Pathways

Price £ 3.75 (Free to members)

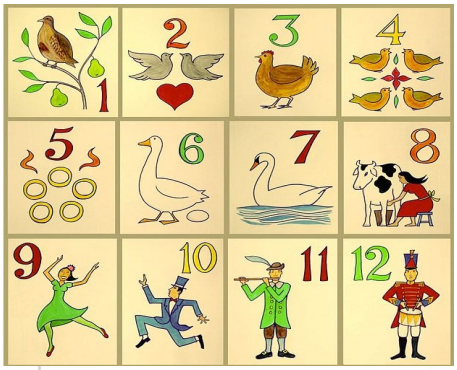
The newsletter of Leger ME/CFS Supporting Myalgic Encephalopathy or Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome (PVFS), Fibromyalgia Syndrome (FMS), Patients & Carers.

Welcome to the Christmas 2013 Edition of Pathways.

Over the last 12 months we've seen quite a significant number of changes affecting members.

The first PIP applications are now being processed. As Helen Butler from SYCIL said at the recent Leger ME meeting it will be a while before the full implications of the changeover emerge. On the positive side it looks like the powers that be are catching up with ATOS, and the changeover from DLA to PIP has been put back in our area. Many members are experiencing the changeover from Incapacity Benefit to ESA and its knock-on effects, especially when the ESA becomes means tested after the first year, which for a number of members is causing hardship.
The letter finally came from DMBC about room hire charges which started as from the 1st November. We had to increase the group subscription to cover this. We have many of the usual Pathways features which we hope will interest our readers.

Christmas Recipes in Recipe Corner *(See page 7)*



The background behind the popular carol revealed
The Twelve Days of Christmas *(See page 20)*

Out and about (*See Page 11)*

ME/CFS Conference in Sheffield sponsored by Action for M.E. and the Association of Young People with ME *(See page 7)*

How does Santa do it ?

Well—with a little help from his friends at NORAD. Pathways can exclusively reveal that Santa is getting ready for his massive world wide delivery operation again this year. On Christmas Eve have a look at: http://www.noradsanta.org NORAD will be tracking Santa with satellites, jet fighters, radar and their special (only once a year) Santa-Cam. You will be able to follow Santa on his worldwide mission and just maybe get a glimpse Rudolph & his red nose!

You Write

I received an enquiry from a former member who is being prosecuted by the DWP in relation to receiving undeclared payments. This case dates back at least seven years and unfortunately there is nothing I can do that will make a difference. As a result I have issued the following advice.

"If you are working while on Incapacity Benefit, Employment & Support Allowance or Disability Living Allowance or any other means tested benefit you must declare this to the DWP. If you start work through a DWP scheme and are still on DLA you have to declare this separately as well. Things like being a company director, charity trustee or voluntary worker have to also be disclosed. These are 'material' changes which would result in a review of your benefits and most likely result in a benefit reduction or the stopping of the benefit altogether. Benefits & Work have a specific guide about it which I can email to members with a list of do's and don'ts."

Joanne Sheffield ME Group's information officer writes: Good point you made about the voluntary work! We have had the scenario where one volunteer was reluctant to reveal this fact when they went to a Benefits assessment as they felt it might be misinterpreted as being capable of work – caused a lot of stress and worry resulting in the person stopping their voluntary work. On the other hand, another volunteer notified DWP – kept a copy of the letter sent and received a letter back from them acknowledging this information – this reply letter was also saved. At a later date when a big issue was made about doing voluntary work this was not known by the DWP as it was not on their computer records. The person in question was able to provide copies of the written notification and acceptance. It is always a valid lesson learned that one should keep copies of documents sent by the DWP as most of the time they don't seem to understand what their left and right hands are doing. It also seems to indicate that only selective information is being amalgamated onto personal records.

Agreed. Here is an extract from the Benefits & Work Guide on Supported Permitted Work

Guidance suggests that 'Supported Permitted Work' is work done by people who have a long term disability that has had "a significant impact on their ability to learn or sustain a traditional job which will always, or for a number of years, prevent them from working more than a few hours each week". It should also be work that a person can do only with the support and supervision of someone other than their employer and be supervised by someone employed by a public or local authority or voluntary organisation which provides or finds work for people with disabilities. The support worker must direct and oversee the performance of the worker regularly and the supervision must be more than the normal support provided in the workplace by employers.

'Other allowed work': The following kinds of work are also allowed:

- *care of a relative or domestic tasks carried out in your own home*
- *Work done as a Councillor. If you receive a Councillor's allowance that pays more than £101.00 a week (excluding expenses), an amount equal to the extra money will be deducted from your contributory Employment and Support Allowance, Incapacity Benefit or Severe Disablement Allowance.*
- *any activity in an emergency, to protect another person, or to prevent serious damage to property or livestock*
- *duties undertaken as an appeal tribunal disability member – one day a week is allowed (or two half days)*
- *an approved work trial arranged in writing with the employer by the DWP (or an organisation providing services to the DWP) for which you will receive no wages*
- *self-employed work done whilst you are 'test trading' for up to 26 weeks with help from a self-employment provider arranged by Jobcentre Plus.*
- *work which is so minimal that it can be regarded as trivial or negligible*

Dr Damien Downing writes: After more than 30 years of practice I am closing my York clinic at the end of the year. I shall be focusing on my London practice from now on. It was a very different world when I first set up my York private practice in 1980, in the old City Club premises within sight of the Minster. There was no internet, no edge-of-town business parks, and even rail travel was a somewhat slower affair. And the recessions every decade or so were brief affairs lasting no more than a couple of years. Nowadays there are fewer local practices and even local hospitals. People attending my York clinic come from as far away as Newcastle, Blackpool and Birmingham. With a very efficient rail link, they can get to London in not much more time, or even in less time, than to York. My London practice, at the north end of Harley St, is 25 minutes by bus, tube or taxi from King's Cross and Euston stations, and on the very edge of the congestion zone, with out-of-zone parking nearby.

Nowadays too, all doctors, including myself, conduct a large and increasing proportion of our medical practice by phone, by Skype or video link, and by email. Indeed this year the GMC issued new guidelines on the issue of "remote prescribing". And a growing number of my patients come from Europe, from the USA, even from Australia. All this means that the Nutrition Associates premises in York represent an outdated business model, and an expense that I can no longer afford. The end of our lease on the Clifton Moor premises makes a logical moment therefore to close the York operation and consolidate in London. I myself will continue doing Consultations and LDA (Low Dose Antigen) treatments (the new EPD) in London, and we finally have an excellent provider of intravenous treatments, and blood testing, at Independent Nursing Services, just 100 yards from my colleagues and myself at the New Medicine Group.

For members in South Yorkshire, there is an EPD Clinic held on the 1st Monday of the month in Sheffield. Contact me for further details. *Mike*

Susan Writes: I'm pleased to announce the arrival of four new books for our **LEGER ME** library. Don't forget that all you have to do to get a book sent to you is e-mail Legerme.library@yahoo.co.uk At times not all of us are up to reading a lot, especially when laid low with fatigue and brain-fog. These books could prove very useful for ME/CFS related problems when they need to be to be explained to a friend or relative.
The first new book, as seen on the front cover of the last Pathways, is *Ramsay's Disease* by Leslie O. Simpson, Ph.D. and Nancy Blake B.A., C.Q.S.W. This is a tome best suited to those wanting to find out about the history of the disease and the research and medical opinions around it.
Recovery from CFS - 50 personal stories, compiled and edited by Alexandra Barton, does exactly what it says on the cover. His could be viewed as a negative book in as much as it reminds us that ours is a very unique condition and personal to us all. What proves helpful to one person may be of no use to another. The positives however are wonderful. Here are people, lots of them, who have found a way through the misery of ME/CFS. Each person became ill and experienced the illness in a different way and each tells how they came through it. I'm going to list and research some of the things these people have tried, but my priority will be to focus on the techniques that helped those people whose life-style and symptoms I can most relate to.

Beating Chronic Fatigue by Dr Kristina Downing-Orr is written by a clinical psychologist who describes herself as a former CFS sufferer. This is a chapter-by-chapter walk through the history and diagnosis of the illness and contains information on all the many symptoms together with techniques and advice on dealing with them. Dr Downing-Orr worked closely with Dr David Mason Brown, an Edinburgh University graduate who worked as a GP before contracting CFS. This book, then, comes from two professionals and so the approach is from both a personal and professional viewpoint.
Fighting Fatigue by Ann Pemberton & Catherine Berry is possibly my favourite of the new titles. It's an easy to read, well laid out book with step by step chapters, explaining ME/CFS and how various symptoms might affect us. It's full of anecdotes, charts, self-assessment questionnaires and useful hints and tips for self help.

If you have a book you would like to donate to our library that you think others might benefit from reading, we would be grateful. We are always open to ideas for future purchases.

