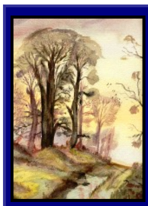
Price £ 3.75 (Free to members)



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. 54. (Winter 2017)

You write in:

Thanks goes to Evelyn Hargraves for this front page picture of a robin taken on 11/12/17

Jane Colby (from the Tymes Trust) writes: - We were delighted to hear that NICE decided to have a complete rewrite of its 'Guideline on ME/CFS'. We are also pleased to see that they have taken note of points we made in our submission, such as the problem of false allegations against families with children, and the need to have regard to the heterogeneity of "CFS" - a woolly category into which true ME has been incorporated, meaning that doctors may not know which patients will be made worse by undertaking therapies involving exercise. We look forward to the rewrite, which will be **out in 2020.**

Good news! For the benefit of Pathways readers the Tymes trust is an award-winning charity that deals with children and young people with ME/CFS. See page 3.

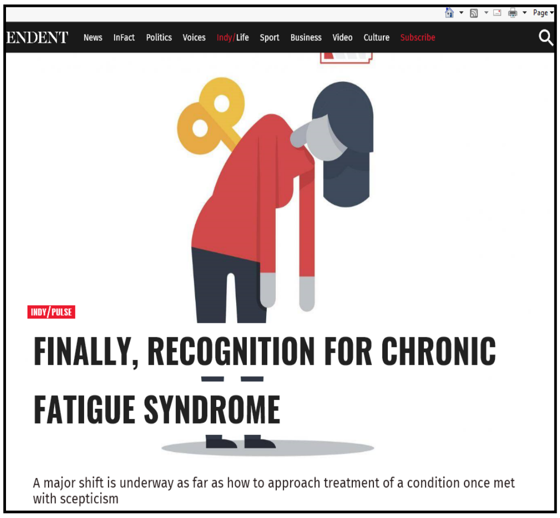
Nicola Writes: When I first spoke to you, you said there were people in the Thorne area that met up every so often at the Punch Bowl. I am very isolated here and would love to meet new local people who have M. E. Please would you introduce me to those people, either by giving my mobile and email to them or asking them if you can give theirs to me.

Would anyone like to contact Nicola in the Thorne area? Please let me know and I will pass her details on.

Rosie Writes: I've just seen a feature entitled 'Finally, recognition for chronic fatigue syndrome'. Is this information of any use to the group?

This feature is old news. Recognition for us the UK finally came with the Chief Medical Officers report around 2000 followed by the NICE guidelines in 2004 and shortly after formation of the Sheffield ME/CFS Clinic. A lot has happened since then, and I do report anything significant in Pathways from time to time. For the benefit of Pathways readers, this feature can be found on the 'Independent' Website.

http://www.independent.co.uk/life-style/health-and-families/new-recognition-for-chronic-fatigue-a8081751.html



FINALLY, RECOGNITION FOR CHRONIC FATIGUE SYNDROME

A major shift is underway as far as how to approach treatment of a condition once met with scepticism

Dawn Writes—I've just received a UC 50 form for my Universal Benefit Claim. I can't seem to find anything about it on your website. Can you help?

The UC 50 form is almost identical to the ESA 50 form except in name. We have dealt with these types of form for many years. As you are a Leger ME member, contact me and I will arrange all the necessary help and resources for the form fillout. Normally members have very little trouble providing advice is followed.

NICE announces review of ME/CFS clinical guidelines

With thanks to Action for ME and InterAction

In September, the National Institute for Health and Care Excellence (NICE), announced that it will undertake a full review of the guideline on ME, Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management, following consultation with stakeholders including Action for ME Based on evidence highlighted during an initial consultation, which include Action for ME reports *Time to deliver* and Close *to collapse*, NICE will be considering a full update of the guideline.

NICE highlighted some of the themes that emerged from stakeholder comments, which include: -

- **Considering changes to the diagnostic criteria: newer diagnostic guidelines have been introduced in the US and the criteria currently used by NIHCE have been criticised as too broad**
- **Patient surveys regarding the safety and efficacy of cognitive behavioural therapy (CBT) and graded exercise therapy (GET) contradict findings from randomised controlled trials**
- **Introduce a section specifically on ME in children, which is not currently mentioned, to raise awareness and increase the knowledge of professionals**
- **Considering an update to the definition and aetiology, for example newer terms for the disease and a greater consideration of biological models.**

NICE have announced their plans to conduct a full review, having initially proposed not to update the guideline. ME charities and other organisations urged the need for changes to the guideline, based on changing policy and practice globally. US agencies no longer recommend CBT or GET, the interventions recommended in the current NICE guideline.

The Position of Action for ME

Action for ME submitted comments, both individually and in a joint response with Forward ME, that NICE had an ethical obligation to ensure clinicians and patients were fully aware of international policy and practice when considering any health intervention. We stated that:

- **There is not presently a conclusive evidence base for treatments for ME, including those recommended in the guideline such as CBT or GET**
- **The current evidence base has led major international health agencies, including the Centres for Disease Control and Prevention in the US, to alter their guidance regarding CBT and GET**
- **NICE has an ethical obligation to present a full, accurate and balanced picture of current international clinical practice when it comes to managing and treating ME The guideline in its current form does not do this.**

We also highlighted our findings in '*Time* to *deliver* 'that most people with ME found pacing to be helpful, and while some people found either CST or GET helpful, a considerable proportion also felt that their condition got worse following these interventions. NICE determined that these findings, as well as those in our 2015 report into social care, '*Close* to *collapse',* that 97% of survey respondents experienced two or more difficulties with the daily living activities listed in the 2014 Care Act, met criteria to be included in the surveillance review and may potentially impact on the guideline's current recommendations.
As well as sharing the experiences of people with ME, Action for ME will call for the updated guideline to:

- **Recognise the experiences of people with ME and take account of how these impact on the guideline recommendations, including the significant number of patients who state that pacing has been helpful for them**
- **Ensure it provides a full and accurate picture to patients and clinicians of the diversity of current international practice**
- **Recommend further biomedical research into the aetiology and potential treatments of ME/CFS, to increase knowledge and understanding of the condition.**

Sonya Chowdhury, Chief Executive of Action for ME, said" lit is very encouraging to hear that NICE have considered the evidence submitted by us and other advocates and decided to review the guideline in full. It is essential that the guideline enables patients to make an informed choice about their healthcare, and Action for ME will continue to engage with NICE to ensure that the new guideline listens to the voices of people with ME/CFS "

What happens next?

NICE has announced an expected publication date of 2020. At the beginning of the process, developers will draft a scope for the guideline, consulting with stakeholders including Action for ME, before reviewing evidence and drafting the full guideline. We will continue to provide updates on the NICE guideline throughout the review process.

Welfare Rights Matters

by Steve Donnison from Benefits and Work.

In this update we have the extraordinary news that the DWP is searching for claimants to whom they can award a higher rate of personal independence payment (PIP). Though we also reveal that they are going to be doing their best to find as few as possible We also learn that 20% of DLA to PIP claimants get no award at all. And we hear from the most senior tribunal judge in the country that 6 out of 10 social security appeals are no-brainers that the DWP has no hope whatsoever of winning. Plus, some feedback from members that proves his point.

Benefits and Work
Guides you can trust

Fully paid-up members of Leger ME have access to Benefits and Work Guides as part of the membership benefits. As these guides change frequently, we recommend requesting a copy when you need. Copies are provided as PDF files, but can be printed by request to the Leger ME office. While electronic copies are free, printed copies cost between £7-10 per guide.

The search for PIP claimants entitled to more.

A shameful 7 months after it lost a PIP court case, the DWP has finally backed down and changed the way it makes decisions about PIP. It has also begun searching for thousands of claimants who have lost out because of the delay. Until last week, the DWP had argued that a claimant could only score points for being unsafe if harm was likely to occur on more than 50% of the occasions on which they attempted an activity. But, back in March a panel of upper tribunal judges held that the decision maker should look at whether there is a real possibility that harm might occur and at how great the harm might be. The greater the potential harm, the less likely it needs to be that it would happen on any specific occasion. It has taken the DWP some almost criminal seven months to update their guidance to health professionals and decision makers. The DWP believes that an extra 10,000 claimants will benefit by £70-£90 a month because of the change. Penny Mordaunt, former minister for disabled people, told the Commons earlier this month:

"In the case of existing claimants, the Department for Work and Pensions will undertake an exercise to go through all existing cases and identify anyone who may be entitled to more. We will then write to those people affected and all payments will be backdated to the date of the change in case law".

However, few claimants would trust the DWP to identify all those who should receive a higher award, or any award at all if you got nothing. It would be worth getting advice if you believe your case should be looked at again, especially as the DWP seem to be focusing almost exclusively on claimants with epilepsy.

There is a parallel case here with ME/CFS patients due to brain fog and fatigue relate attention problems. Ed.

As few PIP safety awards as possible?

Whilst the DWP have no choice but to change the way they assess PIP claimants on safety grounds, new guidance to decision makers issued following Mordaunt's statement show that they aim to change as little as possible. The new guidance gives five imaginary examples of claimants who will need their claims reconsidering in the light of the upper tribunal ruling. As a result, the number of claimants who get an increased award is: Can you guess? Yes, its zero. Not one of the claimants in the guidance is better-off because their safety has been properly considered. Tribunals, however, may take a very different view. Especially considering the utterly scornful no-brainier opinion of DWP appeals voiced by the senior president of tribunals below.

Tribunal no-brainers.

