVES. – Bempton Cliffs RSPB, Yorkshire coast
One of the easiest places in England to see, hear and smell seabirds! More than 200,000 birds inhabit the dramatic cliffs (from April to August) making the cliffs seem alive. With huge numbers to watch, beginners can easily learn the difference between gannets, guillemots, razorbills, kittiwakes and fulmars. The easily recognizable puffins (between April and July) are always a delight. Specially-created cliff top viewpoints are wheelchair accessible with care. Some of the paths are a little bumpy as they are natural rather than covered in tarmac, but this is all forgotten when the birds and cliffs are in view.

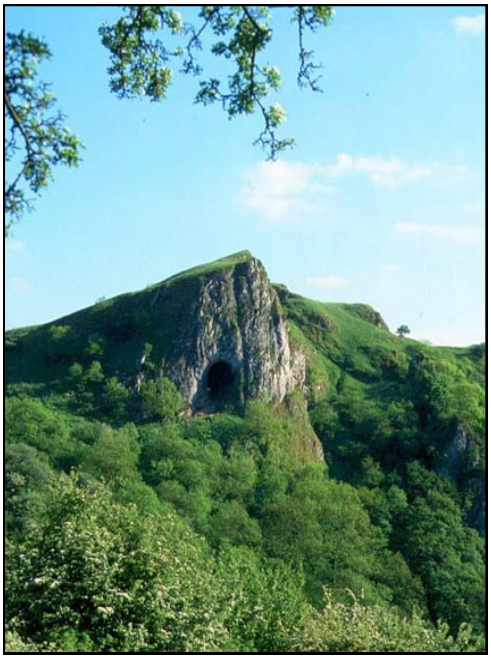
Opening times: The reserve is open all year. From March to October, the visitor centre is open daily from 9.30 am to 5 pm, and from November to February, 9.30 am to 4 pm. There are toilets and light refreshments available at the centre. Entrance charges: Entry is free of charge to members of the RSPB. There's a charge for non-members of £5 per car. There is a wheelchair available but it has to be pre booked. Tel:01262 851179 for more details

COUNTRY PARK. – Fountains Abbey and Studley Royal. National Trust. Only last week I had a lovely if not exhausting day out here, the snow drops were in flower and many daffodils were starting to grow promising a lovely show in a few weeks' time. Situated close to Ripon, it is easy to reach. The grounds are good while you are on the paths and you are allowed to visit the Abbey but you do have to cross the grass to get there, so you are better going when the ground isn't wet or the grass muddy. For disabled access you need to park at the West gate. There are toilets available in a number of places and refreshments in 2 or 3 sites ranging from snacks to full meals. The access map given on entry shows the paths available and the gradients of some that you may want to avoid.

Wheelchairs are available but it would be advisable to pre book. Tel No: 01765 608888

COASTAL WALKS. – Llandudno I found Llandudno a very wheelchair-friendly resort. Most of the pavements were lowered to cross roads and the promenade was a very comfortable place to sit. We went round the Great Orme on my scooter which was a very long ride ($4^1/_2$ miles) and took us about 4 hours. There is a steep gradient on each side so it may be too difficult for a wheelchair user (or rather their pusher). About $^1/_3$ of the way round from Lllandudno Bay there is a café and toilets. The views and solitude are wonderful, it can be quite a lonely place but for us this was what we were looking for, sitting looking out onto the sea and watching the seabirds soaring overhead, the amazing cliffs and the sea crashing on the rocks below. This solitude was only broken by the occasional walkers who were amazed to see me there on the scooter. Bliss. There is no shelter if the weather turns inclement.

ME/CFS ADVICE If you don't have your own scooter or wheelchair then try some of the places listed that loan or hire them. Build up slowly the amount you can do in a day and try somewhere close and only stay out for a short time at first (you can always go back for a second visit). You may need to rest before you go and be prepared to rest afterwards until you know how much you can do. I also recommend that you take a hat, gloves, scarf, blanket and dress warmly as the wind seems to be very chilling even on mild days when in a wheelchair or scooter; my hands suffer the most from holding onto the handles of the scooter. The blanket is also useful for picnics and an afternoon nap if needed. I hope you have as much fun as I have done by being able to go 'Out and About' again.



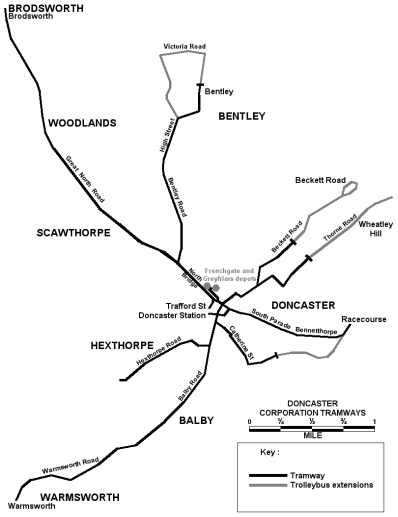
Top right
The author

Middle left
Bempton cliffs

Middle right
Manifold
Valley
Great Orme

Bottom left
Fountains
Abbey

Trolley busses are still around Doncaster



Many people will know I'm a fan of electric transport. Not a lot of people know that not far away is a working trolleybus system. I'm just old enough to remember the last days of the Doncaster trolleybus system which replaced the Doncaster Corporation Tramways. The trolleybus system in Doncaster was a moderately sized one, with a total of 6 routes, and a maximum fleet of 47 trolleybuses which closed on 14th December 1963. Some of the trolleybuses has a diesel engine installed and continued in service for some years after but that was not quite the end of trolleybuses in Doncaster. In the late 70's a route was laid out in Leger Way from the bus deport for a trolleybus research project sponsored by several companies to test the economics of reintroducing a system. Some 30 years later the research vehicle is still around. (*See left, below the last Doncaster trolley bus*)

One of the former Doncaster trolleybuses is now preserved, at the Trolleybus Museum at Sandtoft, Lincolnshire. (See Below).