LEGER ME GROUP LIBRARY BOOK LIST

1. Action for ME	Pacing for People with ME
2 .Fiona Agombar	Beat Fatigue with Yoga
3. Nick Bamforth	ME/CFS and the Healer Within
4. Prof J Brostoff	The Complete Guide to Food Allergy
& Linda Gamlin	& Intolerance
5. Jan Brumfitt	The Final Surrender – A Journey to Wellness
6. Dr J & Mrs F Campling	CFS/ME – Your Questions Answered – 1998 Edition
7. Dr J & Mrs F Campling	CFS/ME – Your Questions Answered – 2001 Edition
8. Leon Chaitow	Candida Albicans
9. Deepak Chopra	Boundless Energy
10. Jane Colby	Zoe's Win
11 .Hazel Courtney	What's the Alternative?
12 .Drs Dawes & Downing	Why ME? Guide to Combating Post-Viral Illness
13. Patrick Holford	Optimum Nutrition
14. Alex Howard	Why ME
15. Dr Darrel Ho-Yen	Better Recovery from Viral Illness
16. Dr Darrel Ho-Yen	Unwind, Understand & Control Life Better
17. Janet Hurrell	A Helping Hand Through ME
18. Gill Jacobs	The Natural Way, CFS
19. A Macintrye	ME Post-Viral Fatigue Syndrome – How to live with it
20. Dr M Midgley	A Life Worth Living-A Practical Guide to Living with ME
21. Optimum Health Clinic	ME In The 21st Century
22. Dr R Perrin	The Perrin Technique
23. A Melvin Ramsay	ME & Post-Viral Fatigue States
24. Sheffield City Council	Easy Going Trails
25. Dr C Shepherd	Living With ME
26. J Tietelbaum MD	From Fatigued to Fantastic
27. Kat Duff	The Alchemy of Illness
28. Kay Gilderdale	One last Goodbye
29. L O Simpson & N Blake	Ramsay's Disease – ME & the unfortunate creation of CFS
30. S Pemberton & C Berry	Fighting Fatigue
31. A Barton	Recovery from CFS, 50 personal stories
32. Dr K Downing-Orr	Beating Chronic Fatigue
33. C O'Brien	Chronic Fatigue busters-what to do when the doctor gives up
34. J Steincamp	Overload – Beating ME

Maria Writes: I've just been to the York Fatigue Clinic. I am now 48 and live in North Lincolnshire. I was around 24 years old when I started suffering ME type symptoms. I was leading a full and active life with a good job, family and friends. At 24 I had a severe case of chicken pox and was very ill for about a month. This started what I know now as slow onset of ME. I never felt right again experiencing crushing fatigue, mental fog and lack of concentration, picking up infections, dizzy spells etc. It took 5yrs to get a diagnosis. At this stage I still could work part time but had to rest a lot. I tried lots of different things reading all the info available, alternative therapies, taking vitamins and minerals etc., with no real progress. Over the 20 years since, my ME has gradually become worse with the introduction of bowel problems, labryrinthitis and constant viral infections but I have somehow muddled through. Then 3 years ago years ago my health took a big step down. I feel trapped in a body which is not functioning physically and mentally. I find it so frustrating. I live alone and every day it varies for me. I spend a lot of time in bed. It can last for weeks. There are days I can do little amounts but everything I do has a payback which leads to more fatigue.

I tried the Lightning Process approximately 4 years ago. It helped initially but the improvement wasn't sustained. This left me feeling disillusioned. I have constant battles with benefits which drive me mad with frustration due to the lack of knowledge and empathy given to ME/CFS people. At a recent Leger ME group meeting I came across a member who had been to see a fatigue specialist in York and he suggested that I go to see her. After some thought I decided to make an appointment to see Sue Pemberton at the clinic. The aim of the programme is to understand how ME/CFS affects every part of the body and how it's so out of balance. Here are the costs for the York Fatigue Clinic.

- The first consultation takes a full history which takes about 2 hours to complete at a cost of £130
- Workshop with other people on how ME/CFS affects the whole body (I found this very interesting) cost £30
- Appointment to assess the personal history and a programme on ideas to help with ME/CFS cost £65
- The follow-up appointments cost £65 at a time

The main aim of the Clinic is to get the most of whatever energy anyone has and address all aspects e.g. sleep, medication, mental state etc. I found Sue Pemberton, the specialist who I'm seeing, to be very knowledgeable (24 years of working with ME/CFS people), she has empathy, is very professional, caring, upbeat and realistic. Sue Pemberton also does written reports which can be passed on to benefits. I approached my GP for funding for the treatment and I received a letter saying it was declined so I'm funding it myself. Its early days for me, my aim is to use the knowledge given to me to improve my health in a realistic way.

Sounds like you are a grade 3 case. I'm sorry to hear about your problems and your doctor's refusal to fund support for you. This is something I feel very strongly about, but it is a reality with NHS budgets being tight . If anyone knows about dealing with ME/CFS management it's Sue Pemberton.
I've known her for around 20 years from the early days of the Leeds Fatigue Clinic. I note your unsuccessful try with the Lightning Process, which is of course a form of cognitive behaviour therapy (CBT). Unfortunately, I hear about this too often. You can be assured that you will get a better deal from the Yorkshire Fatigue Clinic.

ME/CFS Conference in Sheffield:

Action for M.E. and the Association of Young People with M.E . are hosting a conference at the University of Sheffield on Tuesday 11th February 2014 the programme is as follows:

If there is enough interest I will organise a coach for Doncaster.—Mike

Programme

9.45 **Refreshments & Registration**

10.15 **Welcome & Housekeeping**

10.20 **Current CFS/M.E. Research**
Gina Rutherford PhD Student

10.50 **Q&A**

11.00 **The National Picture**

Sonya Chowdhury Chief Executive Action for M.E.
Mary-Jane Willows Chief Executive AYME

11.20 **The Local Picture**

Anne Nichol Service Manager/Lead Occupational Therapist
CFS/ME Service for South Yorkshire and North Derbyshire

11.40 **Q&A**

12.00 **Lunch**

1.00 **Workshop 1:** Options

Children, Education: Sheila Carruthers, National Support Worker, AYME

Benefits: Sarah Lawrence and Bill Booth,

Welfare Rights Advisors, Action for M.E.

Health: Jack Czauderna, GP with Specialist Interest in CFS/M.E.

Diet: Sue Luscombe, Specialist Dietician and Dietetic Lead on CFS/M.E.
or British Dietetic Association and BACME

Employment: Sue Pemberton, Therapy Director, Yorkshire Fatigue Clinic

2.05 **Workshop 2**
Options are as Workshop 1

3.10 **Refreshments & Networking**

3.30 **Event close**

Place booking: e-mail Sara Brooks Head of Support Services, Action for M.E.
sara@actionforme.org.uk

Recipe Corner

by Carolyn

Baileys and Chocolate Cheesecake

(Naughty, but then it is Christmas!)

The smooth, creamy liqueur gives this celebration cheesecake the wow factor. Top with grated chocolate and a dusting of cocoa.

● Melt the butter in a pan and add the crushed digestive biscuits. Mix well until the biscuits have absorbed all the butter.
● Remove from the heat and press into the bottom of a lined 18cm/7in springform tin. Place in the refrigerator and allow to set for one hour.
● Meanwhile, prepare the filling. Lightly whip the cream cheese then beat in the Bailey's and icing sugar. Fold in the whipped cream and grated chocolate. When smooth, spoon evenly onto the biscuits.
● Refrigerate and allow to set for a further two hours. Once set, remove and decorate with whipped cream and cocoa powder dusted over the top. Serve.

Ingredients

100g/3½oz butter
250g/8¾oz digestive biscuits, crushed
600g/1lb 5oz Philadelphia cream cheese
25ml/1fl oz Baileys
100ml/3½oz icing sugar
300ml/10½oz double cream, whipped
100g/3½oz grated chocolate
To garnish
200ml/7¼oz double cream, whipped
cocoa powder, to dust

Alpine Tart Vegetarian*

Serves 4 Prep Time 30mins * Cooks in 40 mins

● Heat the oven to 200˚C/180˚Cfan/Gas6.
●In separate pans, par boil the potatoes and butternut squash chunks until just tender (about 5 minutes for the squash and 10 minutes for the potatoes). Drain and set aside.
●Score the edge of the pastry sheet to mark a 1cm border and brush it all with beaten egg. Prick the pastry (not the border) with a fork.
●Sprinkle ½ the cheese over the pastry.
●Toss the potatoes, squash and onion in the oil and then pile into the tart. Bake for 25-30 minutes, until the pastry is golden brown. If the centre of the tart starts to puff up too much, prick it with a fork.
●Around 10 minutes before the tart is cooked, add the rest of the cheese and the chopped rosemary to the tart.
●Tear the filo into 3 pieces, form into ‘mountain’ shapes and arrange on top, then brush the filo with the melted butter.
●To serve, garnish with the remaining rosemary sprigs and serve some crème fraiche on the side.

Ingredients

400g new potatoes, cut into small chunks
400g butternut squash, peeled and cut into small chunks
1 sheet ready-rolled puff pastry
1 egg, beaten
200g smoked Cheddar cheese, grated
2 small red onions, peeled and cut into wedges
1 tbsp olive oil
4 sprigs fresh rosemary, ½ chopped
1 sheet filo pastry
10g butter, melted

What happens to Motability Support if you lose DLA?

With thanks to Bolton & Bury ME Group for bringing this to our attention.

For several years now Leger ME has been recommending that that people with ME do not take out new mobility lease agreement because in our opinion is that when they are moved over to Personal Independence Payment (PIP) there is a strong possibility that they would not qualify for the mobility component of PIP.

However for those who are still relying on Mobility agreements the Motability Scheme has agreed to provide one-off transitional support to customers who, following their initial reassessment by Government for the new PIP benefit, lose their eligibility to remain on the Motability Scheme.

Lord Sterling has released a statement detailing the support on offer if this happens.