Sir Ernest Ryder, senior president of tribunals, has condemned the DWP for forcing so many claimants to go to appeal when it is a no-brainer that the DWP will lose. According to Ryder, the percentage of appeals that the DWP lose has risen from 44% in 2007 to 61% now. He told a barrister meeting that the quality of evidence put forward by the DWP was so bad it would not be accepted in any other court. In relation to PIP and ESA medical assessments, Ryder said that often the tribunal didn`t even know what the professional qualification or registration number was of the author and that in expert evidence terms in any other organisation you and I know of, it would be wholly inadmissible. Ryder added that judges had done a spot check on outstanding cases and found that 60% of it is a no-brainer that the DWP are going to lose. The Tribunals Service are now considering either sending cases back to the DWP where there is no reasonable defence to the appeal or charging the DWP for defending such cases.

Massive drop in legal aid cases.

It may be no coincidence that the standard of appeal submissions has plummeted at a time when only a tiny number of claimants are fortunate enough to have a representative. The number of claimants getting legal aid to help with social security appeals has plummeted by 99.5% because of massive cuts to the legal aid budget. Figures produced by the government show that the 83,000 claimants received legal help in 2012-13, before the cuts came in. This plummeted to a tiny 440 claimants in the last financial year. Meanwhile our experience of DLA to PIP via Tribunal and Unexpected ESA Tribunal success are appeals that illustrate the no-brainer principle above. But it does prove the point that it is often overwhelmingly clear to a tribunal what their decision is going to be, based solely on the written evidence provided by the claimant, before a word is spoken.

DLA to PIP Claims.

Finally, the latest DWP figures show that almost one in five claimants who are forced to move from DLA to PIP get no award whatsoever. Up to July 2017, 649,480 DLA claimants were reassessed for PIP by IAS, formerly known as Atos. Of these, 125,680 (19%) received no award at all. We very much hope, especially given the no-brainer insight above, that any Benefits and Work readers who have found themselves with no award will have no hesitation in going to appeal.

The Leger ME Case Review and Form Fillout Service

The Case Review Service is available to all fully paid up Leger ME members. It is available to none members starting at £60. A case review is an interview to focus on how you are progressing with your Health and Welfare matters. It is to gather information: -

- To help you find out more about your health and welfare management of your condition.
- To help identify your current needs and review how they are being managed.
- To help ensure that you get all the help and support that is available to you.
- To try and identify any future problems that may arise.

We will make recommendations which we think will be in your best interest to follow. We can only consider available information supplied by yourself, what is available publicly, and from our own experience. This information will be then used for the form fill in assistance service to help you to fill in a DWP form or another similar type of form.

We will: -

- Help you draft the form prior to filling it in.
- Explain any issues that many arise from the form fill out service.
- Provide additional information and help that is available to you from other sources.
- Try to identify any future problems that may arise.

There Is no guarantee about the outcome of this service. The DWP and other organisations check all information you provide and compare it with their own sources to obtain information and advice which is outside our control. Assumptions are often made if the information is insufficient which may be against your interest.

The case review and form fillout service may incur additional cost related to printing, photocopying and room hire. There may be addition costs for letters or professional work. As individual cases and needs vary it is very difficult to give a general cost but if you assume that it will cost overall less than a weeks' worth of the benefit you are claiming. Our success rate is high, 90% plus. To access this service and to discuss your needs contact the Leger ME office in the usual way or ask at the Redmond Centre.

Fatigue Syndromes and the World of Work.

The problems that Leger ME members present at meetings tend to run in episodes. For example, this summer there was an epidemic of PIP cases to deal with. This autumn I've had a cluster of ME/CFS and Work cases. One thing in common is finding that the DWP, health professionals, doctors, patients and employers have difficulty in assessing the prognosis. As a result, advice is given which is always over optimistic on the true reality and the outcome never meets expectation. I am using the word Fatigue syndrome to cover ME, CFS, PVFS, CFIDS and FMS. While all have different meanings, and are given by medical different medical specialties, when it comes to works matters then approach is always the same. There are two different mode of onset.

Firstly, there is an acute mode, where some event can be identified as triggering the onset of fatigue syndrome. The fatigue syndrome is triggered by a life event e.g. vaccination, infection, operation, accidents, mental trauma, chemical exposure. It is only after the triggering problems start to clear that the fatigue syndrome starts to emerge after a few weeks to several months. Usually the patients are off work or school, return to normal health does not happen. Typically, this mode of onset results in a variable degree of recovery, but is never complete and there are always chronic health problems. These people contact us, usually after a diagnosis for assistance.

Secondly there is the insidious mode. This is where there is no definite point of onset, and the patients gradually slide into fatigue syndrome until some crisis or other occurs and someone realises that something is seriously wrong. Very often in the early stages the fatigue syndrome is mistaken for other health problems like depression. The prognosis for someone with this pattern of onset is poor. The people who contact us with this pattern of onset usually don't have a formal diagnosis.

Whatever the pattern of onset there is always a period of absence from school or work. After a reasonable time, questions start to be asked why that person is not returning to work by employers and the DWP. Very often explanations are demanded by employers, the DWP or schools. It is only after 3-6 months that a diagnosis of fatigue syndrome can be formally given. In all cases any fatigue syndrome should be fulling investigated by the GP, and various blood and other tests carried out to see if another condition e.g. cancer or MS is causing the problem. The diagnosis should be confirmed by a consultant and then the patient referred to a condition management clinic like Sheffield or York. At the clinic, after the first assessments, the patient will be invited to attend various sessions to help with rehabilitation. The role of Leger ME is to provide information, signposting and a mentoring service to patients' families and friends of patients with Fatigue syndrome.

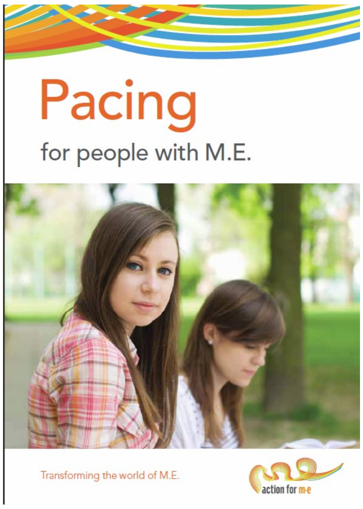
Once fatigue syndrome is established, it is lifelong chronic condition that yet, cannot be cured. The only realistic options are condition management that is lifelong. Considerable improvements can be made to people's lives with the correct strategies in place, but the problem is always there. There may be periods of unpredictable remission and relapse. This is where the work problems begin.

To work or not to work?

Although there are frequent reports of 'Fatigue Syndrome patients being able to sustain par-time jobs, at Leger ME, we don't seem to see people who have successfully carried on working without major problems. When people come to us, it is usually in desperation. Most cases involve people in full time employment who have gradually drifted into ME/CFS. Although there may have been some acknowledgement by employers, and a token effort by employers to meet the needs and obligations for a ME/CFS patient sooner or later there comes a crisis. Problems are commonly around sustainability, and quality of work, and when people are required for work. Even in the case of most willing employer we've often see pressure to perform, and expectation to do work when required. Sooner or later there are disputes, resentment from work colleagues, 'leaning' that result in cat and mouse tactics on both sides. This usually means a work exit strategy is called for. There have been a number cases from one of the biggest employers in Doncaster usually an agency the equivariant of ATOS to manage this sort of problem. I've never seen a satisfactory handling by these thirds party agencies, mainly due to misunderstanding and inaccurate assessment of cases. The actual solution varies case by case.

There are three resources in the group library from Action for ME which are useful, and are reviewed on the following pages.

Pacing for people with ME



'Pacing' is about balancing activity and rest to help manage ME and work towards recovery. Patients and many professionals recognise its value. Pacing yourself when you're ill might sound like common sense, but that doesn't mean that embarking on an effective pacing programme is second nature, or easy. It requires a good understanding of the principles of pacing, combined with commitment to making them work for you. Pacing can help you to take control of your condition and enable you to become an expert in managing your illness. The booklet has been produced with the help of health professionals and people with ME to give you a step-by-step guide. Whether you are following this at home or you are working with a healthcare professional we hope it will help you to pace successfully. The Sheffield ME/CFS Clinic pacing practice very closely follows this publication. Their strategy is based on

.

Contents

NHS guidelines
What is M.E?
What is pacing?
Pacing as part of your treatment package
How can pacing help?
What is the evidence?
What do the professionals say?
Who can pace?

Understanding the basics
Pacing in practice:

- 1. Activity 1
- 2. Rest and relaxation
- 3. Finding a baseline and stabilising activity
- 4. 'Increasing as able'
- 5. Stumbling blocks

Common questions
People with ME discuss pacing

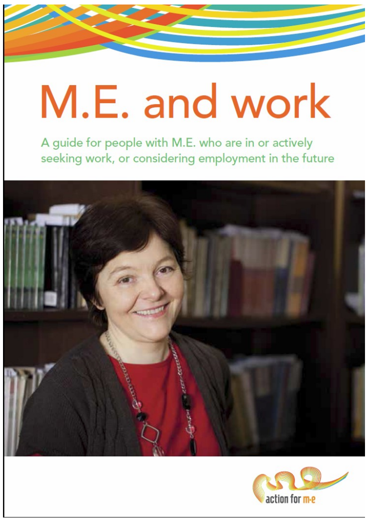
- Adaptive pacing therapy (APT) is a version of pacing that has been found to be helpful in chronic pain disorders. It is usually administered by an occupational therapist.
- CBT is a form of psychotherapy, often administered by a psychologist, which may offer help in finding new ways of coping with the illness.
- GET, which is usually administered by a physiotherapist, is about gradually increasing physical activity from a sustainable baseline level.
- Standardised specialist medical care (SSMC) to solve medical problems.

In the book it states, "We need to recognise that pacing up did not lead to increased function for a significant proportion of the research participants".