The museum occupies part of the former RAF Sandtoft, an operational bomber airfield during the Second World War. RAF Sandtoft was disposed of by the RAF in 1958 and the site was acquired for the museum in November 1969. Since that time, volunteers have transformed a barren site into a museum with the addition of workshop, vehicle depot and exhibition building. The museum is recognised as having the largest collection of preserved trolleybuses in Europe, if not the world, with over 60 examples. Whilst the exhibits are predominantly from the UK, a collection of international examples is growing at the museum. A part from trolleybuses and transport, the museum also features a collection of 1950s/60s memorabilia. Over the years, many items related to the trolleybus era have been donated. A 1950s/1960s street scene features shop windows, complete with displays, whilst the prefab utility bungalow, previously used as the Museum's souvenir shop, has now been fitted out as a home to show even more of these period artefacts. The museum is open on selected days only, for further details please see the website . http://www.sandtoft.org.uk/

Rituximab: Personal Perspective *by Tony Golding.*

(Adapted from Outreach Autumn 2012, Network MESH West London. This is a Conference Report of the 'Invest in ME Research Conference',1 June 2012:

Ten leading scientists and doctors made presentations at the 7th International ME/CFS biomedical research conference in London but the highlight was undoubtedly the presentation by the two Norwegian oncologists, Dr. Fluge and Professor Mella, on their remarkable chance finding that a well-established drug, Rituximab, used to treat a certain type of cancer and several autoimmune diseases, significantly relieved the symptoms of ME in some people. Rituximab, a complex monoclonal antibody, is one of a new class of biological drugs, as opposed to standard chemically-derived drugs. Monoclonal antibody therapy can be highly targeted towards specific cells or proteins that are operating abnormally. One of the ways in which it does this is by stimulating the immune system to attack those cells. This is a personal, lay view of what was said, and I cannot vouch for its scientific accuracy. I make no apology for focusing on this development to the exclusion of the other interesting lines of enquiry that we heard about, notably research into the autoimmune system and the biology of the brain in relation to infection and inflammation.

There is, given the numerous false dawns we have seen in the search for a cure or, failing that, a treatment for ME, an understandable reluctance to hail this result as "the discovery that will change everything for people with ME". But, in all my 27 years with this illness, I can't remember any kind of medical intervention as promising as this. And, it is important to remember, it is based on a product that has been used and tested for 15 years, so there is no need for the long wait to develop a drug from a pure science discovery. Nor is Rituximab (Rituxan in the USA, MabThera in Continental Europe) some minor drug with a highly specialised application. It is a big selling drug by any standards, accounting for $6bn of annual sales for Roche, one of the two big Swiss pharmaceutical companies. So it has a high profile and there is plenty of interest on the part of the pharmaceutical industry in finding ways to move beyond the diseases that Rituximab currently covers. Its main use is as a treatment for non-Hodgkin's lymphoma and severe active Rheumatoid Arthritis. Until now, the pharmaceutical industry has taken zero interest in ME, despite the fact that a large patient population is intrinsically attractive to drug companies. We must hope that the apparent usefulness of Rituximab will change this.

However, it is important to keep a sense of perspective: Rituximab is not - at least in its current form - a cure. It seems to help the majority of those who receive it, some significantly, some less so. And the clinical trial (described below) that demonstrated its efficacy was a small one---the numbers involved were not sufficient to prove that this finding wasn't a fluke result. To get to that point will require more trials with many more participants. In short, we are at the beginning of a road that could lead to an effective treatment for many people with ME, but it is an exciting beginning.

What the Norwegian doctors have found

Eight years ago Drs. Fluge and Mella happened to be treating a woman with non-Hodgkin's lymphoma who also had serious ME. They noticed, with amazement, that the woman reported substantial improvements in her ME symptoms. They then tried Rituximab on two other people with ME and found that they too experienced a significant diminution in their ME symptoms. They then set up a controlled trial with 30 ME patients, 15 of whom received the drug and 15 of whom received placebo, which extended from June 2008 to June 2010. Two-thirds of those who received the drug responded positively: all of their symptoms receded. The lag in response from a course of Rituximab therapy averaged three months. There were few side-effects. One-third showed no response. Fluge and Mella then published a paper last October on the results of this trial that was read by 35,000 people, compared with the 1,000 "hits" that a typical cancer paper receives.

Fluge and Mella decided they were on to something and decided to devote time to pursuing it, even though it took them away from their "day job" as oncologists. They then set up two new studies with 28 ME patients but this time without the placebo group. Six of these were classified as severe. The results are still coming in but, so far, 18 out of the 28 (again, two-thirds) have responded to a Rituximab regime of periodic infusions over a period of fifteen months. Of the one-third who did not respond, seven experienced a direct worsening of their symptoms. Fluge and Mella speculate that the non-responders belong to a particular sub-group of ME patients.