In April 2013, the Government introduced a new benefit - Personal Independence Payment (PIP) - which will gradually replace Disability Living Allowance (DLA) for disabled people aged between 16 and 64. Motability acknowledges that there are positive aspects of PIP compared to DLA in the longer term. However, over the last two years, the Governors of Motability have considered how PIP will affect Motability Scheme customers and, in particular, the degree to which we can assist those customers who lose their eligibility to remain on the scheme when they are first reassessed for the new benefit. Between October 2013 and 2018, the Department for Work and Pensions (DWP) will reassess some two million disabled people aged between 16 and 64, who currently receive DLA, for the new PIP benefit. This reassessment process will include approximately 360,000 of the 620,000 disabled people who currently lease a vehicle through the Motability Scheme. Because PIP is a new benefit with different criteria from DLA, some disabled people may not qualify for mobility support under PIP or may do so at a lower level than they had under DLA. As a consequence, they will no longer be eligible to use the Motability Scheme. Since its inception over 35 years ago, the standard of service and support provided by the Scheme has always reflected the very special needs of our customers. Some two years ago when the Government initially proposed the adoption of PIP, we decided that we wanted to help those customers who can no longer use the scheme to retain their mobility outside of it. Therefore, over the next five years, as PIP is introduced, the Motability Scheme plans to provide a one-off transitional package of support and advice regarding alternative mobility arrangements to these former customers.

Disability Living Allowance (DLA) is a Government benefit to help with the extra costs arising from disability. Once in receipt of the Higher Rate Mobility Component of DLA, a disabled person is eligible to join the Motability Scheme. It is entirely up to the recipient whether they wish to spend their allowance joining the Motability scheme or in some other way. Once an eligible disabled person decides to join the Motability Scheme, they ask the DWP to pay the Higher Rate Mobility Component of their DLA directly to Motability Operations (who operate the scheme under contract to Motability) irrevocably for the duration of their lease agreement. At the end of the lease, which is usually three years, the customer returns the car for resale by Motability Operations. However, we cannot extend the Scheme to disabled people not in receipt of the Higher Rate Mobility Component of DLA. For more than 35 years, the availability of the mobility allowance from Government (most recently, the Higher Rate Mobility Component of DLA) has provided a sound financial basis for the Scheme and this linkage remains fundamental to the Scheme's viability.

Introduction of Personal Independence Payment (PIP):

The Motability Scheme will work with PIP in exactly the same way as it does with DLA; disabled people who receive the Enhanced Rate of the Mobility Component of PIP will be eligible to use the Motability scheme, if they choose to do so, in the same way as people who receive the Higher Rate Mobility Component of DLA.

Today, the Motability scheme supports over 620,000 disabled people and their families across the United Kingdom, for whom an affordable and suitable vehicle provides levels of freedom and independence that would otherwise be beyond their reach. However, PIP is a new benefit with different eligibility criteria to DLA. As the DWP reassesses current DLA recipients aged between 16 and 64 for PIP, those who are Motability Scheme customers may qualify for the Enhanced Rate of the Mobility Component of PIP, in which case they should enjoy a seamless service as they move from DLA to PIP. Some customers, however, may not qualify for mobility support under PIP or may do so at a lower level than they had under DLA and, as a consequence, they cannot continue to lease a vehicle from the Scheme. Although they had properly claimed and received DLA, these changes are the result of a new benefit being introduced by the Government with different eligibility criteria.

As a consequence, some disabled people may have enjoyed the benefits of the Motability scheme for many years but find that they can no longer use it as they are no longer in receipt of the relevant mobility component of DLA or PIP. While we cannot replicate the benefits of the Motability scheme for them on an on-going basis, because we have a long history of offering a unique service to disabled people, we aim to provide a one-off package of support and advice to help such customers through this difficult transition.

One-off transitional support for customers who lose eligibility to remain on the Motability Scheme:

Since 2010, Motability has maintained a close dialogue with DWP as they developed their plans for the introduction of PIP through a number of public consultations. Over the last two years, Motability has also consulted disability organisations including Disability Rights UK, Disabled Motoring UK and groups representing customers with specific impairments, as well as undertaking considerable research with our own customers, to discuss what help would be most useful for those customers who are no longer eligible to use the Scheme. We are very grateful to all of the organisations and individuals who have helped us in developing and prioritising proposals for how we support these customers.

In order to ensure that the Motability Scheme is sustainable for the long term to continue to help the disabled community for at least another 35 years, we have the responsibility to identify risks, long term as well as short term, especially in these uncertain times. Taking account of these considerations as well as of our customers' needs, Motability and Motability Operations have concluded that the following support can be provided to customers leaving the Car Scheme as a result of a PIP reassessment:

● DWP has already announced that they will allow DLA payments to continue for four weeks after they make their decision regarding PIP. In addition to this, the scheme will allow customers to retain their vehicle for up to a further 3 weeks from the date the DLA payments end. The customer will therefore be able to retain their vehicle for close to two months after the DWP decision is made. Customers will need to return the car to the dealership in good condition and within the agreed timeframe in order to qualify for the following transitional support:

● For customers who entered into their first lease agreement with the Scheme before January 2013 and therefore could not have been aware of PIP and the associated risks when they joined (the vast majority of customers), we will provide transitional support of £2,000. For many customers, this will enable them to continue to have mobility by purchasing a used car.

● For customers who entered into their first lease agreement with the Scheme with an awareness of PIP being introduced and of the risk that they could lose eligibility following a future PIP reassessment i.e. after January 2013 and up to December 2013, we will nonetheless provide transitional support of £1,000.

We will review these levels of transitional support during 2015 to take account of economic conditions and of any possible changes the Government may be making to PIP at that time.

● For customers who have made an Advance Payment (an additional upfront payment to lease a larger or more complex vehicle on the Scheme), the Scheme will continue to refund any Advance Payment on a pro-rata basis. No further costs will be applied to customers whose leases end early as a result of a PIP reassessment.

● We will work with our scheme suppliers, including RSA and RAC, to provide general information on motoring, insurance and other motoring services outside of the scheme. This will include information, for example, on buying a new or used car, and arranging insurance and other services such as breakdown cover. In particular, we are working with a leading UK insurance broker who will offer insurance quotes to former scheme customers that will recognise their no-claims history on the scheme. We are also working with manufacturers and dealers to ensure that they are aware of the issues faced by these customers and are able to discuss possible alternatives to maintain their mobility once they have left the scheme.

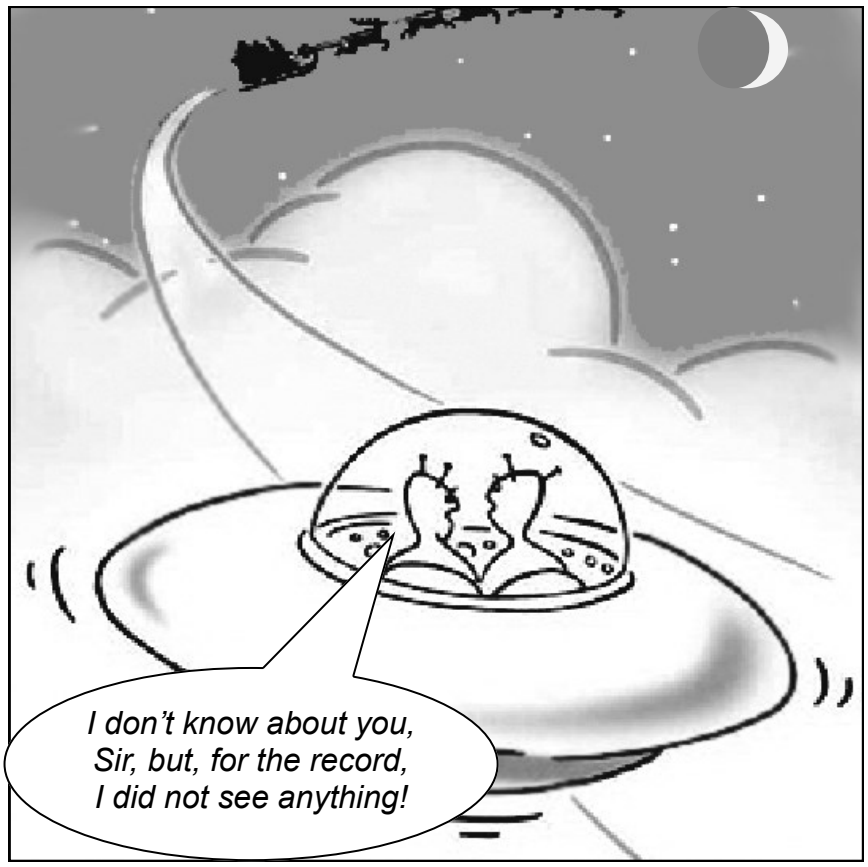
● The scheme will offer customers an opportunity to purchase their vehicle following the end of the lease. The payments that they would otherwise have received upon returning the vehicle can be directed towards the purchase price.

● We will work with customers who have wheelchair accessible vehicles on the scheme on a case by case basis to understand and assist with their future mobility arrangements including, where appropriate, enabling them to retain their current vehicle.

● For customers with adaptations, we will help them with the costs of fitting the same adaptations to a non-scheme vehicle.

The Motability scheme will also provide a package of support and advice to customers currently leasing a scooter or powered wheelchair, with the objective of allowing them to retain their current product wherever possible.

As the DWP plans to begin reassessments of existing DLA recipients in October 2013 and each reassessment will take several months to complete, we do not expect any scheme customers to become eligible for this support until early 2014. We will monitor customers' feedback on the support and advice we provide and we may make changes to it based on experience. We will also formally review all aspects of our support package in Autumn 2015, to take account of economic circumstances and any possible changes the Government may be making to PIP at that time.

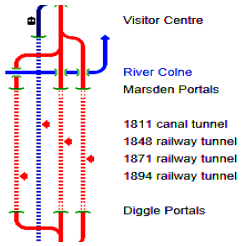


In the years to come, the Motability scheme will receive applications from recipients of PIP as well as from recipients of DLA and we will continue to meet the needs of disabled people, as we have done since 1977.