Those who did not improve in terms of function may still find pacing and baseline setting to be helpful strategies to:

- improve control over a challenging illness
- reduce the frequency and severity of setbacks
- provide some ability to plan and problem-solve around limited capacity.

ME and work



A guide for people with ME who are in or actively seeking work, or considering employment in the future There is no doubt that ME can have a significant impact upon a person's ability to work. For some, their symptoms are so severe that they are not able to consider working at all, while others may be able to work or volunteer when fluctuating symptoms allow.

Many people of working age are in employment when they first experience ME and this can lead to a challenging and uncertain time. In addition to having to come to terms with symptoms and learning to manage them, there is the worry about how returning to and sustaining work can be managed, or whether their job can be held open.

Losing or being unable to work can have an impact across many areas of a person's life, including income, career development and social life. Work can be an important and meaningful activity, that forms a fundamental part of person's sense of identity. Fortunately, a range of professionals with expertise and experience in the field of long-term health conditions and work can support you to seek, secure and sustain employment wherever this may be possible. Seeking well-informed advice to plan and prepare for success doesn't guarantee it will happen but we have found that, for a lot of people with ME, it has made the crucial difference. This resource aims to offer key information and signposting for people with ME who are in work, considering work in the future or actively seeking work now. We know that, for others, working or training is sadly not an option. Action for ME continues to support these individuals through our other support services.

An employer's guide to ME


An employer's guide to M.E.

Information, advice and guidance for managers and employers supporting an employee with M.E.

The booklet starts by saying ME/CFS is a chronic, fluctuating, neurological illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems. It affects an estimated 250,000 people in the UK, and around 17 million people worldwide. Within the NHS, a diagnosis of Chronic Fatigue Syndrome (CFS) or CFS/ME is often given. ME is sometimes also diagnosed as Post-Viral Fatigue Syndrome (PVFS). This can make can confuse for many. Action for ME uses the terms ME, CFS and ME/CFS because we do not wish to withhold support from those who have been given a diagnosis of CFS, as opposed to ME to keep things straightforward, we use the term ME consistently throughout this booklet. People with ME experience severe, persistent fatigue associated with post exertional malaise, the body's inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms. Not everyone with ME will experience the same symptoms. People with ME can vary enormously in their experience of the illness, and how long their symptoms last. Some make good progress and may recover, while others can remain ill for many years. Some people find that they don't go back completely to the way they felt before they became ill, but they do recover sufficiently to lead happy, fulfilling lives. This is like other chronic illnesses.

Contents

- You, ME and work
- The legal context
- Identifying and communicating what you need
- Positively managing disclosure
- Reasonable adjustments
- Specialist support
- If you are off sick from work
- Return to work planning
- If working isn't working: leaving work well
- If you lose your job (or are about to)
- If you are aspiring to work in the future
- Looking for work
- Money matters
- Useful contacts

As ME is a fluctuating illness, symptoms can vary day-to-day as well as over longer periods. This can make it difficult to maintain a consistent level of working, which can be frustrating and challenging for you and your employer. People who have ME tell us that they, their employer and the people supporting them need more information about how to effectively manage ME at work. This booklet is primarily for people with ME and will be a useful resource for anyone supporting them to achieve their employment aspirations.

This booklet outlines the employment rights and support available for people with ME, as well as providing advice on seeking, returning to or staying in work. It also offers advice on how to leave your job in the best possible way and what you can do if you do lose your job. It provides information relating to welfare benefits and other work-related finances. Throughout this booklet we suggest a range of free, expert, impartial services that you might find useful. They are highlighted in green boxes and you can find further details in 'Useful contacts' on p 41-The legal context

Your employer's legal responsibilities to you as an employee with ME include:

- standard obligations under your contract of employment
- duties under the Equality Act 2010
- responsibilities under the Health & Safety at Work Act 1974.

Information on the law and guidance on reasonable adjustments can be found at www.equalityhumanrights.com/your-rights/employment/ work-place-adjustments

When considering any reasonable adjustment, you should also always find out if they are likely to have any provision of a quiet area where you can have rest breaks without being disturbed.

Unrest Screening at Sheffield University on Tuesday 21 November 2017

Report with Thanks to Michele and Sheffield ME Group

The event was organised through a collaboration between the Sheffield Clinical Academic Society, the Sheffield Academic Medicine Society and UK Producers Shella Films and Together Films.

About Unrest. Unrest world-premiered in January in the documentary competition at the 2017 Sundance Film Festival, where it won a Special Jury Prize for editing. It has since screened at several documentary festivals including River Run (Audience Award for Best Documentary Feature), the Nashville Film Festival (Grand Jury Award for Best Documentary Feature) andDoc/Fest (Illuminate Award). It also has a companion VR piece which the Jury Award for best VR at Sheffield/DocFest earlier this year.

The Plot. The film is about Jennifer Brea, an active Harvard PhD student about to marry the love of her life when suddenly her body starts failing her. Hoping to shed light on her strange symptoms, Jennifer grabs a camera and films the darkest moments unfolding before her eyes as she is derailed by ME (commonly known as Chronic Fatigue Syndrome), a mysterious illness some still believe is “all in your head.”

Action. Time for Unrest is a global impact campaign that seeks to increase awareness, education, research and funding around ME. As the condition is generally not taught in undergraduate medical education and can be misunderstood within the medical profession. Unrest gives a perfect insight into how debilitating ME/CFS can be and an opportunity to discuss the condition with a panel of clinicians and those with first-hand experience, so that they may learn more about it.

Local screening. The event was used to educate and is therefore free to medical students, junior doctors, consultants and other medical professionals.

Copies of Unrest are available through Amazon

The Panel consisted of:

Professor Liddy Goyder – Chair in Public Health with interest in Inequalities in Health and in Access to Health Services
Dr Charles Shepherd - Honorary Medical Advisor to the ME Association
Victoria Strassheim - ME/CFS researcher University of Newcastle
Ms Anne Nichol Sheffield—ME/CFS Service Manager
Ms Diana Shapiro -Carer of severe sufferer
Beatrice Greenfield - Trustee at Sheffield M,E. and Fibromyalgia Group

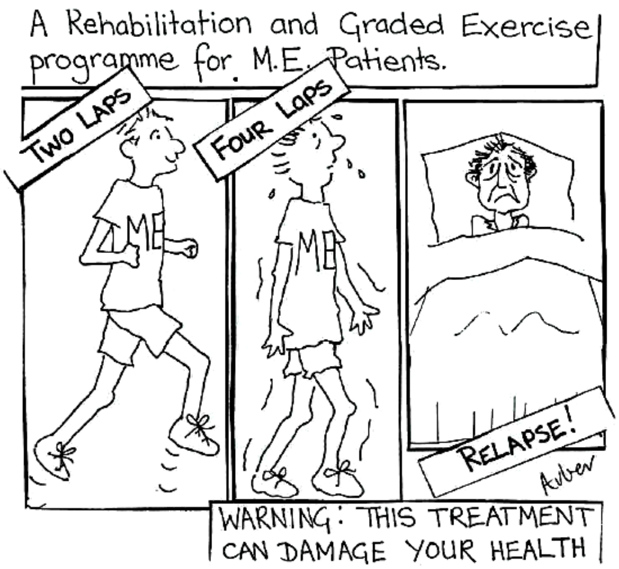
Unrest: ME film premieres at Sheffield Doe/Fes

Reviewed by Hillary from the Sheffield ME Group

The film is 90 minutes long and follows Jen Brea's journey from being an active child and PhD student at Harvard to being struck down with a mysterious and extremely debilitating illness. This followed a very high fever and flu-like symptoms as well as several infections.

The film opens on a black screen with the sound of someone sobbing in the background. The camera then comes into focus and we see Jen struggling to raise herself from the floor and crawling on her belly to get back to bed. Jen is taken to hospital by her husband, who warns her not to say too much, because if she does the doctor's will think it's hysteria and "all in her mind". The film often flashes back to when she was a young student at Harvard and shows photos of her wedding to Omar, a computer scientist. It documents her life as a person with such a debilitating illness she is bed-bound and unable to sit up. She is highly sensitive to sound and light and must wear earmuffs and an eyemask. However, she has had little help from the medical profession and no diagnosis!

Jen decides to make a film diary of herself and to research her illness on-line. This then leads to Jen meeting a whole worldwide community of fellow sufferers. She seeks permission from several of these online friends and their friends and families, to record their day to day lives and stories. The film then shows snapshots of not only herself but those who were bravely willing to show their lives as "The Missing". There are scenes of great compassion, frustration, emotion and personal grief for a life of loss. Loss of family members, friends, relationships, of being unable to have children, of losing hopes and dreams for the future. All this with little or no support from the "Establishment".



The film shows a scene where an eminent scientist proves that there is a root cause to ME/CFS in the Mitochondria. Another, in which a leading Psychiatrist speaks to an audience about how ME is a Psychosocial condition. In the same clip, another Psychiatrist appeals on behalf of people with ME (PWME) and vehemently denies this. Sadly, he is asked to stop speaking by the Chair on more than one occasion. Finally, he must step down, but he receives a spontaneous standing ovation for his stance.

A further scene, records how a young woman from Scandinavia, was physically removed from her home and institutionalised for, I believe, 4 years. This time being spent with absolutely NO contact from her family and friends. Following a protest and subsequent Court Case, the young woman is finally allowed home to live with her family.
The film is often difficult to watch, it is moving and challenging but somehow a beautiful portrayal of the hidden condition which blights so many people's lives. There is also hope, as people throughout the world are getting together to stage organised protests against the recommended treatment and bias towards the Psychosocial model. One such demonstration was "The Missing Millions", when hundreds of pairs of shoes were lined up outside Government and Medical Profession buildings to show what they never see ... the Missing Millions.