They also speculate that, for these, there is another factor involved in symptom maintenance, something they are starting to investigate. As for severity, the only comment made was that they thought that the response is lower for the bedbound. They have applied for funding to undertake a 140 person study of ME patients, all fulfilling the Canadian diagnostic criteria (the previous studies used the less stringent Fukuda criteria though all but two patients in the 30-person study also met the Canadian criteria). Although Rituximab acts on the autoimmune system, Fluge and Mella are not actually saying that ME is an autoimmune disorder - yet. They believe that the evidence indicates that "ME/CFS is a defined biological disease in at least a sub-group of patients".

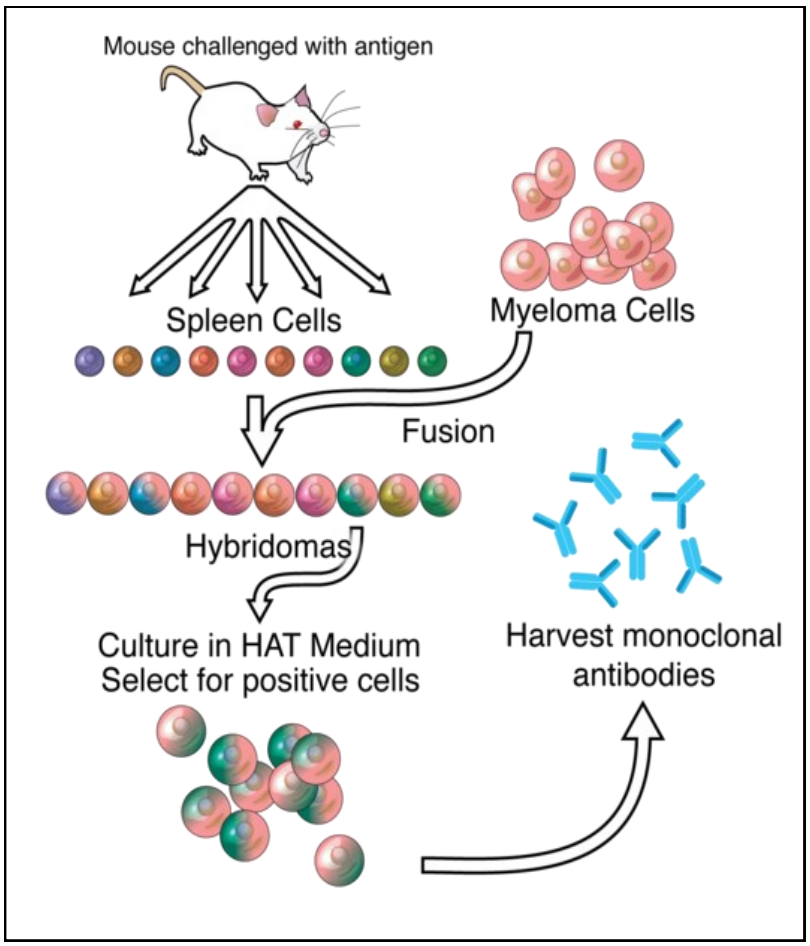
Rituximab (trade names Rituxan and MabThera) is a chimeric monoclonal antibody against the protein CD20, which is primarily found on the surface of B cells. Rituximab destroys B cells, and is therefore used to treat diseases which are characterized by excessive numbers of B cells, overactive B cells, or dysfunctional B cells. This includes many lymphomas, leukaemias, transplant rejection, and some autoimmune disorders. This drug shows promise in treating hairy cell leukaemia. There is a lot of evidence that ME/CFS is immune system-mediated. As it is active against B lymphocytes, it does give a glimpse into the possible mechanism of ME/CFS. As to whether this is a potential treatment needs to be further researched.

Monoclonal antibodies

Monoclonal antibodies (mAb or moAb) are monospecific antibodies that are the same because they are made by identical immune cells that are all clones of a unique parent cell, in contrast to polyclonal antibodies which are made from several different immune cells. Monoclonal antibodies have monovalent affinity, in that they bind to the same epitope.

Given almost any substance, it is possible to produce monoclonal antibodies that specifically bind to that substance; they can then serve to detect or purify that substance. This has become an important tool in biochemistry, molecular biology and medicine. When used as medications, the non-proprietary drug name ends in -mab .

Below: A general representation of the method used to produce monoclonal antibodies.



Heart Dysrhythmias, Irregular Pulse, Missed Beats and Palpitations

Pathways has reproduced some of Dr. Myhills views on the topic Following a number of issues raised on this topic on the group helpline.

A normal person's heart should beat somewhere between 65 and 80 beats per minute with the rate slightly speeding up as one breathes in and slightly slowing down as one breathes out. Fit athletes have a slower pulse because, as a result of training, the heart beats more powerfully at rest. A regular beat is achieved by the pacemaker, which is comprised of cells at the top of the heart, i.e. within the atria. The pacemaker generates an electrical pulse, which firstly flows down the top of the heart thereby making the atria contract, there is a small delay whilst the electrical wave flows into the bottom half of the heart, which makes the two ventricles contract. It is this alternate contraction of the atria which fires blood into the ventricles to fill them up, followed by a contraction of the ventricle, which fires blood out of the heart and sends it on its way round the body. One can, therefore, get irregular heart rate or lack of co-ordination between the atria and the ventricles, or lack of co-ordination of the ventricles as a result of disturbances of the pacemaker and/or the tissues that conduct the wave of electricity away from the pacemaker to the rest of the heart.