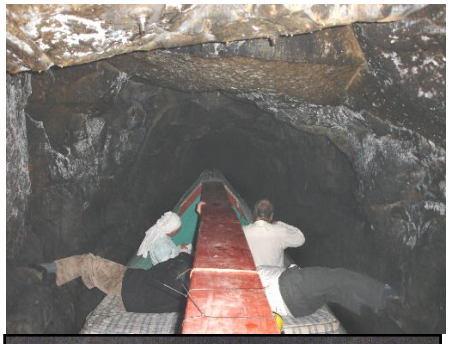
Lord Sterling.
Chairman,
Motability Board of Governors.
September 2013

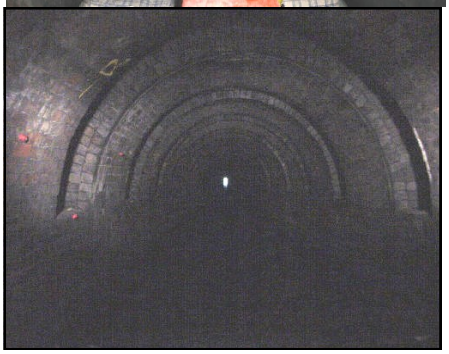
Out & About: The Standedge Tunnel & Visitor Centre

We visited the centre on Waters Road, Marsden near Huddersfield on a grey November day. Historically the Standedge Tunnel is the longest canal tunnel in Britain, opened in 1811 and in 1944 closed to commercial traffic. Recently the tunnel has been restored and on certain days narrowboat owners can pass through the tunnel. The Tunnel End Cottages, which formerly housed canal maintenance workers, house a cafe and the booking office for boat trips. They use the same electric tugs used to tow private boats, but in this case pushing a passenger-carrying barge. There are disabled parking facilities nearby just off the right hand side of the picture. There is also an exhibition & visitor centre, children's playground and wildlife garden.

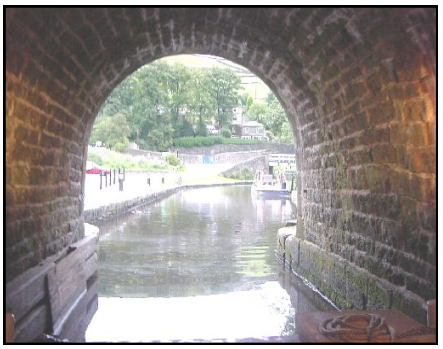


There are frequent trips into the tunnel throughout the day, normally 30 minutes long. We chose the 2pm boat trip as it was 50 minutes long going deeper into the tunnel. The cost was £8 adults and £6 concessions. The passenger barge is just a little wider than a big car - so there is only one seat at either side of the aisle. On each seat was placed a white helmet, and in a corner a large umbrella was propped up. Once we started to move the tour guide gave us a brief history of the tunnels. The canal tunnel, which forms part of the Huddersfield Narrow Canal, is the longest and oldest of the tunnels, and holds the record as the longest and highest canal tunnel in the United Kingdom. All four tunnels are linked by cross-tunnels or adits at strategic locations within the tunnels. These allowed the railway tunnels to be built much more quickly, reducing the need for construction shafts, as waste could be removed by boat in the construction phase. Only the tunnel built in 1894 is currently used for rail traffic. The adjacent disused railway tunnel has telephone control points and allows a shadow emergency vehicle access via the adits if someone were taken ill or an emergency occurred. The canal is not deep enough for the boat to sink. When it was operational, the barges were propelled through the tunnel by 'legging'. Two men walked the barge though with their legs while laid on a plank.





At about the halfway point the boat stopped and the pilot disappeared through an adit to report to tunnel control via a landline telephone as mobiles and radios don't work in the tunnel. We put on our helmets and were allowed to go outside the barge onto the viewing platform. We literally could see the daylight at the end of the tunnel. However there was a little unpleasant surprise in store. Suddenly everyone rushed back into the covered part of the barge. Water was pouring down from the heavy roof. It was explained that the canal was topped up with water from the reservoir on moors above. The pilot's control panel is in the middle of the tug which has no roof. He had grabbed and opened the umbrella which we had seen on first entering the tunnel. Suddenly the light at the end of the tunnel grew bigger and we emerged into daylight. Just two things to remember—take a hooded waterproof jacket with you, and keep calm—don't panic.



Review: How to make friends with, and influence your Doctor

By Susan Harrison, (September 2013)

I recently read an article taken from a blog, by a doctor in the USA. Dr Rob's letter to his patients' was a heartfelt plea to people with chronic conditions to have a bit of a think about seeing things from the other side of the consulting desk.

He started by stating "You have it hard, much harder than people understand." Which I thought was a very good start! He spoke with 16 years experience of seeing patients with long term, unsolvable illnesses and went on to say that in his opinion, we scare doctors! Or rather the fact that we have a chronic, unsolvable illness scares a lot of doctors. As human beings, as professionals doing a job, they want to help, they want to solve our problems and for us to go away cured and happy with them. The fact that we don't get better and refuse to go away can frustrate and upset some of them.

The fact that we very often have so much knowledge about our condition can also a bit off-putting for a GP. Especially if we go see a new doctor and every time they come up with a suggestion, we just pipe up with "Yes, I've done that, no, it doesn't work for me." If you were trying to help you, how would you feel? Some doctors can feel inadequate. "We are human beings", cries Dr Rob, "we have feelings".

However much they may want to, they have a limited time for us and for all their other patients. They don't have specialist knowledge of any illness or condition but have to be as knowledgeable as they can on all of them. Don't forget that we tend to become experts of our particular illnesses. I don't know about you, but just keeping up with the latest thoughts and ideas on ME/CFS/Fibromyalgia can be hard work.

Dr Charles Sheperd wrote an article recently, about how to get the best out of a visit to your doctor and I've combined some of his suggestions and more of Dr Rob's views below.*

A common plea is for us not to expect a new doctor to figure things out quickly. It takes time to build a rapport and understanding between doctor and patient. The best care happens when each understands the other.

Another big ask is for a complicated patient not to stay away for a long time and then go see their GP with a long list of complaints. It's better for both if a patient attends regularly with a couple of problems. In this way, things don't get too complicated. How many of us have come away from the surgery and struggled to remember the whole conversation and all the advice given? Doctors like lists of complaints and questions as it helps them get an overall view and then prioritise treatment/advice. This can also help us foggy-brained souls. Just remember doctors cannot deal with a huge list in one ten minute time-limited visit.

Do change your doctor if you feel you are not getting anywhere with them. It may well be that another doctor in the same practice is better at, or prefers dealing with long-term illness patients or, actually knows and understands you better because they are a bit more knowledgeable of your condition, say through a current patient or through a friend or relative with the same condition. This isn't to say give up on a doctor immediately if they seem a bit stuck. Help them out with being as concise as you can and perhaps pointing them in the direction of some reading material, be it a leaflet from ME Essentials or Action for ME or a reference to a web article.

An ideal patient-doctor relationship needs to be based on mutual respect and understanding and it will help us all, patients and professionals, if we can work towards that goal.

*Dr Shepherd's article can be found on pages 8 & 9 of the Spring 2013 issue of the *ME Essential* magazine.

Breakthrough Corner

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Immunological Mechanisms in ME/CFS and Cancer: A newly funded study in Leeds

ME/CFS is not well understood nor, in many cases, properly recognised, and there is great debate about its underlying causes. Early symptoms include severe fatigue, sore throat, raised lymph nodes and pain in joints, similar to those associated with viral infections, so it is possible that an abnormal immune response to the initial viral infection is responsible for the continued symptoms.

The immune system of ME/CFS patients has been the target of medical researchers for many years, and the abnormalities found have included reduced natural killer cells, and increases in various types of cytokines (which regulate the immune system) such as interleukins and interferons. In fact, some of these immune abnormalities are similar to those found in cancer (see the table on this page). There is still much more to learn, however, and an immunological smoking gun remains to be found. Immunity in ME/CFS can also be studied in comparison with other chronic illness in which patients suffer from similar related symptoms such as debilitating fatigue and pain. For instance, 70 to 90% of breast cancer patients treated with chemotherapy have fatigue that can, in some cases, be severe and persist long after treatment, greatly affecting their quality of life. No-one is quite sure why this chemotherapy-induced fatigue happens, but chemotherapy is known to cause widespread alterations to lymphocytes (white blood cells that fight infections), and this may play a role. Could it be that changes in white blood cell populations underlie the fatigue experienced by ME/CFS patients and post-chemotherapy breast cancer patients?

Given this possibility, ME Research UK has actioned funding for an investigation by a team at St James' University Hospital, Leeds, involving a range of complex immune tests to assess the type and functional competence of lymphocytes, focusing on activated and regulatory cells (T and B cells). In particular, the team plans to recruit 25 ME/ CFS patients and 40 breast cancer patients to observe how lymphocyte surface proteins (and the cytokines released by lymphocytes) change before and after treatment.

In the case of breast cancer patients, treatment refers to chemotherapy; for ME/CFS patients, the treatment centres around their clinical care. All participants will complete outcomes questionnaires before and after treatment, and ME/CFS patients will be requested to complete the DePaul Symptom Questionnaire which assesses core symptoms of their illness and helps diagnostic classification.