The Q&A session following the screening started with a standing ovation for Jen Brea and her team. She sat in a wheelchair but was very relaxed, happy and smiling. She was accompanied by her husband as well as the producer of the film. There were also some of the families who contributed to the film in the audience. One young lady from the UK, Jessica, is housebound but her husband of only a few weeks, "brought her along" by Skype, so everyone could wave and cheer at her!

Jen was asked why she had decided to film herself. She replied that no-one could see her when she was at her worst, so she decided to make a video diary. She wanted to prove that the headlines were wrong and that it wasn't "all in her mind". There were few questions, most just wanted to speak about their frustration in getting the correct treatment and support and how the film has inspired them.

Many of the audience expressed their views in the following quotes:

[The film is] everything you want to say but don't know how."
"You've just filmed my life up there."
"[You've shown] how we're invisible when we are unwell."
"Services let people and their families down."

A lot of the audience were very emotional. Some confessed to crying all through the film whilst most had cried at the emotionally charged scenes. All just wanted to say, "Thank You".

The family of one person with ME spoke about their agony because as Psychiatrists, they were confronted with the same disbelief and denial from their peers as many, when their own child was diagnosed.

Someone spoke about the fact that Doctors do want to help but they are given little or no education in the condition and therefore have no tools to help, other than GET and CBT (which are the UK guidelines now). It was agreed that there is a lack of research into the bio-medical cause, but that when finances are limited, priorities are changed.

One further question was about why no-one had organised a campaign to go to litigation about the insufferable treatment PWME receive. This person gave a call for a combined lawsuit.

Finally, Jen said she hoped that her film would be shown in Medical Schools, Universities, etc., as well as to a wider audience, when it goes on general release in the Autumn.
Hilary (Sheffield ME group)

I would like to arrange a screening of the film in the new year at the Redmond Centre, but the film has not yet been released on DVD. Please let us know if you wish to attend such a screening. Mike.

So why is ME/CFS treated with psychotherapy?

With thanks to the Nursing Times

Psychiatrists have long been interested in attempting to explain the medically unexplained. Sigmund Freud, the father of modern psychiatry, explored the connection between the mind and health. The famous French neurologist J. Charcot believed traumatic life events may bring about a form of hysteria or paralysis in patients; while George Beard put forward the theory of neurasthenia (exhaustion of energy within the nervous system). These theories continue to influence how doctors perceive medically unexplained illnesses, particularly ME/CFS.

Here is a brief time-line of how ME (neuro-immune disease) became CFS (a psychosomatic fatigue syndrome)

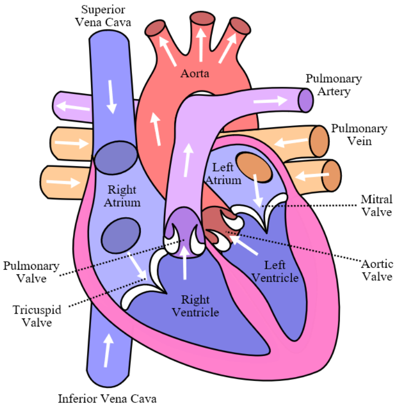
- · 1955: Melvin Ramsay describes a viral outbreak illness among staff at the Royal Free Hospital in London as a post-infectious disease affecting brain, nerves and muscle tissue (Myalgic Encephalomyelitis).
- · 1970s: UK psychiatrists McEvedy and Beard state that ME is nothing more than a case of ‘mass hysteria’.
- · 1980s: A London newspaper runs a story about ME being ‘Yuppie Flu’. Since then, ME has been indelibly linked with stressed-out professionals complaining about exhaustion.
- · 1988: The US Centres for Disease Control recommend replacing ME with a new syndrome (Chronic Fatigue Syndrome).
- · 1990s: UK psychiatrist Simon Wessely argues ME (now CFS) is a biopsychosocial syndrome, partly created by social trends and maintained by the patient’s illness beliefs and behaviours.
- · 2000s: Colleagues of Wessely, including nurse/researcher Professor Trudie Chalder, conduct clinical trials of psychotherapy to treat CFS, including the £5 million PACE trial testing cognitive behavioural therapy and graded exercise therapy.
- · 2007: The UK National Institute for Health and Care Excellence (NICE) conducts a review and recommends CBT and GET for the treatment of ME/CFS.2 This decision is criticised by ME/CFS patient groups who deem CBT and GET inappropriate treatments. In particular, GET attracts much criticism.
- · 2015: A large patient survey finds CBT has little impact on the condition: 74% of patients report that GET makes their symptoms worse, while simple pacing is preferred by patients. Such concerns are echoed in scientific studies that suggest exercise therapy may be harmful, given biological abnormalities found in ME/CFS.

The Leger ME Group members report that CBT and GET do not help and as such Leger ME do not encourage these therapies.

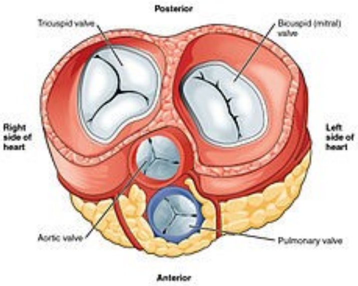
The Heart and ME/CFS Images *curtesy of Wikipedia*

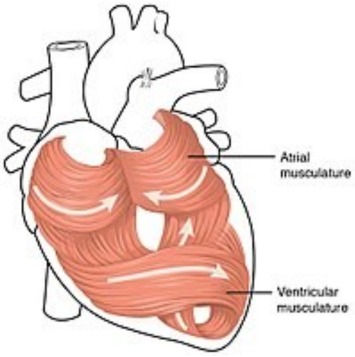
In this feature I'm going to cover common problems experience by Leger Members

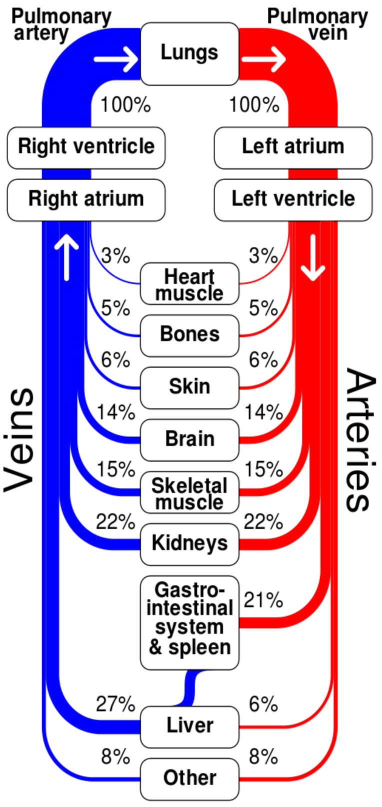
Heart Construction and Function



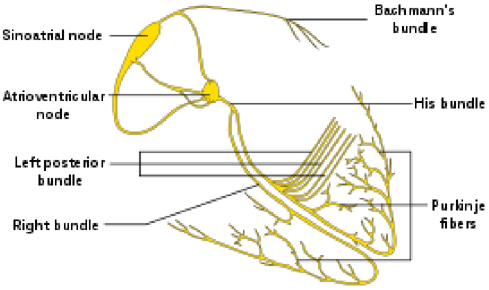
The heart is one of the most long studied body organs. The heart is a bag of specialised muscle which pumps blood around the body. It is a double pump for the circulation with atrial and venous sides. In a normal heart, the atria both contract first, pumping the blood from the veins into the ventricles, effectively priming them. The atria then relax, and the ventricles contract pumping blood into the arties.





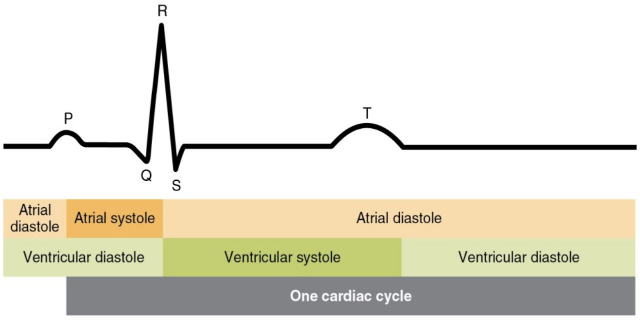


There are four main valves which ensure that blood flows the right way through the circulatory system. The heart muscle divided into atrial and ventricular parts contract separately to facilitate this double pump action. Unlike skeletal muscle and smooth muscle in hollow organs which only contract in on direction, heart muscle contains many branching fibers so that when it contracts, it does so in all directions.



The Heart Beat Cycle

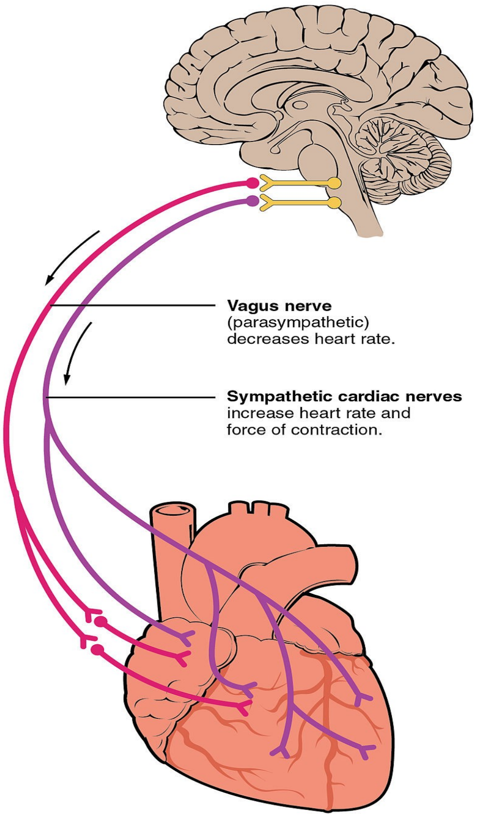
To synchronise the parts of the heart, there is a local neurological network which effectively behaves like the ignition leads in a petrol engine. Doctors detect muscle and neurological activity through an electrocardiograph.