Disturbances of the pacemaker and conducting tissue cause a whole variety of heart dysrhythmias from the heart going too slow or going too fast, to missed beats, irregular beats, or a complete disassociation of heart activity such as atrial fibrillation or even ventricular tachycardias or fibrillations. However, whatever the nature of the disturbance, the fundamental causes are pretty much the same. Many of these disturbances such as ventricular ectopics are fairly harmless and do not cause too much trouble. However, you should see them as a warning sign to change your lifestyle and address the underlying factors that are causing them in order that they do not progress to anything more serious. Should you have established dysrhythmias requiring prescription medication, then no changes should be made to medication without informed discussion with your GP and ideally cardiologist. All dysrhythmias need medical input from your GP and/or cardiologist but the following interventions may be additionally helpful.

Causes and Treatment

As a doctor, what I am interested in, of course, is why that person has heart irregularities and is it likely to be due to the damage to the pacemaker and/or conducting tissues. Firstly, apply the general approach to maintaining and restoring good health with respect to diet & nutrition, sleep is vital for good health - especially in ME/CFS, and exercise, good balance between work and play. But to be more specific electrical disturbances of the heart are caused by:

1. Poor blood supply. All the risk factors pertaining to this should be explored, not just the obvious ones of diabetes and high blood pressure, but the less recognised factors such as homocysteine. Damage to the muscle of the heart as a result of an infarction also results in poor blood supply and possible dysrhythmias.

2. Micronutrient deficiencies. The pacemaker requires adequate levels of trace elements, in particular magnesium. Magnesium deficiency alone can trigger atrial fibrillation.

3. Poor energy supply at the cellular level. We now know that a substantial part of heart disease is due to mitochondrial failure in the heart - that is to say the supply of oxygen and fuel to the heart is adequate, but the mitochondria cannot translate this into energy for the heart muscle to work properly. I see this same problem in patients with chronic fatigue syndrome who suffer with generalised mitochondrial failure. These patients with chronic fatigue syndrome often have very abnormal mitochondrial function tests, but more research is needed.

4. Thyroid disease. Both underactive thyroids and overactive thyroids can cause atrial fibrillation. An underactive thyroid may cause AF because a thyroid being underactive is a major risk factor for arterial disease, which in itself can disturb the blood supply to the pacemaker.

5. The heart is particularly susceptible to toxic stress. For example, some studies have demonstrated people with heart disease have high levels of mercury in the heart. Heavy metals can certainly interfere with normal electrical activity of the heart and are best tested for by measuring toxic metals in urine following a chelating agent such a DMSA. Chelation therapy is the most effective way of removing heavy metals, and much can be achieved simply by using oral therapy with DMSA.

6. **Allergies to foods** There is no doubt that tachycardias can be caused by allergies to foods. Indeed, this is the basis of the "Coco pulse test". Doctor Coco demonstrated that patients who are intolerant of food may change their pulse rate by 10 beats per minute or over. I certainly have had patients who have switched into atrial fibrillation as a result of eating foods to which they are allergic. Some stimulants such as caffeine can also cause dysrhythmias.

Symptoms of Heart Irregularities If the heart is irregular (dysrhythmic), sometimes one becomes abnormally aware of the heartbeat and this is called a palpitation. If the dysrhythmia is more severe then the heart will cease to function effectively as a pump. If the cardiac output is impaired then the blood pressure will drop. In the early stages this means that the body can do less work, i.e. clinically you will have difficulty getting fit or maintaining your fitness. In more severe cases if the blood pressure drops then one can feel light headed and dizzy - the clue here is that if you feel much better lying down then that suggests poor cardiac output.

Diagnosis Ideally all dysrhythmias need diagnosing with an ECG. If the dysrhythmia is only there for some of the time then you need a 24 hour ECG. By making an electrical recording of the heart at the time of dysrhythmia the type can be ascertained. However, it can be very helpful if you can describe your dysrhythmia. Feel your pulse at the time of the dysrhythmia and count how many beats there are per minute. Work out if the dysrhythmia is regular or irregular and how long it lasts for. Make a note of anything that may have triggered it because this helps diagnose the cause.

Your physician will want to know:

1. How fast the dysrhythmia is e.g. sinus tachycardia (normal pulse but fast), atrial tachycardia (normal pulse very fast)
2. If the pulse is regular or irregular
3. If irregular, what is the nature of the irregularity.

For example:
In ventricular ectopics - basically a regular beat, then suddenly an early beat, then a pause before the next one comes along

In atrial fibrillation - pulse all over the place, irregular in time and consistency - sometimes a strong beat, sometimes a beat that is obviously weak.

Common Problems

Ventricular ectopics - this occurs when another pacemaker throws in an extra beat. When you feel your pulse at the wrist, it is regular, then suddenly a beat is completely missed. If you feel the pulse over the heart (or listen to the heart) you feel a regular pulse, then an early, perhaps weak, beat then a pause before the next beat. Once felt, never forgotten! These are a very common problem often caused by excessive caffeine, thyroid disorders, allergies or possibly hypoglycaemia.