Immune abnormalities in ME/CFS and cancer

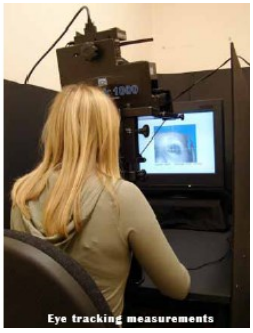
Factor	ME/CFS	Cancer
Ribonuclease L	Increased activity leading to increased apoptosis	Decreased activity leading to decreased apoptosis
Nuclear factor kappa beta	Increased activation	Increased activation
Natural killer cells	Decreased activity	Decreased activity

Source: *Meeus et al, Anticancer Research, 2009*

The main aim of the investigation is to shed light on any major common immunological mechanisms that might be responsible for the catalogue of symptoms shared by people with cancer or ME/CFS. The study could well reveal novel and immunologically important information, leading to new treatment options to protect against fatigue and increase the quality of life, particularly for the ME/CFS patients who presently have few treatments available to them.

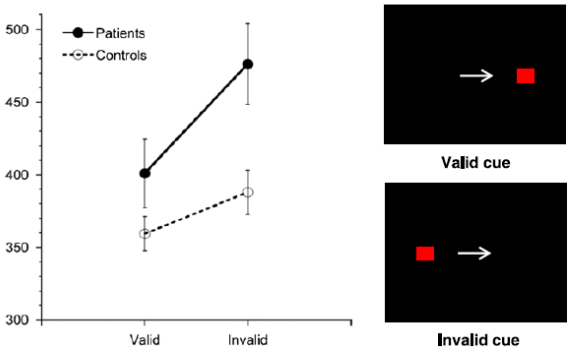
Common vision-related defects in ME/CFS

Around three-quarters of people with ME/CFS report problems with their eyes and vision but you wouldn't know it from the mainstream scientific literature. Apart from a small group of observational studies, there is very little formal published evidence that these symptoms exist, despite the fact they greatly affect quality of life and can be easily measured. This means that there is no solid, evidence-based scientific data to back up patients' reports of their disabling visual disturbances.



In order to redress the balance, Dr Claire Hutchinson and Dr Steve Badham of the Vision and Language Research Group, University of Leicester have been busy trying to identify and quantify vision-related problems in the disease, with funding from ME Research UK and the Irish ME Trust. They are part of a multidisciplinary group of researchers working on key issues in vision, visual cognition and language comprehension, with access to a range of state-of-the-art techniques. Based on the visual and vision-related symptoms most commonly reported by people with ME/CFS (summarised in the table opposite) the researchers initially set out to examine two main categories of visual impairment. The first concerns heightened visual awareness (including hypersensitivity to light and difficulty suppressing irrelevant background visual information), and the second consists of eye-movement problems, such as difficulty focusing on images or tracking objects.

Patients are slower at shifting attention



The first scientific paper reporting their findings has just been published (Optometry & Vision Science, June 2013), and it makes fascinating reading. Their report describes the specialised and quite intricate measurements undertaken on 29 ME/CFS patients and 29 matched healthy controls across three specific aspects of vision. The first of these was visual processing speed, divided attention and selective attention all of which involve assessment of the useful field of view, which is the visual area over which information can be extracted at a brief glance without eye or head movements. The other aspects were spatial cueing (the ability to shift attention from one thing to another), and visual search which involves the ability to locate a target in a field of distractors .

Common vision-related deficits in ME/CFS

Symptom cluster	Self-reported subjective visual symptoms
Heightened visual awareness	Hypersensitivity to light
	Difficulty suppressing visual information or directing visual attention
Eye-movement and tracking problems	Difficulty focusing on images
	Slow eye movements
	Difficulty tracking object movement
Reading difficulties	Confused or distracted by irrelevant print
	Difficulty tracking lines of print

Overall, patients performed worse than healthy people in each of these specific areas they were less able to selectively attend to a specific target while ignoring other irrelevant information; they were slower when it came to moving their attention to a target (see the graph on the right), particularly a target appearing at an unexpected (invalid) location; and they were slower at scanning visual stimuli and more easily affected by distractors during a visual search. These important findings provide much-needed experimental evidence of visual impairments in ME/CFS, and support patients' own reports about some of their vision symptoms. But what are the causes of these abnormalities?

These remain to be teased out, but it could be that processing speed is impaired, particularly as we already know that reaction times are significantly slower in people with ME/CFS (see page 14 of this issue). However, the researchers suggest that problems with eye movement itself might underlie some of these findings, and their next scientific paper, due out shortly, will address this particular aspect.

Postural Orthostatic Tachycardia and ME/CFS

One of the key difficulties facing ME/CFS patients is standing, especially standing still, which can bring on symptoms such as dizziness, altered vision, nausea and fatigue. So it is certainly possible that some dysfunction of the autonomic nervous system is involved in the disease. Since 2006, with the financial help of ME Research UK, Professor Julia Newton and her team at the School of Clinical Medical Sciences, University of Newcastle have been investigating autonomic nervous system function in ME/CFS. In fact, their scientific papers have reported autonomic dysfunction in three-quarters of ME/CFS patients, and that their blood pressure is lower and its regulation abnormal compared with healthy people. A new scientific paper from Prof Newton's group (published this year in the *Journal of Internal Medicine*) describes postural orthostatic tachycardia syndrome (POTS), an aspect of autonomic dysfunction that can produce substantial disability among otherwise healthy people.

POTS is defined as symptoms of orthostatic intolerance (problems with standing), and it is easily diagnosed by observing the increase in heart rate on moving from lying to standing (a person with POTS has an abnormally large increase). The team wanted to test a large group of ME/CFS patients for the presence of POTS, and to look for clinical differences between those with and without the disorder. If differences exist, it might be possible to treat and manage POTS patients as a distinct clinical subtype of ME/CFS, since we already know that this diagnosis includes a wide range of different kinds of patients.

In total, 179 consecutive patients from the Newcastle CFS Clinical Service were examined, and they underwent a series of demographic and symptom assessments, as well as autonomic function tests including heart rate variability (HRV) and left ventricular ejection time of the heart. The patients had been ill for just over 7 years on average and, overall, the prevalence of daytime sleepiness and orthostatic symptoms was high, as was physical and cognitive impairment.

In total, 24 patients (13%) had POTS, and they were younger (average age 29), less fatigued, less depressed, and reported less daytime sleepiness than the 155 (87%) without POTS. Crucially, they also had greater orthostatic symptoms and autonomic dysfunction. In fact, it was possible to predict which patients would be in the POTS group with 100% accuracy from a combination of high orthostatic intolerance and low daytime sleepiness. Of particular interest was the significantly lower HRV in the patients with POTS indicating a greater level of autonomic nervous dysfunction in this subgroup.

These interesting results were the subject of an expert commentary in the same issue of the Journal of Internal Medicine by Prof. Jo Nijs and colleagues from Brussels. They point out that the investigation provides compelling data for a novel subgroup within the ME/CFS population, and that the results support the view of ME/CFS as a central nervous system disorder. Clearly, it is important that POTS is recognised and managed, whether in ME/CFS or other groups of patients, since treatment can improve function

The science of ME – What do we know?

There are more than four thousand scientific publications on ME, many under different names, such as Post Viral Fatigue Syndrome, ME/CFS, Chronic Fatigue Syndrome, Chronic Fatigue & Immune Dysfunction Syndrome, etc. Significant progress has been made in the scientific understanding of the disease, particularly in the last 20 years, and in the list below we summarise some of the headline findings. Inflammation and immune activation are involved: Chronic T-cell activation, increased cytokines, raised oxidative stress and low natural killer cells point to a chronic state of low-grade immune up-regulation. Infection is important: in many patients, illness started with an acute, infectious-like episode. The main agents implicated in causing or maintaining the disease include enteroviruses (such as coxsackievirus), Epstein-Barr virus, cytomegalovirus and human herpes virus 6.

Neurocognitive abnormalities are prevalent: It is well established that cognitive problems mainly with memory, attention/concentration and reaction time, occur frequently.

Endocrine (hormonal) abnormalities can be found: Hypothalamic pituitary- adrenal axis (HPA) dysfunction is a well-recognised feature.

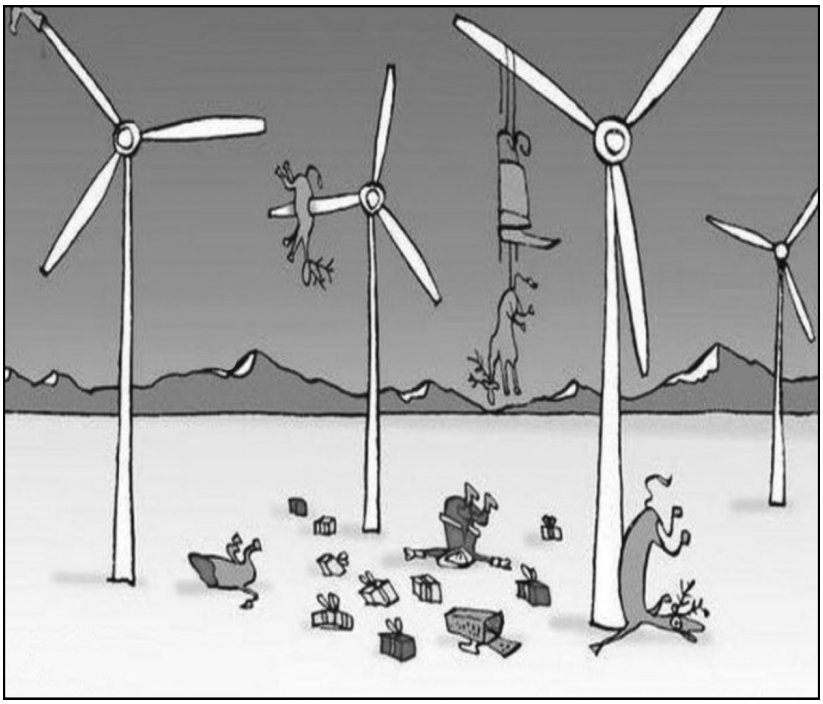
Symptoms are serious, and chronic illness is common: We now know that the most common symptoms of ME (pain, sleep disorders and vision problems) are daily challenges affecting the quality of life of patients, most of whom endure long-term illness. Between 10 and 25% of patients are severely affected housebound, bedbound or immobile and severely overlooked.