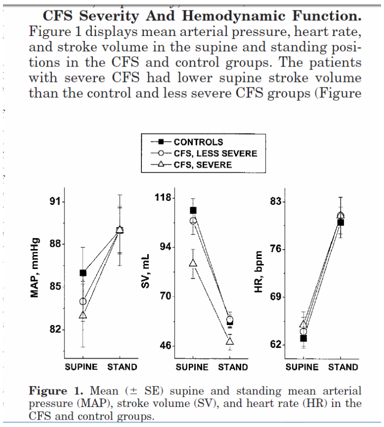
The trace PQRST corresponds to electrical signal, which correspond to the contraction of the atria and ventricles. The medical term Systole is the contraction phase and diastole is the relaxation phase.

Control of the heart

The speed of the heartbeat is under autonomic neurological control from the brainstem. The vagus nerve slows down the heart rate, which is known as bradycardia, and the sympathetic nerves increase the heart rate which is known as tachycardia. The heart rate slows down at rest by parasympathetic vagal simulation. At the same time blood is diverted from the peripheral muscles to the hollow organs to give emphasis to digestion and other normal everyday body housekeeping functions. This corresponds to sleeping and relaxing. Conversely, heartrate is increased via sympathetic nervous system as a response to the need to move around. The body housekeeping functions are slowed down, and blood flow is increased to the skeletal muscles and brain. In primitive man, this is thought to facilitate hunting or fleeing from predators.



The low heart output state *with thanks to Dr. Myhill*



CFS Severity And Hemodynamic Function. Figure 1 displays mean arterial pressure, heart rate, and stroke volume in the supine and standing positions in the CFS and control groups. The patients with severe CFS had lower supine stroke volume than the control and less severe CFS groups (Figure

Figure 1. Mean (± SE) supine and standing mean arterial pressure (MAP), stroke volume (SV), and heart rate (HR) in the CFS and control groups.

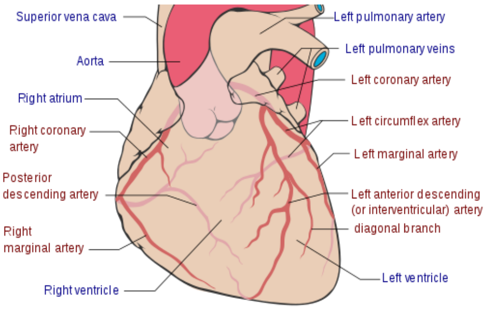
The heart is a simple mechanical pump and to work well it needs a good supply of fuel and oxygen and this is achieved through good blood supply. However, there is a second aspect which is largely ignored by cardiologists and other doctors. The heart needs to be able to convert this fuel and oxygen supply into a usable form of energy for the muscle cells to work. This is achieved by mitochondria. They take fuel and oxygen from the blood and through a complex series of biochemical reactions, including Krebs citric acid cycle and oxidative phosphorylation, they generate ATP, the currency of energy in the body. Each heart cell will hold between 2,000 – 3,000 mitochondria. The reason it needs so many is that the heart never gets a rest – it must work 24/7! Common causes of poor heart function are: -

- Poor blood supply to the heart, e.g. due to arthrosclerosis
- Poor conversion of fuel and oxygen into ATP i.e. Due to mitochondrial failure.
- Not enough blood in circulation. e.g. due to injury or Anaemia.
- Valve problems - i.e. blood leaking back so the heart does not beat efficiently.
- Heart does not beat regularly. Heart Dysrhythmias, Irregular Pulse, Missed Beats and Palpitations.
- Part of the heart muscle has died following a myocardial infarction.
- Magnesium deficiency resulting in diastolic dysfunction. Anatomical abnormalities e.g. Pericarditis and patent foramen ovule.
- The heart muscle itself is diseased - e.g. Cardiomyopathy. It is likely this is caused by mitochondrial failure, so the heart cannot cope with the stress put on to it, e.g. High blood pressure.

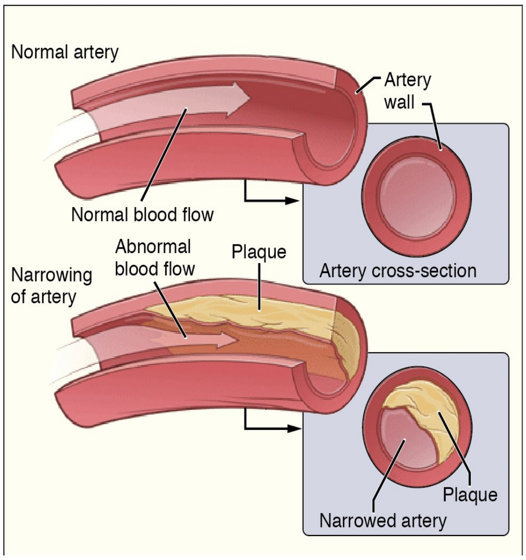
Common problems experienced local by ME/CFS patients

Apparent heart attacks and chest pain.

It is an accepted principle by all doctors that any unexpected or unexplained chest pain MUST be treated as a medical emergency. At group meetings or on the ME/CFS networks I often hear stories of ME/CFS patients being rushed into the local hospital emergency department, via ambulance with blue lights flashing. However, for the majority, after about six hours, and many tests, nothing abnormal is found, and they are sent home. Because some people with ME/CFS have frequent A&E visits, these are viewed as attention seeking people with a mental health problem. Occasionally - real heart abnormalities are found and treated so the problems can’t be ignored.



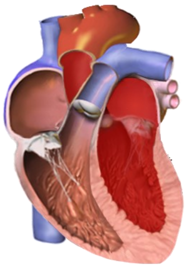
One of the first feeds of freshly pumped blood is the heart itself via the coronary arteries. When the heart contracts it squeezes blood out of itself, so only receives blood a fraction of the time. This makes the heart very vulnerable to circulatory problems. Reduced or blocked blood flow causes cramp like pains which are felt as the typical pain of a heart attack. A common cause of this blockage of the coronary arteries is by plaque or atherosclerosis. If the blockage is partial, temporary relief can be obtained with nitrate type medicines. These work by relaxing (dilating) the smooth muscle within the coronary arteries enabling better blood flow. In more serious cases, anti-coagulant drugs are given, and emergency stents inserted. Plaque can be prevented by reducing cholesterol. Most cardiologists recommend the statin family type drugs. However, a problem overlooked in ME/CFS patients is that statins cause fatigue including that to the heart muscle itself because they deplete Q10 which is part of the energy production. There are reports of unexpected deaths with ME/CFS patients attributed to statins. I’ve dealt with this issue and fixes in previous issues of Pathways.

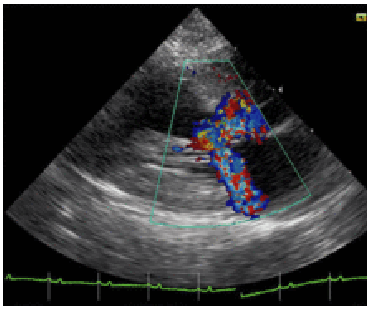


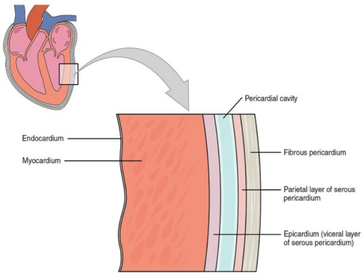
The cause of the false chest pain / heart attacks is most likely due to a temporary blockage in the coronary arteries due to spasm in the muscle walls. This causes angina pain to be felt. Muscle spasm is common in ME/CFS like white finger, fasciculation and myoclonus. The actual fix is rest and them getting the pacing right. There is a type of angina where no anatomical abnormalities are found known as Prinzmetals.

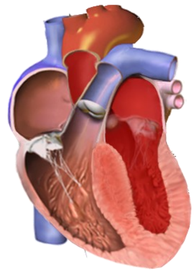
Abnormally Fast Heartbeat (Tachycardia)
Many ME/CFS patients report abnormally fast heartbeats, especially at resting. Heart rate is governed by the balance of the sympathetic and parasympathetic nervous system, and is a response to action or stress. Fast heartbeat can be a sign of anxiety, very often due to White Coat Syndrome or more serious problems like abnormally high levels of thyroid hormones. A fast heartbeat can be a self-compensation mechanism for low output or early failure. With ME/CFS according to Dr. Myhill, the heart muscle needs magnesium to relax - without this it becomes stiff and cannot easily fill with blood during the relaxation phase. This makes it inefficient as a pump because it must work harder. The fix for this is often a magnesium food supplement. Doctors usually treat a fast heartrate with a low dose of a beta blocker like propranolol. Apart from its direct action, some people find it sedating. There are cardio specific betablockers if this is a problem. Very often I find that after a time a doctor will stop beta blocker treatment after no physical heart problems are found.

Thickening of Heart Muscle Wall and Cardiac Atrophy.


Normal






Hypertrophic

When the right side of the heart pumps blood at relatively low pressure, the real workhorse is the left ventricle. The left ventricle myocardium is thicker naturally. Abnormally thickened heart muscle is an adaption like a weight lifter exercises to build muscle. It is usually an unexpected finding after an ultrasound echo cardiogram has been taken for other reasons. This may occur because of high blood pressure, or as a compensation for failure of the muscle itself due to an inherited condition. It is a common finding in highly trained athletes. The thickening is described as concentric, and circular. In ME/CFS this thickening is due to poor energy production within the muscle. It often results in a smaller chamber with knock-on effects of low output like fatigue. There is no easy fix, and many ME/CFS specialists recommend checking Q10 blood levels as a first step. In the USA and Canada, this is an acknowledged problem, whereas in the UK it is not considered. This is different to heart enlargement caused by congestive heart failure. Myocardium thickening which is usually asymmetrical is very often the result of scarring or other damage e.g. from a heart attack.

