



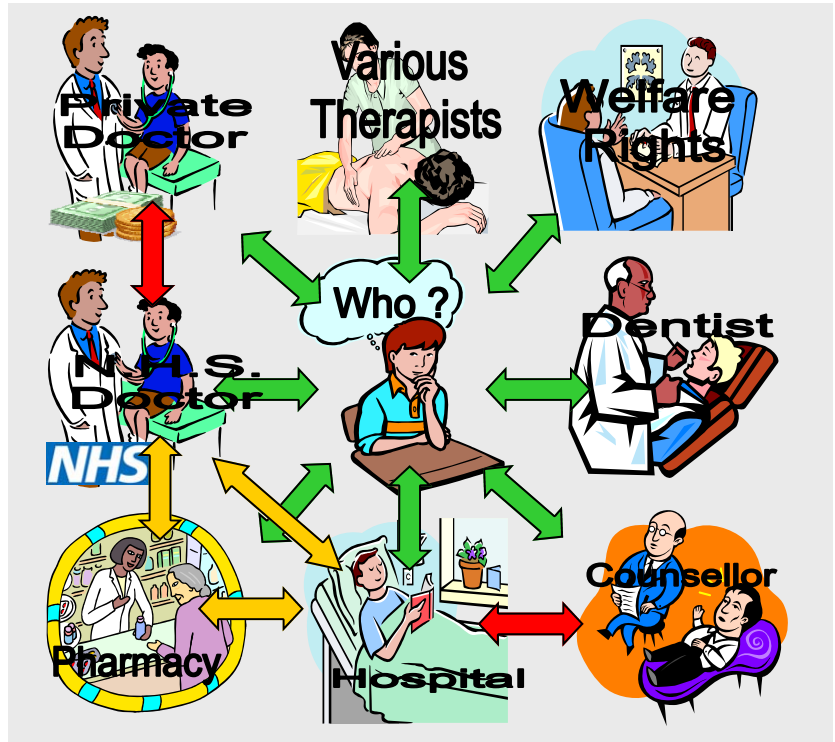
Pathways

Price £ 2.50 (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.

Communicating Between Different Healthcare Providers.

What is quite certain is that many members are experiencing problems when information has to be transferred concerning their healthcare. It is quite common for NHS doctors, private doctors, hospitals etc not to pass on relevant information to each other. Really the only person that knows your healthcare details is you. This is not helped by hospitals and doctors using different information technology systems and there is no common interface. So over the page for hints and tips on how you can overcome this problem while the NHS gets its act together. See page 2.

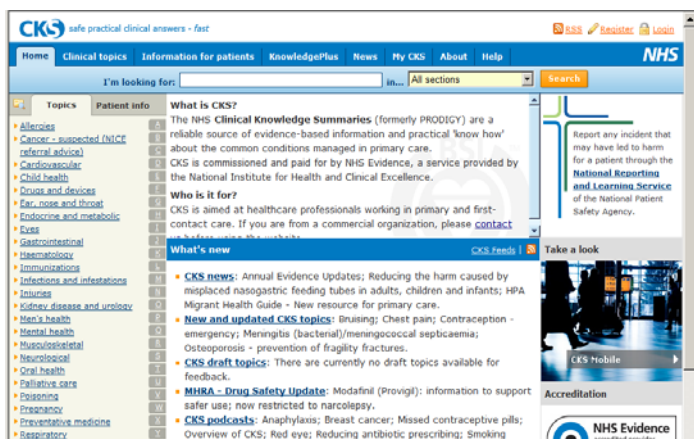


ME/CFS & The ESA 50 3/11 Section 10 'Staying Conscious When Awake'

The law says one thing, the DWP seems to imply something different. See page 5.

The CKS Website Reviewed:

This website carries NHS information about ME/CFS. See page 12



**North of
Doncaster:
Personal
American Travel
Diary - See page 21**

**Clouds
Community
Counselling**



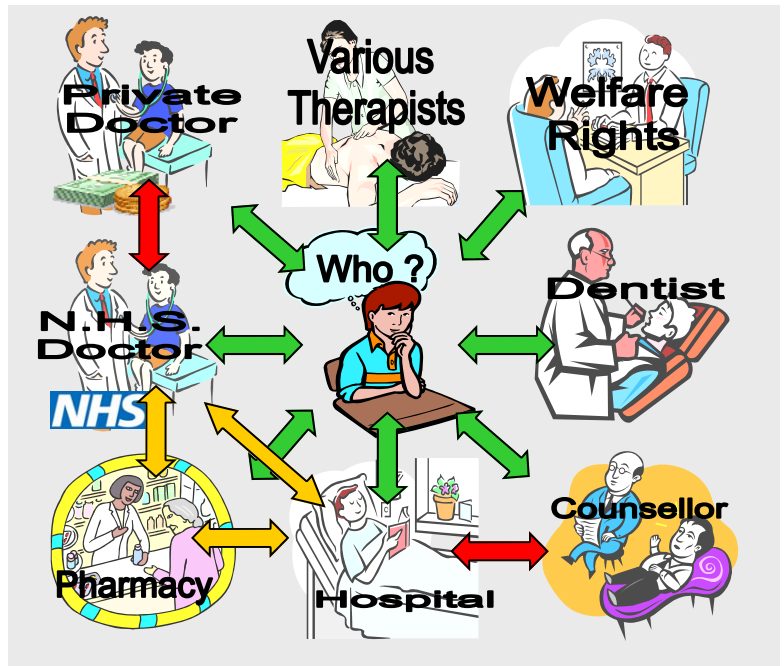
New Services Available -
See page 7

Communicating Between Different Healthcare Providers.