Psychiatry is not the answer: We know that the illness is not a form of depression, nor a primary psychiatric condition. As in other chronic diseases, psychological interventions can help some people to cope and to manage their symptoms until a cure is found. Genetic factors play a part: This has been shown by family and twin studies.

Neurological abnormalities can be detected: There is good evidence of autonomic nervous system dysfunction, including orthostatic intolerance which causes problems on standing. Brain structure and blood flow abnormalities have also been identified, and central sensitisation, due to an abnormal increase in the firing of nerve cells in the spine, may be important.

Muscle function is impaired in some patients: This includes abnormalities to skeletal muscle and impairments to cardiac bioenergetics.

Prevalence is high: Epidemiological studies show that ME affects around 200,000 people in the UK and 1 million in the USA. This makes the disease more prevalent than multiple sclerosis, systemic lupus and HIV infection. Biomedical research has made significant progress, but imagine the advances that could be made by a concerted effort to fund programmes of research across the globe! Our strategy for ME has to mirror that of other illnesses, such as cancer, which obtains most of its revenue (500 million per year in the UK) from private sources and ground-level fundraising. It is a huge task, but much can be achieved by a determined effort to mobilise the resources of the wider community.



Sleep abnormalities

Sleep problems affect a large majority of people with ME/CFS, and they can have a very great impact on all other aspects of patients lives. For this reason, scientists in the Centre for Sleep Research at Northumbria University decided to look for objective evidence of severe sleep disturbance in the disease, including the range and variety of problems experienced. The researchers analysed data from 343 Fukuda-defined patients from the Netherlands, who all underwent a single night of polysomnography investigations (all-night recording of EEG, electromyography, electrooculography, ECG and respiration) at a specialist sleep clinic.

Overall, there were two major findings. First, 104 of the patients (a full 30.3%) had a primary sleep disorder (mainly sleep apnoea) which might, in itself, explain some of their symptoms, including muscle aches and pains, fatigue and problems with concentration. Second, the remaining 239 patients could be grouped into four different sleep categories each with a distinct sleep profile ; two of these groups have mainly insomnia-like symptoms, while two are characterised by poor quality of sleep showing that different types of sleep dysfunction can exist, even though all patients have the same diagnosis.

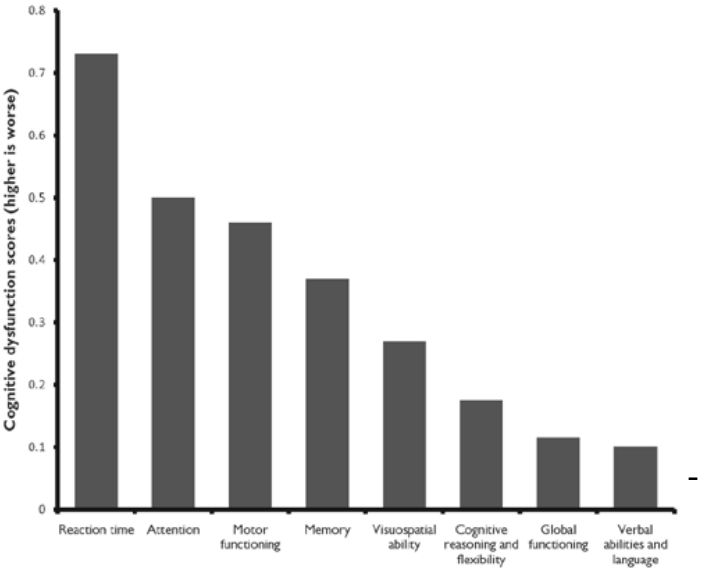
There seems to be no consensus as yet on the science behind sleep derangement in ME/CFS, though the most common research findings include problems with initiation of sleep (i.e. dropping off =no surprise to readers!) and also reduced slow-wave stage (non-REM) sleep. The causes, however, remain a mystery - and one that needs to be unravelled. Source: Gotts et al., BMJ Open, 2013

Slowing of information-processing

Neurocognitive problems are one of the most frequent and disabling symptoms associated with ME/CFS. In fact, around 90% of 2073 patients in one large study reported having memory/attention-deficit problems, and patients often say that physical or mental exertion makes their cognitive problems worse. The latest results from researchers at the University of Adelaide on cognitive performance in ME/CFS confirm some patients reports, and go further.

In 50 patients, they found that the main cognitive deficit was in reaction time (assessed as reaction times to both simple and complex choices presented on a computer screen) which was about 50 milliseconds slower on average in patients than in the control group of 50 healthy people. Researchers point out that a basic slowing in information processing speed seems to be the cause, rather than a deficit in more complex decision making. Interestingly, the slowing of reaction time was not related to psychological status (including depression or anxiety), the number or severity of ME/ CFS symptoms or everyday functioning.

This very active Australian research group also published, in 2010, an excellent overview of all relevant clinical trials examining cognitive functioning in people with ME/CFS. Their meta-analysis found convincing published evidence (see the graph on the left) of deficits in reaction time, attention (encompassing attention span and working memory), and memory (assessed by verbal and visual memory tests, mostly memory for word lists). Moreover, the deficits in performance of ME/CFS patients were around 0.5 to 1.0 standard deviations below those of healthy people, a fact which helps to explain the significant impact cognitive problems have on patients day-to day activities and quality of life. Source: Cockleshell & Mathias, Neuropsychology, 2013



VITAMIN D: Time for reassessment

by Dr Damien Downing MB BS.

It is a fact of life in the current scientific world that publicity, hype and spin are more important in spreading information - and disinformation - about nutritional medicine than peer-reviewed scientific studies. The recent publicity over vitamin C is an obvious instance of this; a paper from the University of Pennsylvania Center for Cancer Pharmacology was the subject of a press release that presented it as new data that may have shown a damaging effect of vitamin C, even though any number of other studies have shown the opposite. When the principal author, Ian A Blair, was finally contacted by telephone (the press release was issued while he was out of the USA on holiday), he apparently said; "Absolutely for God's sake don't say vitamin C causes cancer". This did not stop the media from reporting exactly that, with the result that many patients worldwide have been stopping or reducing their vitamin C intake, with possible detrimental effects on health. As has been pointed out repeatedly, if the study had shown a positive effect from vitamin C, or any other nutrient, experience tells us that it would not have been 'hyped up' in this manner.

Which is also exactly what did not happen with a crucial review article on vitamin D in the American Journal of Clinical Nutrition in 1999[1]. This paper, by Dr Reinhold Vieth in Toronto, laid out strong arguments that we are all deficient in Vitamin D because we have grossly misjudged the necessary intake for adults, and the amount needed to cause toxicity. Since then Dr Vieth has continued to accumulate evidence of this, his central thesis, and the further ramifications of it. In this issue he brings the argument up to date[2] and discusses the implications, not just for bone health, but for a number of other diseases as well.

Ironically, this comes at a time when the US Environmental Protection Agency is advising that ultraviolet light, and therefore sunlight, is so dangerous that we should "protect ourselves against ultraviolet light whenever we can see our shadow". Following this advice is likely to lead to an increase in vitamin D deficiency diseases, and is effectively discriminatory against the many individuals with darker skin types who now live in higher latitudes. As a physician who has seen 2 cases of rickets this year, I find this of great concern. Whether sunlight is the direct and principal cause of skin cancers and other skin damage is a separate debate, which we cannot cover here, but the evidence is mounting that following current guidelines on sun-protection will have detrimental effects on other areas of health.

There are several important, only recently understood, and not yet widely appreciated, points to be made about Vitamin D:

Healthy/desirable levels are much higher than was thought. Laboratory reference ranges for 25-hydroxyvitamin D (25(OH)D) are still stated at around 40-100 $nmol/L^{-1}$. But people who live in equatorial regions and spend much of their days in the sunlight (farmers and lifeguards, for instance), consistently show levels over 100 $nmol/L^{-1}$, and even above 200$nmol/L^{-1}$. Since humanity evolved in such an environment, it is clear that the vitamin D exposure that parallels the "Stone Age Diet" as the environment in which humanity evolved was much higher than the levels we have now come to regard as normal. Yet Vitamin D deficiency is widespread in developed countries, and food-fortification is disappointing as a solution to this. Sunlight gives much more than we can get in (even fortified) food

Our understanding of the chemistry of vitamin D now makes it clear that it is not really a vitamin; the reason we need dietary intakes is only because we are so deprived of ultraviolet light, which triggers its synthesis in the skin. A whole-body sunlight exposure barely sufficient to trigger tanning. The Minimum Melanogenesis Dose, which may be as little as 15 minutes for pale-skinned individuals, has been established to be equivalent to the consumption of as much as 10,000 I.U. of Vitamin D. Compare this to the US RDA for adults under 50, which now stands at 200 I.U. Studies of everyday sunlight exposure conducted in San Diego California, found that normal urban inhabitants spend very little of their time in full sunlight[3], which accounts for the generally lower Vitamin D levels, most of which will have been obtained from food, rather than from the effect of sunlight.