Heart Rhythm Disturbances (Arrhythmias)

Ectopic heartbeats are extra abnormal beats outside the normal rhythm. The atria and ventricles neural network can lose co-ordination for many reasons and work independently. This can happen in otherwise normal hearts. Mostly these are not serious, but often cause anxiety. However, they need to be monitored for any emerging problems.

More seriousre fibrillation problems. When a heart goes into fibrillation, all the muscle does not contract at once, and can't pump. Heart surgeons when using it as a technique to stop a heart for surgery often describe a fibrillating heart as looking like a bag or worms, quivering or rippling.
Atrial Fibrillation is an irregular and uncoordinated contraction of the cardiac muscle of atria. It can be a chronic condition, usually treated with anticoagulation, statins and medicines to encourage o normal sinus rhythm. In this condition the normal electrical pulses coming from the sinoatrial node are overwhelmed by disorganized electrical impulses usually originating in the roots of the pulmonary veins, leading to irregular conduction of impulses to the ventricles which generate the heartbeat. This is a common cause of strokes, and is vigorously treated by the NHS.
Ventricular Fibrillation is an irregular and uncoordinated contraction of the cardiac muscle of ventricles. It is a common cause of cardiac arrest, particularly in heart attacks and is usually fatal if not treated immediately.

Mistletoe: A botanical curiosity associated with Christmas.

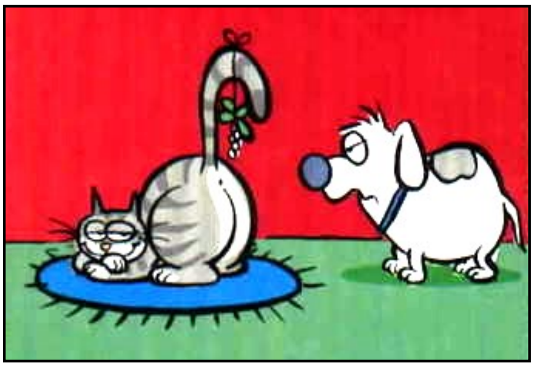
Mistletoe is associated with Christmas as a decoration under which lovers are expected to kiss. Mistletoe played an important role in Druidic mythology in the ‘Ritual of Oak and Mistletoe’. Mistletoe is relevant to several cultures. In Norse Mythology, Loki tricked the blind god Hodur into murdering Balder with an arrow made of mistletoe, being the only plant to which Balder was vulnerable. Some versions of the story have mistletoe becoming a symbol of peace and friendship to compensate for its part in the murder.

Mistletoe continued to be associated with fertility and vitality through the Middle Ages, and by the 18th century it had also become incorporated into Christmas celebrations around the world. The custom of kissing under the mistletoe is referred to as popular among servants in late 18th century England: the serving class of Victorian England is credited with perpetuating the tradition. The tradition dictated that a man could kiss any woman standing underneath mistletoe, and that bad luck would befall any woman who refused the kiss. One variation on the tradition stated that with each kiss a berry was to be plucked from the mistletoe, and the kissing must stop after all the berries had been removed.

No Earthy Root. Mistletoe is the most common name for the obligate hemi parasitic plants. It has no earthy root. Instead, it is attached to a tree or shrub by a structure called the haustorium, through which they absorb water and nutrients from the host plant. The mistletoe seed germinates on the branch of a host tree or shrub, and in its early stages of development it is independent of its host. It commonly has two or even four embryos, each producing its hypocotyl, that grows towards the bark of the host under the influence of light and gravity, and potentially each forming a mistletoe plant in a clump. Possibly as an adaptation to assist in guiding the process of growing away from the light, the adhesive on the seed tends to darken the bark. On having contacted the bark, the hypocotyl, with only a rudimentary scrap of root tissue at its tip penetrates it, a process that may take a year or more. In the meantime, the plant is dependent on its own photosynthesis. Only after it reaches the host's conductive tissue can it begin to rely on the host for its needs. Later it forms a haustorium that penetrates the host tissue and takes water and nutrients from the host plant.

The white berries of Mistletoe have been tried in some European traditional medicines. However they are very poisonous.

Most mistletoe seeds are spread by birds that eat the 'seeds' (called drupes). Quite a range of birds feed on them, of which the mistle thrush is the best known in Europe. Depending on the species of mistletoe and the species of bird, the seeds are regurgitated from the crop, excreted in their droppings, or stuck to the bill, from which the bird wipes it onto a suitable branch. The seeds are coated with a sticky material called viscin. When it touches a stem, it sticks tenaciously. The viscin soon hardens and attaches the seed firmly to its future host, where it germinates and its haustorium penetrates the sound bark. Although found on many trees, cultivated mistletoe is grown on apple trees.



Midwinter Holiday, Yuletide and Christmas Season Act, 1974

NOTICE IS HEREBY GIVEN compliance of these guidelines is advised in order for you to fully participate with the festive spirit.

1) Please be advised that those who dash through the snow in a one-horse open sleigh, going over the fields and laughing all the way are required to undergo a Risk Assessment addressing the safety of open sleighs. This assessment must also consider whether it is appropriate to use only one horse for such a venture, particularly where there are multiple passengers. Please note that permission must also be obtained in writing from landowners before their fields may be entered.

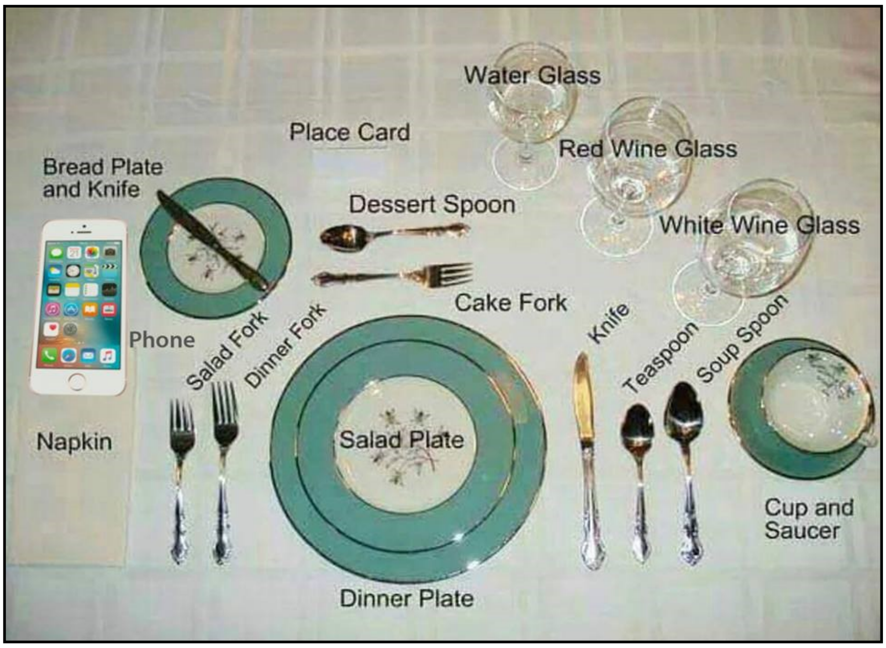
2) To avoid offending those not participating in celebrations, we request that laughter is moderate only and not loud enough to be considered a noise nuisance.

3) Benches, stools and orthopedic chairs are now available for collection by any shepherds planning or required to watch their flocks by night. While provision has also been made for remote monitoring of flocks by CCTV cameras from a centrally heated shepherd observation hut, all facility users are reminded that an emergency response plan must be submitted to account for known risks to the flocks.

4) The angel of the Lord is additionally reminded that prior to shining glory all around he/she must confirm that all shepherds are wearing appropriate Personal Protective Equipment to account for the harmful effects of UVA, UVB and the overwhelming effects of Glory Halo.

5) Following last year`s well publicised case, everyone is advised that EC legislation prohibits any comment regarding the redness of any part of Mr. R. Reindeer. Further to this, exclusion of Mr. R. Reindeer from reindeer games will be considered discriminatory and disciplinary action will be taken against those found guilty of this offence.

6) The table setting for seasonal meals must comply with the following picture to the right. Please note that the correct placing of the phone is below and slightly to the left of the bread plate.



7) While it is acknowledged that gift-bearing is commonly practiced in various parts of the world, everyone is reminded that the bearing of gifts is subject to Hospitality Guidelines and all gifts must be registered. This applies regardless of the individual, even royal personages. It is particularly noted that direct gifts of currency or gold are specifically precluded under provisions of the Foreign Corrupt Practices Act. Further, caution is advised regarding other common gifts, such as aromatic resins that may initiate allergic reactions.

8) Finally, in the recent case of the infant found tucked up in a manger without any crib for a bed, Social Services have been advised and will be arriving shortly.

By order

Administration Risk Management Team

Recipe Corner by Carolyn

Spicy Turkish kebabs with `Ezme` salad. Serves 4

Cooking and Preparation method.

Cut the chicken into chunky 3cm (1 1/4in) pieces, in a bowl, mix the olive oil, tomato purée and red pepper paste together, then stir in the rest of the ingredients and the chicken. Cover and leave to marinate at room temperature for 30 minutes or at least 2 hours in the fridge.

To make the Ezme salad, finely chop the green pepper, cucumber, red onion and tomatoes. Mix in the crushed garlic, scoop into a sieve set over a bowl and leave for 30 minutes until most of the excess liquid has drained away.