Atrial tachycardia - pacemaker going too fast

Bradycardia - pacemaker going too slow. (Betablockers are a common cause)

Atrial fibrillation - completely irregular pulse. This occurs when the top of the heart (the atria) do not beat at all - they just wobble about (fibrillate). The problem here is that the heart may become inefficient through going too fast or clots may form inside the heart on the wobbling surface - anticoagulants may be necessary. Clots are also a problem if you keep switching from regular to irregular rhythm.

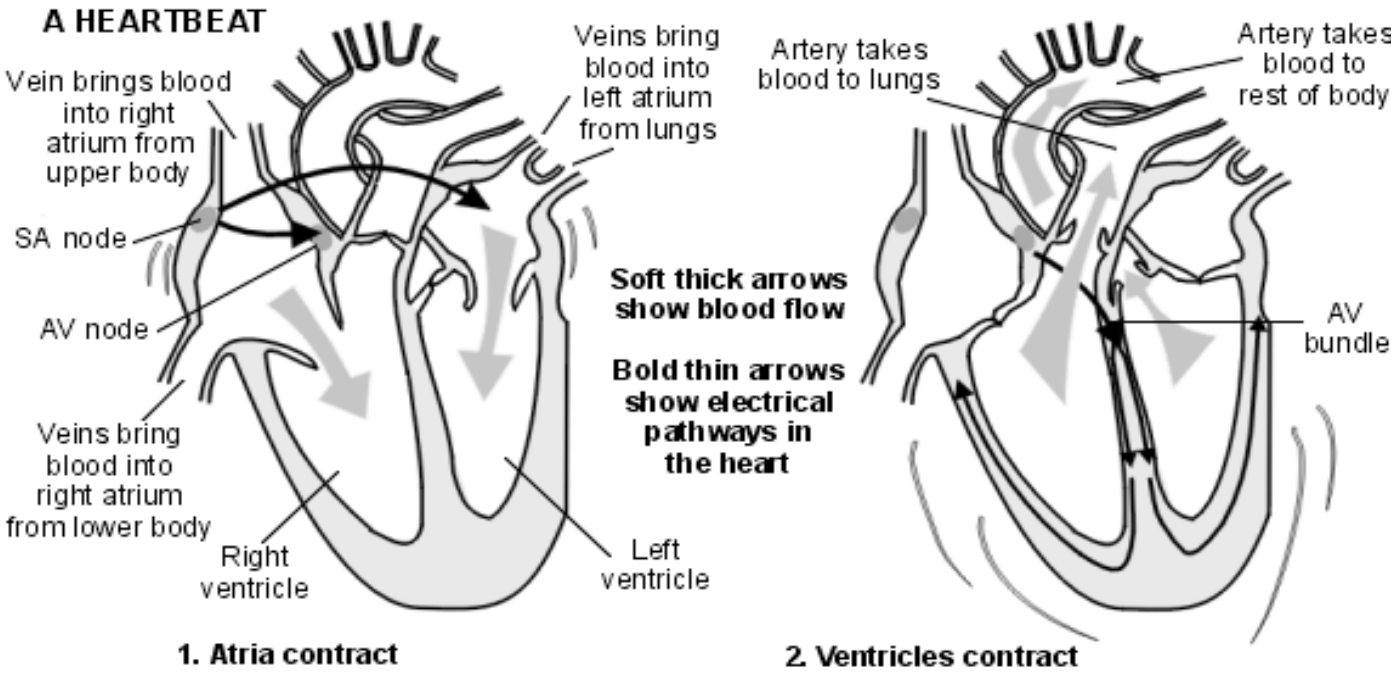
Sick sinus syndrome - intermittent fault of the pacemaker

Bundle branch block - the passage of electricity from the pacemaker to the ventricles is slowed so the heart becomes slightly uncoordinated.

Atrial Fibrillation and it's Treatment

Understanding a normal heartbeat

The heart has four chambers - two atria and two ventricles. The walls of these chambers are mainly made of special heart muscle. The chambers have to contract (squeeze) in the correct order for the heart to pump blood correctly with each heartbeat. The sequence of each normal heartbeat is as follows:



- The sinoatrial (SA) node in the right atrium is a tiny inbuilt 'timer'. It fires off an electrical impulse at regular intervals—about 60-80 per minute when you rest, and faster when you exercise. This controls the heart rate. Each impulse spreads across both atria. This causes them to contract and pump blood through one-way valves into the ventricles.

- The electrical impulse gets to the atrioventricular (AV) node at the lower right atrium. This acts like a 'junction box' and the impulse is delayed slightly. Most of the tissue between the atria and ventricles does not conduct the impulse. However, a thin band of conducting fibres called the atrioventricular (AV) bundle acts like wires and carries the impulse from the AV node to the ventricles.

- The AV bundle splits into two - a right and left branch. These then split into many tiny fibres (Purkinje's system) which conducts the electrical impulse throughout the ventricles. This makes the ventricles contract and pump blood through one-way valves into large arteries:

- The artery going from the right ventricle (pulmonary artery) takes blood to the lungs.
- The artery going from the left ventricle (aorta) takes blood to the rest of the body.