Toxicity requires much more than was thought. Clearly the high levels of Vitamin D synthesis, and of serum 25(OH)D, mentioned above are not toxic. A number of studies have in fact shown that toxicity requires doses in the milligram range (1mg=40,000 I.U.). Vieth suggests that the widely-held view that Vitamin D is the most toxic of all the vitamins derives from the fact that physiological doses are in the microgram range, not the milligram as with most other vitamins.

Vitamin D2 is a poor substitute, other analogues probably too. Textbooks still assume that ergocalciferol, Vitamin D2, manufactured by yeast organisms, is equivalent to cholecalciferol, D3, the human physiological form. But the evidence currently available indicates that it has about 25% of the potency of D3 in humans. Nonetheless it is still used widely. In Australia, where sunlight is close to becoming illegal, for instance, D3 is not licensed for use in food, only D2.

Older people need more than young adults; dark skinned people more than white people. The USA RDA for people over 70 has recently been trebled to 600 I.U./day, an impressive increase. Laboratory evidence shows that with increasing age, the skin becomes progessively less efficient at synthesising 25(OH)D. Yet older people typically spend less time in the sunlight, are more prone to Vitamin D deficiency, and to the consequent diseases - osteomalacia, osteoporosis, bone fractures. Recent evidence indicates that Vitamin D strengthens muscles, thus presumably improving balance and movement and preventing falls, thus reducing fractures independently of its effect on bone density.

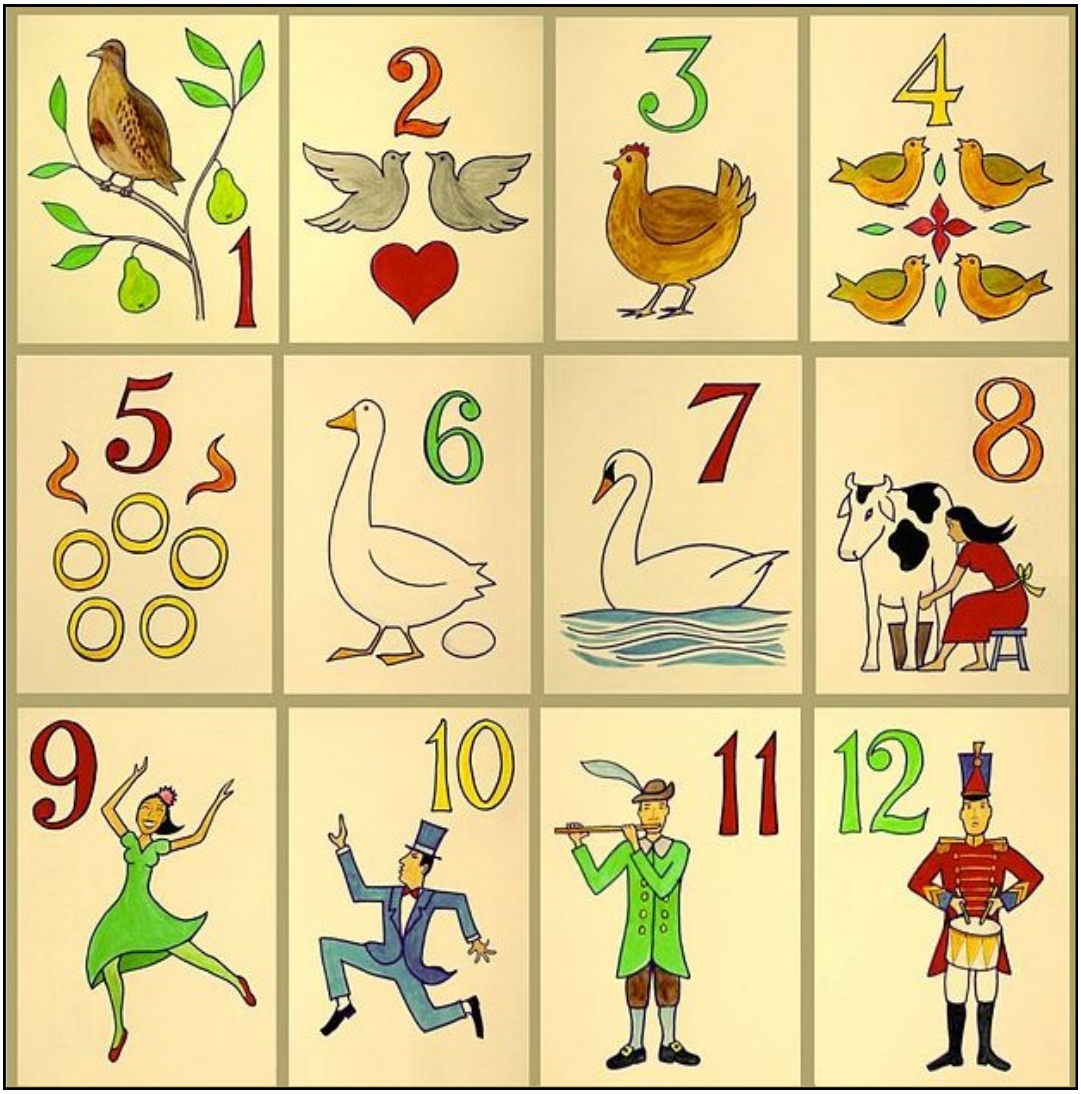
The RDA was derived from what is in a spoonful of cod liver oil, not from what we actually need. A spoonful of cod liver oil, such as so many mothers used to give to their children daily (in some countries such as Iceland this is still a breakfast custom) contains a little less than 400 I.U. As has been observed with other nutrients, the original RDA appears to have been set on a pragmatic basis, rather than in relation to human needs. 400 I.U. has proved ineffective at preventing deficiency levels of Vitamin D, and estimates of requirements continue to rise over the years. The vitamin appears to be 25(OH)D, whereas 1,25-dihydroxyvitamin D (1,25(OH)2D) is the hormone. 25(OH)D has always been thought to have no physiological role, needing to be converted to 1,25(OH)2D, with the deficiency diseases, rickets and osteomalacia. Only a surprisingly small proportion of 25(OH)D is converted into 1,25(OH)2D, which has a clear hormonal effect on the active uptake of calcium from the gut. The physiological role of 25(OH)D appears to lie elsewhere.

Our current sun-phobia is contributing to many other diseases. Recent work has demonstrated the presence of receptors for Vitamin D in an enormous range of tissues, and physiological roles for the nutrient in a number of different contexts (preventing and treating SAD, enhancing activation of thyroid hormone in the periphery, and modulating immune function, for instance). Epidemiological data points to an effect of sunlight exposure and Vitamin D in reducing the prevalence of a number of the major degenerative diseases that have been increasing in recent decades - cancer, hypertension, hypercholestolaemia (see previous volumes of this journal), diabetes and heart disease in a wider sense - probably all the components of Syndrome X, in fact - multiple sclerosis, and vulnerability to infections.

In the light of all this new evidence, it is clear that we must revise our policies and our advice, not only to sufferers from the bone diseases of old age, but to those suffering from or at risk from a range of other degenerative diseases, and indeed to all those wishing to prevent such diseases and to maintain good health. Our current phobic recommendation for the avoidance of sunlight exposure starts to look like the worst possible public health measure.

The Twelve Days of Christmas

"The Twelve Days of Christmas" is an English Christmas carol, first published in England in 1780 without music as a chant or rhyme, and is believed to be French in origin perhaps from a seasonal carol or dance. The standard tune we know today originates from a 1909 arrangement by the English composer Frederic Austin who is believed to have introduced the slower and longer phrase "five golden rings". There are various versions of the tune, and in the north it was called "Ten Days of Christmas", the gifts numbering ten.



Depending on your point of view, the first day is Christmas day or alternatively Boxing Day (St. Stephen's Day). The 12th day can be January 5th or 6th likewise which corresponds to the Epiphany- in ancient times being the last day of the Christmas festivities. I've heard of it being used as a forfeit party song –but there is another interpretation. that it is an underground Catechism song of the Catholic Faith. Certainly these days it seems to be a popular source of questions for pubs quizzes and games shows.
Just in case you are ever asked the total number of gifts—it is 364 the days in the year minus one.

Day	Gift	Religious meaning	Gifts in Song
1	Partridge in a pear tree	Jesus Christ the Son of God	12
2	Turtledoves	The Old and New Testaments	22
3	French hens	The theological virtues of faith hope and charity	30
4	Calling birds	The four gospels (Matthew, Mark, Luke and John)	36
5	Golden rings	The first five books of the Old Testament	40
6	Geese a-laying	The six days of creation	42
7	Swans a-swimming	The seven gifts of the Holy Spirit	42
8	Maids a-milking	The Eight Beatitudes	40
9	Ladies dancing	The nine fruits of the Holy Spirit	36
10	Lords a-leaping	The Ten Commandments	30
11	Pipers piping	The 11 faithful disciples (less Judas)	22
12	Drummers drumming	The 12 Apostles'	12

Will it be a White Christmas

With thanks to the Met office

For many people, a White Christmas means a complete covering of snow falling between midnight on the 24th December and midday on 25th December. However, the definition used most widely, notably by those placing and taking bets, is for a single snowflake (perhaps among a mixed shower of rain and snow) to be observed falling in the 24 hours of 25 December at a specified location. The UK gets on average 33 days of snow fall or sleet a year (1971 - 2000). Most of this is snow falling on higher ground where temperatures are lower, as can be seen on the map.