Shortly before you are ready to cook, preheat a barbecue or non-stick, ridged cast-iron griddle or griddle pan until hot, then lower the temperature to medium. Thread the pieces of marinated chicken onto 4 metal skewers. Barbecue or griddle for 12-15 minutes, giving them a quarter turn every 3 minutes or so, until the pieces of chicken are browned and cooked through, but still moist and juicy in the centre.

Tip the chopped vegetable mixture into a bowl and stir in the rest of the Ezme salad ingredients and some black pepper to taste. Serve with the kebabs and some whole-wheat couscous on the side.

Nutritional values per serving:

Energy 428 kcal
Protein 36.8g
Fat 12.7g
Saturated fat 2.3g
Carbohydrate 42.3g
Sugar 5.8g

For the kebabs:-

500g (1lb 2oz) skinned boneless chicken - thighs and breasts
2 tbsp olive oil
1 tsp tomato purée
1 tsp Turkish red pepper paste
½ tsp coarsely ground black pepper
½ tsp dried chilli flakes
1 tsp chopped fresh thyme leaves
1 tsp Aleppo pepper OR, ½ tsp sweet paprika
1 ½ tbsp chopped fresh mint leaves
600g (1 lb 30z) steamed whole-wheat couscous, to serve.

For the Ezme salad:-

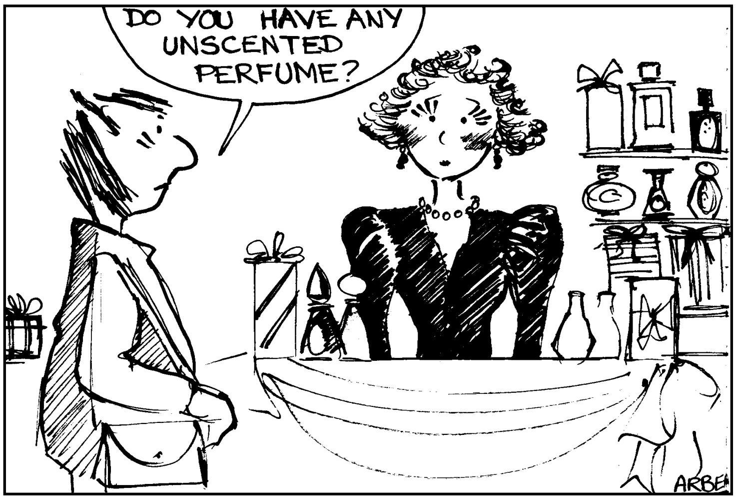
½ large green pepper, seeded
¼ large cucumber, peeled, halved and seeded
1 small red onion
225g (8oz) vine-ripened tomatoes, skinned
1 fat garlic clove, crushed
1 tbsp extra-virgin olive oil
1 ½ tsp red wine vinegar
½ tsp Aleppo pepper or a pinch of chilli powder
1 small bunch of fresh flat-leaf parsley, chopped
Leaves from 2 fresh mint sprigs, chopped
Freshly ground black pepper

* * *

Two ME specific problems at Christmas.

A high proportion of people with ME are abnormally sensitive to Volatile Organic Compounds (VOC). Toiletries and perfumes unfortunately contain VOC's a high proportion.

Likewise a high proportion of people with ME are abnormally sensitive to certain foods, which can exclude them from the Christmas festivities.



BDA The Association of UK Dietitians

Food Fact Sheet

Eat well, spend less

It is getting more expensive to live in the UK making it difficult to eat healthily. This Food Fact Sheet will give you some ideas to help you eat well and spend less.

Ten money saving tips

1. Plan ahead, write a shopping list and avoid impulse purchases.
2. Cut food waste by eating leftovers from your evening meal for lunch or freezing for the following week.
3. Look out for weekly fruit and vegetable deals at superstores, markets and local shops.
4. Cut your meat – swap for pulses (beans, lentils and peas) and vegetables for example when making spaghetti Bolognese, replace the mince with tinned chickpeas, lentils or kidneys beans and add frozen vegetables.
5. Use leftover vegetables from your evening meal to make soup for lunch the next day – simply pop in a pan with a stock-cube, cover with water and cook on a low heat for 10 minutes, then blend or eat it chunky with some wholemeal or seeded bread.
6. Try superstore value brands, which often taste just as good for a lower price.
7. Try tinned or frozen fruit and vegetables – buy fruit in natural juices/water instead of in syrup when you can, to avoid extra calories from the added sugar.
8. Rely less upon 'ready' or manufactured food like takeaways or processed meats and cook from scratch. Look at the resource list (*turn over*) for where to find easy, healthy low-cost recipes.
9. Ask members of staff at local supermarkets for fresh food reduction times to grab a bargain. Use within date or freeze for later.
10. Buy some dried herbs and spices, for example chilli powder, paprika and mixed Italian herbs – they are not expensive and they add great flavour to simple homemade dishes.

5-a-day for 50p

Look out for seasonal fruit and vegetables like strawberries in the summer or root vegetables (parsnips, beetroot or swede) in winter as they are widely available and less expensive when in season. When comparing prices of packaged and loose fruit and vegetables use unit pricing as it shows the price of a food for a specific unit of weight (or volume).

For example bananas cost 68p/kg. Unit pricing also helps you to compare the cost of one portion of fruit or vegetable to another. For example:

1. Fresh carrots approximately 5p per 80g portion (unit price 59p/kg).
2. Tinned garden peas approximately 5p per 80g portion (unit price 21p/300g tin).
3. Frozen broccoli florets approximately 10p per 80g portion (unit price £1/907g bag).
4. Small banana approximately 10p per 80g portion (unit price 68p/kg).
5. Frozen fruit salad approximately 20p per 80g portion (unit price 90p/450g bag).

(One portion of fruit or vegetable is 80g. The above prices may vary from shop to shop and over time.)

Recipes *(serves four)*

Homemade Apple Crumble

Ingredients

150g plain wholemeal flour
75g reduced-fat spread, cold, cut into small cubes
75g sugar, plus extra to sprinkle on the fruit
3 cooking apples, peeled, cored and sliced
pinch of cinnamon

Method

1. Put flour, sugar and reduced-fat spread into a bowl; rub together using fingers until you have a mixture like breadcrumbs.
2. Preheat oven 180°C/gas mark 5. Put the apple into an oven proof dish, and add sugar to taste.
3. Sprinkle the crumble topping over the fruit and bake for approximately 30 minutes until golden brown.

Vegetable and Lentil Soup

Ingredients

1 medium diced onion
2 diced garlic gloves
2 tsp cooking oil
400g vegetables (for example potato, carrot, swede, broccoli - seasonal choices, frozen, tinned or leftovers)
1 vegetable stock cube made up with 750ml boiling water
400g tin of lentils (drained)
2 tsp dried ground cumin
½ tsp dried ground coriander

Method

1. Fry onion and garlic in the oil in a large saucepan for 5 minutes until soft.
2. Add the spices and fry for a further 1 minute, stirring continuously.
3. Add the remainder of the ingredients, bring to the boil and then simmer for approximately 20 minutes (time may vary depending on vegetable type e.g. raw or pre-cooked).
4. The soup can be served chunky or blended with a pitta bread roll or wrap.

Menu overleaf

Meal plan – feed a family of four for £5 a day

This menu offers meal and snack ideas for a family of four to eat for approximately £5 (£1.25 per person) and is colour coded to match the different sections of the eatwell plate.

The menu is based on portion sizes given on the packets. It is important to follow these portion sizes as they prevent you eating extra food, helping you stay a healthy weight and save money. The menu has money saving tips, for example using supermarket value brands, soup made from leftover vegetables, and cooking simple low-cost meals from scratch.

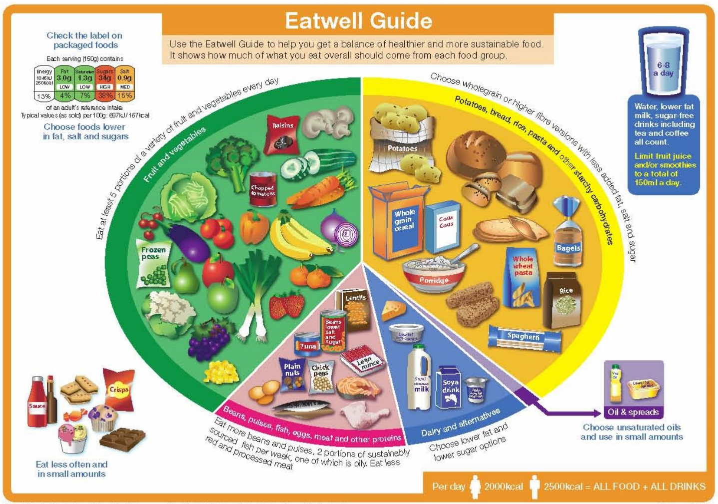
It is only a two-day menu plan, it is important to eat a variety of different foods, have a couple of meat free days in a week and not rely upon processed foods – cooking from scratch is the best way. We have provided two recipe ideas for you to try at home (*overleaf*), they are quick and easy to make and are mentioned in the meal plan.