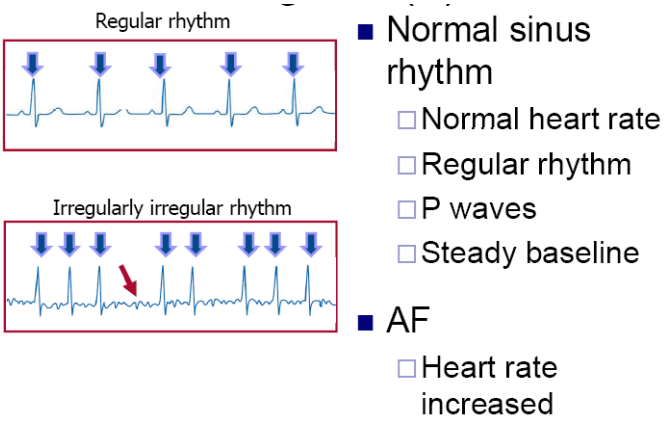
- The heart then rests for a short time (diastole). Blood coming back to the heart from the large veins fills the atria during diastole.

- The veins coming into the left atria bring blood from the lungs (full of oxygen).

- The veins coming into the right atria bring blood from the body (needing oxygen).

Atrial Fibrillation (AF)

AF is common, but mainly occurs in older people. Nearly 50,000 cases are diagnosed each year in the UK. It becomes more common with increasing age. About 1 in 200 people aged 50-60 have AF. This rises to around 1 in 10 people aged over 80 years. It is uncommon in younger people.



When someone has atrial fibrillation (AF) the heart rate is usually a lot faster than normal, And the heartbeat is irregular. That is, an abnormal heart rhythm (an arrhythmia)., and the force of each heartbeat can vary in intensity. What happens is that the normal controlling 'timer' in the heart is overridden by many random electrical impulses that 'fire off' from the heart muscle in the atria. The atria then fibrillate. This means that the atria only partially contract - but very rapidly (up to 400 times per minute). Only some of these impulses pass through to the ventricles in a haphazard way. Therefore, the ventricles contract anywhere between 50 and 180 times a minute, but usually between 140 and 180 times a minute. However, the ventricles contract in an irregular way and with varying force. If you have AF and feel your pulse, you may count up to 180 beats per minute.. Also, the force of each beat can vary, and the pulse feels erratic.

AF is commonly classified in the following way:
Paroxysmal AF. The word paroxysmal means 'recurring sudden episodes of symptoms' that suddenly come and go. Some people take treatment as soon as the AF starts.
Persistent AF. lasts longer than seven days and is unlikely to revert back to normal without treatment.
Permanent AF or Established . AF is present long-term and the heartbeat has not been reverted back to a normal rhythm. Most people with AF have permanent AF.

Causes of AF include the following:
- High blood pressure is the most common cause.
- AF is a common complication of various heart conditions.
- Other conditions and situations that may trigger AF to develop include an overactive thyroid drinking a lot of alcohol; drinking a lot of caffeine (tea, coffee, etc).
- In about 1 in 9 cases of AF there is no apparent cause. This is called lone AF.

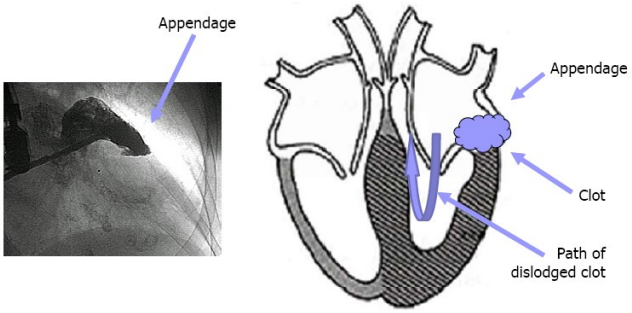
What are the symptoms of atrial fibrillation?
Symptoms often develop quickly, soon after the AF develops. Possible symptoms include: palpitations, dizziness., angina (chest pains), & breathlessness is often the first symptom that develops. However, many people with AF have no symptoms, particularly if their heart rate is not very fast. The AF may then be diagnosed by chance when a doctor or nurse feels your pulse.

Are any tests needed?
A heart tracing called an electrocardiogram (ECG) can usually confirm the diagnosis. This test can also rule out other causes of an erratic or fast heart rate. Sometimes a 24-hour ECG is taken if you have paroxysmal AF and a resting ECG does not show AF.
Other tests such as blood tests and an echocardiogram (ultrasound scan of the heart) are often advised. These tests look for an underlying cause of AF such as a heart problem or an overactive thyroid gland.
Often an underlying cause is already known about. For example, you may already have angina. You may not need any further tests if AF develops as a complication.

Treatment options.
Treatments that may be considered by your doctor include:

- Rate control with betablocker drugs; diltiazem, verapamil and digoxin,
- Rhythm control, with cardio version (electric shock or pacemaker)
- Anticoagulation treatment (aims to prevent a stroke), usually with warfarin or some of the newer drugs. Low risk patients are given low dose aspirin.