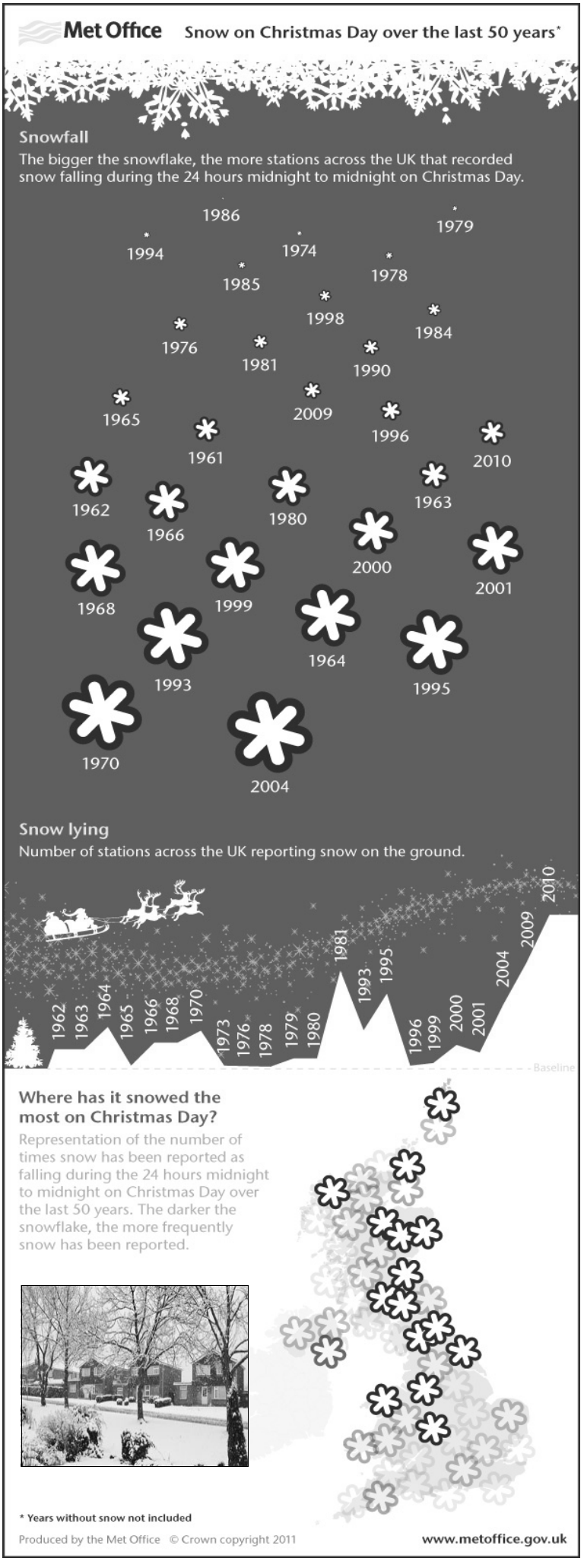
Where gets the most snow?

In Scotland, the figure is much higher, with snow or sleet falling on 52 days on average. Statistically, the snowiest place in the UK is Banffshire in Scotland, with 63.8 days of snow or sleet falling on average. Cornwall is the least likely to get snow, with an average of only 10.2 days of snow or sleet falling a year.

How much snow settles?

Much of this snow fall does not settle, and the figures for snow on the ground (snow lying) are much lower. On average across the UK there's only 16.5 days a year when snow is on the ground, compared to 27.7 days in Scotland. Again, most of the snow on the ground can be found in mountainous areas.

Looking at climate history, wintry weather is more likely between January and March than December. Snow or sleet falls on average five days in December, compared to 7.6 days in January, 6.8 days in February and six days in March. White Christmases were more frequent in the 18th and 19th centuries, even more so before the change of calendar in 1752 which effectively brought Christmas day back by 12 days. Climate change has also brought higher average temperatures over land and sea and this generally reduces the chances of a white Christmas. However, the natural variability of the weather will not stop cold, snowy winters happening in the future.



SYCIL Lifestyle Choices

For many years we have worked with South Yorkshire Centre for Independent Living (SYCIL), particularly Helen Butler who helped many of our members with their disability issues.
On hearing that SYCIL Lifestyle Choices was being set up I decide to ask Director Michaela Etherington along to a Leger ME meeting in October. Here is a summary of what we heard.

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SYCIL Lifestyle Choices provides essential lifestyle services and support for disabled people, as well as their Carers and the wider community. These services enable disabled people to live independent lives and embrace highly individual and personal lifestyle choices. SYCIL is committed to the principle of equality of opportunity for everyone, recognizing that people often experience discrimination on the grounds of class, race, gender, ethnicity and sexual identity as well as impairment.

The organisation was launched on October 23 by the Civic Mayor of Doncaster, Cllr Christine Mills and has been supported by South Yorkshire Centre for Inclusive Living which is already a well-established local charity supporting disabled people to live independently. Due to changes in Government policy and commissioning and contracting arrangements, SYCIL decided to explore different ways in delivering their service. Following a consultation with service users, staff and other professionals, SYCIL Lifestyle Choices was set up as a not-for-profit organisation to offer services that enable people to continue living independently but that are no longer funded. All employees are CRB and reference-checked.

Aims

The overall aim of the project is to improve the lives of all people who wish to remain independent

- Increase service user choice
- Increase quality of life and service user confidence
- Increase service users' independence
- Support greater inclusion

Objectives

- To provide essential Life Style Services and Support for Disabled people, as well as carers and the wider community
- To provide a comprehensive service that will support and enable Disabled people to live independently in the community
- To provide situations where Disabled people can become empowered to have greater choice and control over their lives
- To provide continuity of service that is reliable, and responsive to your needs. We aim to recruit and retain dependable workers who are dedicated to one individual or family
- We will employ and provide Support Workers / Enablers with appropriate skills qualifications, and provide ongoing training in accordance with the service users particular needs.

Services with a difference. People who need support for everyday living can be independent if they have control over the way support is delivered. We help people to realise that independence is not a matter of doing everything for yourself but of having choice and control over your life and a say in what happens to you. Lifestyle choices employ 'Enablers' to work with you to provide the service of your choice. SYCIL Lifestyle Choices Services, include:

Cleaning (home or office), Grocery Shopping, Medical appointments, Ironing (in your home), Gardening, Social outings, Pet care (dog walking etc.), Recruitment and Selection, Hobby sessions Helping with paperwork

I quite frequently hear complaints about home care agencies from some Leger ME members particularly about skills and training. Having first-hand experience of that situation has made me realise that having to make a choice to ask for help is a massive step; allowing strangers in to your own home should not be taken lightly and without support. If you would like to find out more or to book a free one hour assessment please call Michaela Etherington or Barry Coburn on 01302 892967/892949, email admin@sycillifestyle.co.uk or visit www.sycil.org

All the other reindeer *used* to laugh and call him names

Figgy pudding

Figgy pudding dates back to 16th century England. It's possible ancestors include savory puddings such as crustades, fygeye or figge (a potage of mashed figs thickened with bread), creme boiled (a kind of stirred custard), and sippets. In any case, the methods and ingredients appear in diverse older recipes. Today, the term figgy pudding is popularized mainly by the Christmas carol "We Wish You A Merry Christmas," which includes the line, "Now bring us some figgy pudding" in the chorus.

North of Doncaster

Personal comment by Trevor Wainwright

We often hear the story of Good King Wenceslas told from his point of view about himself, but what of the page who went with him? At primary school I read a story from the page's point of view. One Christmas it came to mind so I put it into rhyme.

The Page Boy

The king called me from the fire; I answered him, "what is it sire?"
He asked "tell me page if you can, out in the snow who is that man?"
I saw him there in the moonlight gathering wood on a cold night
"I know where he does dwell sire where it is I can tell"
"If page you show me where we will take provisions there
Now go and get dressed right, we've a task to do this night"
Each of us a load to bear, set of in the cold night air
To where the man did live, he and his family help to give

Slowly over the frozen snow ever onwards we did go
But progress became hard painfully yard by yard
"Sire" I said "the wind blows a gale I fear my strength may fail"
He turned and said "page take heart my strength to you I'll impart
Of my garment take hold, I will shield you from the cold
In his shadow I did tread, no longer filled with dread

At last we reached the mans abode, from my shoulders I eased my load
The journey then seemed all worthwhile met with gratitude and a smile
Soon a fire in the grate, the family's hunger we did sate
Then the King said, "Let's depart, homeward page we've done our part"
Now the time has long passed but still the memory does last
Of the family to whom we brought joy, the King and his Page Boy.

Now what of the carol itself?
Was Wenceslas the good guy he is supposed to be? Below is the result of some research.

Good King Wenceslas.
This carol dates back to the sixteenth-century and began, *Tempest adest floridan* (The time of lowers is at hand), set to a thirteenth-century dance tune. In the mid nineteenth-century John Mason Neale replaced the words to give us the carol we have today. However, there may be some controversy, as King Wenceslas, King of the Romans from 1376, then King of Germany from 1378 to 1389 was apparently a neglectful ruler and very fond of the grape. It is said he would hardly have shown any compassion for the wood gatherer, let alone taken aid to him and his family. The carol though tells of Christmas as a time of giving and seems to be paying tribute to the upper echelon of society, saying that 'wealth or rank' possessing, that those who bless the poor, will themselves find blessing. Yet it gives no indication of how low may be the rank, or how little wealth the donor may have, and despite many a schoolboy's attempt to change it, the wording still remains as popular as ever in Neale's version.

In next issue's column I will be writing about Anne Faulkner and my fundraising for the CFSRF. Meanwhile in the words of Greg Lake from my favourite Christmas Classic,

"I wish you a hopeful Christmas, I wish I wish you a hopeful Christmas. I wish you a brave New Year all anguish pain and sadness leave your heart and let your road be clear."

Merry Christmas and Happy New Year to All