Key

Green	🍏	**fruit and vegetables**
Yellow	🍞	**potatoes, bread, rice, pasta and other starchy carbohydrates**
Blue	🥛	**dairy and alternatives**
Pink	🍗	**beans, pulses, fish, eggs, meat and other proteins**
Purple	🍪	oils and spreads and other foods and drink high in fat and/ or sugar

Meal	Weekday Menu		Price	Weekend Menu		Price
Breakfast	**Value cereals – wheat biscuits/ porridge/cornflakes with skimmed milk**	🍞 🥛	40p	**Egg (poached scrambled or boiled) or baked beans or cheese on toast with butter**	🍗 🍞 🍪 🍏 🥛	60p
Snack	**Banana**	🍏	40p	**Apple**	🍏	80p
Lunch	**Falafel and houmous/tuna and sweetcorn or cheese spread and cucumber sandwich with two slices of 50/50, wholemeal or granary bread**	🍗 🍏 🥛 🍞	80p	**Homemade vegetable and lentil/tomato and herb/pea soup with pitta/slice of bread**	🍏 🍗 🍞	£1
Snack	**Carrot and cucumber sticks with houmous**	🍏 🍗	50p	**Malt loaf with spread**	🍪	30p
Evening Meal	**Jacket potato and salad with cottage cheese or baked beans or tinned sardines in tomato sauce or coleslaw**	🍞 🍏 🥛 🍗 🍪	£1.90	**Tuna/sardine/cheese and tomato pasta bake with frozen broccoli florets and tinned garden peas**	🍗 🥛 🍏 🍞	£1.30
Pudding	**Fruit salad using tinned fruit with low fat yoghurt/rice pudding or jelly**	🍏 🥛	£1	**Homemade apple crumble or fruit yoghurt**	🍏 🍪 🥛	£1

The eatwell guide (below) is a handy guide to show you how much you should eat from each food group for a healthy balanced diet.



Source: Public Health England in association with the Welsh government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

© Crown copyright 2016

Summary

Making the simple changes in this Food Fact Sheet will help you to save money, eat well and contribute towards a balanced diet and lifestyle.

Further information: Food Fact Sheets on other topics including Healthy Eating are available at www.bda.uk.com/foodfacts

Useful resources:
British Heart Foundation *Healthy Eating on a Budget* www.bhf.org.uk; www.Eat4Cheap.co.uk; www.lovefoodhatewaste.com; and supermarket monthly magazines.

Written by Alexandra Harper, Leanne Mc Dowell, Laura Hensley and Hannah Johnston, dietitians. Supervised by Dr Anne Coufopoulos, dietitian. Reviewed by the BDA Communications and Marketing Board.
The information sources used to develop this fact sheet are available at www.bda.uk.com/foodfacts

Health & care information you can trust
The Information Standard Certified Member

BDA

North of Doncaster *Personal comment by Trevor Wainwright*

A travel diary to the Holy Land Part 4:

We drove first to the Mount of Olives to the church at Bethpage where Jesus started his Palm Sunday journey into Jerusalem, we walked in, there was a service going on, so after a brief look at the mural above the altar depicting Palm Sunday we left quietly. It was raining heavily which put paid to the plan to walk the Palm Sunday route, which would have taken us back over the valley. So, it was to the Church of the Pater Noster a Roman Catholic church part of a Carmelite Monastery', also known as the Sanctuary of the Eleona (Greek for olive grove) the traditional site of Christ's teaching of the Lord's Prayer, A small prayer that says so much, and applicable to all whatever language, this was apparent as we entered the courtyard.

The first two languages I saw were Armenian and Hebrew; which were on the walls and in many other languages too, we would hold our service in the church due to the rain. The sanctuary part was indicated by the words “Oratoire des Carmelite”. Next to these words was the cave where it was said Jesus taught the prayer, it fitted so perfectly with “The Sanctuary of the Olive Grove”. There was time for a short look round before we once more headed out into the rain and looked across the valley to the old walled city where we could see the Dome of the Rock and hear incantations of Muslims going to prayer, fellow pilgrims following their own faith. Watching the rain fall I was reminded of Jesus making his way to Jerusalem and weeping over its impending fate. It was as if the heavens were weeping for its fate today as a divided city.

We then got back on the bus and made our way to the Church of All Nations, so called after many nations had contributed to its construction. Like many of the churches it had been built over the ruins of previous ones, dating back centuries. The rain had eased of and we got off the bus to the sound of a young man playing a shofar, (rams horn) used for the Jewish call to prayer. We crossed to the road to the Church the pinkness of its stone is said to represent the blood and sweat of Jesus, built on the spot where Jesus prayed in the “Garden of Gethsemane”, with the imposing frontage consisting of three archways above which was a mural of Jesus with his disciples, and two side arches completed the porch.

The main entrance had an olive tree design and a notice asking for silence. The door was flanked by two large windows made of violet-blue alabaster as were all the windows subduing the natural light to give an atmosphere of sorrowful reverence. We walked towards the nave and to the Rock of Agony, said to be the rock on which Jesus prayed. Surrounding the rock is a circle of thorns made of wrought iron. A mosaic in the main apse symbolizes Christ's suffering and being comforted by an angel.

More representations of occurrences in Christ's Passion, like his arrest and the Kiss of Judas can be seen in the two side apses. We knelt and touched the stone for a few moments each with our own thoughts. We quietly left the church; outside the sun was now shining as if a sign that all was well. Then it was to the ‘Garden of Gethsemane’ and to wander by the olive trees which may well have witnessed the event over 2000 years ago, the olive tree doesn’t die its bark splits and a new tree grows from inside. Already my mind was working overtime as to how I would get it all down, there would be more writing on the bus. Being in the garden was such that I remembered a verse from a poem I read in Scotland years ago on Seil Island, written by a poet called C John Taylor.

“Strong Olive Trees are growing yet, which stand in rows for all to see

Sharing a sadness non can forget, in the Garden of Gethsemane”.

The weather was turning as we boarded the bus, it began to rain as we drove off and headed down the Kidron Valley, time for one last look at the Church and above it a Russian Orthodox church with its golden onion like domes shining despite the rain on the tops of its towers. We drove past Potters Field remembering how it was bought with the money Judas returned to the Pharisees, and how it was a burial place for strangers with no way home. I wondered where Judas was buried.

At our next stop, the rain had stopped and set out on a walk as if following in the path of a couple

Picture 1 The Lords Prayer in its original languages in he Church of the Pater Nostre

Picture 2 The centrepiece of the church said to be where Jesus taught his disciples The Lords Prayer

Picture 3 The stone at the Church of All Nations where a troubled Jesus prayed, known as the Stone of Agony

Picture 4 Outside sculpture of Jesus at prayer watched only by the olive trees, his disciples were asleep

Picture 5: The door of humility, created in Ottoman times. The low door deliberately makes visitors bow on entry.

Picture 6: The manger from what may have been where proud parents sat watching the Shepherds visiting

Picture 7: Inside the Shepherds cave at the Shepherds Fields

Picture 8: Looking at Bethlehem from the Shepherds Fields

depicted in a mosaic we passed, Joseph and Mary. We too were on our way to Bethlehem. A second mosaic showed the immaculate conception and we were on our way to see the result, or rather the place of the result, the site of the Holy Birth. A sign denoted the way, much different than the star on the night Jesus was born.

The Church of the Nativity in Manger Square was opposite a Mosque where Muslims were at worship. It is a large drab grey building; scaffolding was up showing restoration work going on outside. Entry to the church was through The Door of Humility, a small rectangular opening created in ‘Ottoman’ times to prevent carts being driven in by looters, and all visitors having to bow on entry. Inside and down some steps into the ‘Grotto of The Nativity’ and I was there, the place of the Holy Birth.

We knelt and touched the star on the floor which depicted the traditional site where Jesus was born, then to The Chapel of the Nativity and the manger as the first visitors may have seen it, all that was missing was the baby Jesus. It was ornate but not over the top although, I would have preferred to see it in all its simplicity. Emotions under control I sat looked at the manger remembering how I felt when I became a dad for the first time. I wondered what I would have done had I been there, and so another poem formed in my head. We left the chapel and looked round the church.

Silver star marking the place where Jesus was born according to Christian tradition

Although beautiful it still had me thinking was it really needed. Like most churches it had been built on the site of a previous one. The scaffolding for the inside restoration did not detract from the inner beauty. I thought as I looked up at a mosaic of what appeared to be the disciples, under restoration and of a well preserved 4th Century mosaic floor also in the nave. Then time for lunch, after which I would be somewhere else I have wanted to be for a long time.

After lunch it was raining again. We reached our next destination, the village of ‘Beit Sahour’ to the East of Bethlehem. Walking through an arched gateway, a stone plaque bore the words “CAMPO DIE PASTORI” whilst on the archway “GLORIA IN EXCELSIS DEO” we were at Shepherds Field. We walked along the path to a fountain, its centrepiece being a Shepherd watching over his sheep. On the centrepiece and on the base were the words from Luke 2. 8-14, the story of the angels telling the shepherds the news of the Holy Birth. To the left were some excavations of a 4th century monastery amongst which were provisions for outdoor services and Bethlehem was about a mile away. We carried on to where the see which the shepherds would have sheltered in.

The caves had been made fit for purpose as small chapels for worship we held a small service in one of them sheltering from the rain, on a small ledge we saw the nativity scene. Following the service, we went into the Chapel of the Angels. From the outside, it didn’t appear to be anything unique, a small domed building with an angel above the door and three bells above that. A three-bell set up that reminded me of St Michael’s; its modest look, said to be appropriate, given the humble birth of Jesus that took place in nearby Bethlehem.

Inside the pilgrim is treated to wonderful artwork each wall displaying part of the birth narrative from the New Testament Luke 2. In one picture, the angel can be seen to proclaim the *good news* to the shepherds, the expressions on the faces of the shepherds being captured in great detail. The next painting to the right was a scene of the manger. A classic depiction of Mary and Joseph by manger, with the shepherds arriving to observe this miracle. Additional paintings on adjacent walls further the Christmas story in beautiful detail.

To me it was the least commercial site we had visited and beautiful in its simplicity as if like the shepherds it had very little, but that was all it needed. As we left I took a last look at Bethlehem across the valley, wondering how long it would take today to find Jesus; birthplace. What was at the time a shed in the back yard of a pub where it all began. *To be continued...*