An increased risk of having a stroke (or other blood clot problem).
The main complication of AF is an increased risk of having a stroke. AF causes turbulent blood flow in the heart chambers. This sometimes leads to a small blood clot forming in a heart chamber. A clot can travel in the blood vessels until it gets stuck in a smaller blood vessel in the brain (or sometimes in another part of the body). Part of the blood supply to the brain may then be cut off, which causes a stroke The risk of developing a blood clot and having a stroke varies, depending on various other complications
Less common complications of AF include heart failure. Angina pains may get worse if you have angina.

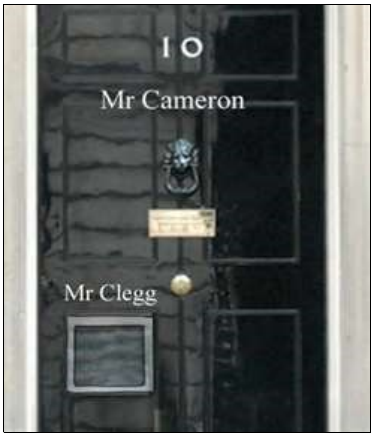


Further help and information
British Heart Foundation Greater London House, 180 Hampstead Road, London, NW1 7AW
Tel (Heart Help Line): 0300 330 3311 Web: www.bhf.org.uk

Sir Isaac Newton's Cat-flap

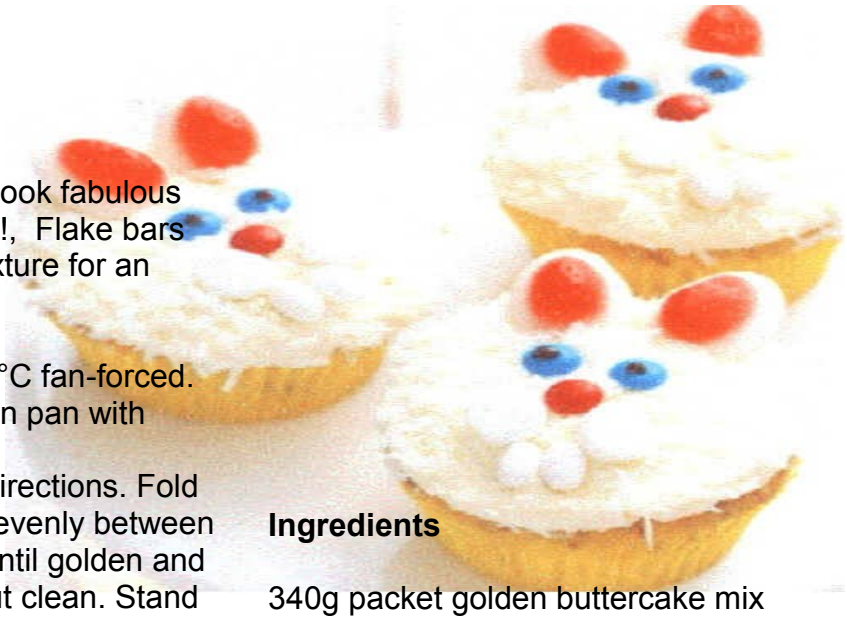
If you believe everything you see on the television or read on dodgy websites, you will know that Sir Isaac Newton's major claim to fame is his invention of the cat-flap in 1700. Newton owned a cat called Spithead, which allegedly had a habit of nudging open the door of her master's darkened attic laboratory, thereby letting in daylight to ruin his optical experiments Newton responded to this inconvenience by cutting a cat-sized hole in the door and hanging over it a black velvet cloth to ke p out the light. It is also claimed that when Spithead had kittens, Newton made them a smaller cat-flap, thus allowing people to ridicule him for not realising that the kittens could use the original hole (although it may be that Spithead's cat-flap was too high or too heavy for her young ones to use).

There is not a single reliable source for these tales. And the Newtonian cat-flap is such a simple device that it is hard to believe it was not invented centuries earlier. In any case, the ruined experiment theory seems to be rubbish, since Newton's research did not involve any photosensitive materials. Any feline disturbance would have been minimal.



However, whether or not Newton invented it, the cat-flap has come a long way since 1700. Modern moggy-doors can be programmed to allow cats to go in or out, or in but not out, or out but not in, or neither in nor out. And a microchip in your pet's collar, implanted under its skin, can ensure that only your own puss can operate the cat-flap, so that the neighbourhood fleabags cannot invade your home. Incidentally the idea that it was a falling apple that awakened Newton to the concept of gravity is as hard to believe as is the cat-flap story. He might just as well have 'invented' gravity - and even his third law of motion, too, after Newton noticed the way Spithead's cat-flap fell back into position once she had passed through.

Recipe Corner



Easter bunny cupcakes

These cute Easter bunnies don't just look fabulous and they only take an hour to prepare!, Flake bars are scattered throughout the cake mixture for an added chocolaty surprise.

Method: Preheat oven to 180°C/160°C fan-forced. Line a 12-hole, 1/3-cup capacity muffin pan with paper cases.
Make cake mixture following packet directions. Fold in crushed flake bars. Divide mixture evenly between cases. Bake for 20 to 25 minutes or until golden and a skewer inserted in 1 cake comes out clean. Stand in pan for 2 minutes. Transfer to a wire rack to cool completely. Meanwhile, make buttercream icing Using an electric mixer, beat butter until light and fluffy. Gradually add icing sugar mixture, milk and vanilla, beating until well combined. Reserve 1/4 cup icing. Spread cupcakes with remaining icing. Sprinkle with shredded coconut. Lightly press to secure. Trim 5mm from 1 short end of each strawberries and cream lolly. Using the picture as a guide, use a little remaining icing to secure two strawberries and cream lollies into top of 1 cupcake to form ears. Press 2 blue mini M&Ms on to cake to form eyes. Press 1 red mini M&M on to cake to form a nose. Press 2 mini marshmallows below nose to form cheeks and add 2 tic tacs for teeth. Use chocolate writing fudge to pipe dots in centre of eyes to form pupils. Set aside for 10 minutes or until set. Repeat with remaining cupcakes, lollies. M&Ms. mini marshmallows, tic tacs and chocolate writing fudge. Serve.

Ingredients

340g packet golden buttercake mix
2 x 30g chocolate flake bars, roughly crushed
3/4 cup shredded coconut
24 strawberries and cream lollies
24 blue mini M&Ms
12 red mini M&Ms
12 white mini marshmallows, halved crossways
24 white tic tacs
rich chocolate writing fudge

Buttercream icing

150g butter, softened
2 cups icing sugar mixture, sifted
11/2 tablespoons milk
1 teaspoon vanilla essence

Easter salad This tasty salad has all our favourite green vegetables.

Method: Blanch the broccoli in boiling water for 2-3 minutes and the sugar snap peas and fresh or frozen peas for 1-2 minutes. Drain, refresh in cold water and drain again. Place the blanched vegetables in a bowl with the cucumber, avocado, sprouts, parsley and mint. Whisk the juice and oil in a bowl. then season and toss through the salad with the salad seeds. Top with crumbled feta.. Serves 6

Ingredients

1 small broccoli, cut into florets
100g sugar snap peas, trimmed
2/3 cup fresh or frozen peas
1/2 telegraph cucumber, cut into large cubes
1 avocado, diced
150g tub mixed salad sprout combo*
1/4 cup finely chopped flat-leaf parsley leaves
1/4 cup finely chopped mint leaves
Juice of 2 lemons
100ml olive oil
3 tbs mixed salad seeds*
(such as sunflower, sesame and pepita)
100g feta, crumbled

North of Doncaster. *Personal Comment by Trevor Wainwright*

Did you notice anything missing from last issue's North of Doncaster? Yes the three words, by Trevor Wainwright, giving way to the anonymous publication of Marr v Wessley correspondence. I was a bit busy at the time having now changed jobs moving from Cancer Research UK for a career on Community Support Work, plus qualifying for Security Guarding if it doesn't work out.

think my experience with ME as both parent and carer helped at the interviews, didn't mention the "awkward sod" bit, and it's been quite entertaining and rewarding so far, various aspects and training courses, working directly with adults with learning difficulties, perhaps the ideal outlet for my offbeat energies, more on that later but someone did say once "who is supporting who".

So to this issue, how many know that May 12th falls on a Sunday this year as it did in 2002, that was when in 2001 I suggested the main groups write to Songs of Praise with a request that they consider doing an ME Awareness day special, thinking along the lines that their so called celebrity endorsers would lend their support. Nothing happened so I wrote myself, no reply so I wrote again at the beginning of 2002, still no reply, the main groups didn't seem bothered, content to let another chance go by as did so often and would later do with Seabiscuit the following year.

To hell with them I thought I'll do something myself, so with the support of the vicar and PCC of my local church I did; they were more than willing to turn the intercession over to me on that Sunday. What follows is a summary of the event. The vicar announced that part of the service would be dedicated to ME at the start of the intercession.

An Intercession is the act of interceding (intervening or mediating) between two parties.
In Christian religious usage, it is a prayer to God on behalf of others.

The logo on my ME polo shirt (which I wore) was a circle of a blue knotted ribbon representing a sufferer. There are 9 knots, one for each year she has suffered the illness. It depicts the never ending circle of Pain, Fatigue, non- refreshing sleep, leading to more pain and fatigue. At the top of the circle is the blue ME Awareness Ribbon, a symbol of hope that one day a cure will be found and the circle broken. Many of the congregation also wore blue ribbons that day. I walked to the centre of the aisle and began:

"Father we remember that today is 'International ME Awareness Day' and bring before you those who suffer from the debilitating illness Myalgic Encephalomyelitis"

After reading out the names of known sufferers I ended with "and others known only to you, Lord in your mercy"

The congregation replied *"Hear our Prayer"*

I would do this for those that had died, those that were left to mourn, and for those who work to ease the burden of those who suffer from Myalgic Encephalomyelitis, each section ending with the responses *"Lord in your mercy"* and "*Hear our Prayer"* and follow with:

Heavenly Father, to whom the need of every heart is known, give patience, courage and hope to those suffering from M. E. and other conditions of Chronic Fatigue, and strength to those who care for them. Increase the sensitivity of doctors, the compassionate understanding of family, colleagues and neighbours, and the skill of the researchers as they seek a cure.

We ask this through the One who restored the sick to the fullness of life, Jesus Christ Our Lord Amen.

The congregation acknowledges the Amen, the man then says *"Merciful Father"*
All acknowledge *"Accept these prayers for the sake of your Son our Saviour Jesus Christ Amen".*
My task over I returned to my seat and the service carried on.