How do you get your health information right when you are dealing with different health care providers? When you see someone else about your care, for example if you go into hospital, it is important that information about any conditions, medicines and therapies you are using goes with you too. Different people take responsibility for your healthcare care in each place. Some places where you will meet them include:

- A planned visit to hospital, e.g. for an operation
- Being admitted into hospital as an emergency
- Visiting a specialist in an outpatient clinic
- Visiting a walk-in centre or a community pharmacy
- Leaving hospital and moving into short term care before going home
- Going home again after hospital
- Going into respite care home after hospital
- Going into respite care
- Seeing a private doctor or therapist

In all of these cases, the person taking over responsibility for your care needs accurate, up-to-date information about your health situation. Health professionals and carers, as well as the places providing your care, should have safe systems in place to make sure they have an accurate record of the medicines you are taking. Unfortunately this doesn't always happen, particularly with private or non-NHS service providers.



There are things that you can do for yourself (or your carer) to help to make sure that the people looking after you get your health information right.

- Know what medicines you are taking and why. If a change is made to any of your medicines or treatments ask why.
- Keep a complete and up-to-date list of all your medicines and treatments. Take it, and your medicines, with you if you are going into hospital or if someone else is taking over your care.
- Only keep the medicines that you are currently taking.
- When you go into hospital your medicines should be checked within 24 hours of your arrival. If this doesn't happen, ask a health professional when it will be done.
- If you have any worries about your medicines, including how to take them, ask if the hospital pharmacist will check them for you.
- If you are being discharged from hospital, you should expect your medicines and treatments to be explained to you before you leave.
- Once you are at home, check that your GP and any other person concerned with your healthcare knows about any changes to your medicines.
- Ask your local pharmacist for a 'Medicines Use Review' (known as an 'MUR') to make sure that you understand the changes fully.
- Above all, if you are unsure about your medicines or treatments, don't be afraid to ask for help.
- If you can't find anyone else to ask, call NHS Direct - or members can call the Leger ME helpline.

We can help with a Case Review. The first two pages of this will list basic health data and interventions e.g. medicines & treatments. This is the sort of information needed when transferring between different healthcare providers and is useful when dealing with DWP forms. Ideally a Case Review or MUR should be done once a year or after any major change in therapy or treatment.

—Mike.

You Write

Lynn writes: I use Boots 'Sleepeaze' on a regular basis, and find that it is very good for getting me off to sleep. Recently I was on holiday and I ran out. I went to the local seaside Pharmacy where they recommended 'Nightcalm'. They told me that they are exactly the same but cheaper. But I tried them and they didn't seem to work as well, so when I got home I went back to Boots and bought another pack of Sleepeaze. I'm confused—was the guy in the seaside chemist wrong?

We checked these products. We have printed the boxes received. Looking at the small print the product licenses are the same product (PL16028/0010), so I would say that the guy in the seaside Pharmacy is right. The tablets themselves and the packaging are identical except for the printing. 'Nightcalm' is made by a local pharmaceutical manufacturing company with its head office in Barnsley. They supply 'Nightcalm' to independent pharmacies. I suspect that the Boots 'Sleepeaze' are manufactured under contract for Boots, with their logo and pack dressing. Boots is a big high street chain. The prices for their products tend to be set by their head office in Nottingham. Big well lighted stores and a head office have to be paid for, whereas most local Pharmacies have a small office in the back and have less overheads—so they can charge a cheaper price and in most cases set their own price. I'm not as sure as to one product being better than another. You are familiar with the Boots brand, and I suspect that you had a degree of mild anxiety which stopped you from sleeping as well because the name and the colour of the box was different. Brand names, trademarks and particular colours are used by manufacturers to distinguish their products from those of their competitors. All traders use these devices which are protected by law. A brand name can be worth millions. The two products under discussion are similar to 'Nytol', which was more heavily advertised and more expensive. There is a bright shiny furniture store on Carcroft High Street near where we meet. I have found the same furniture at the 'Elephant' shop very much cheaper. So 'you pays your money and you makes your choice'.



Getting back to the first question. If you read the instruction leaflet you will find that the active ingredient is diphenylhydramine. This is a sedating anti-histamine which has been around for many years, and has a good safety record. There is no doubt that it will help you sleep—but very often the drowsiness persists over to the following day—so you would have to be careful the following morning, especially if driving. While very effective, these medicines are not really intended for long term treatment. I do appreciate that the cost is cheaper than a prescription charge. I do think you really should be looking at your sleep problems with your doctor as part of the ME/CFS management package. You might find your doctor can prescribe more appropriate medicines that are prescription only.

Gwen Writes: Many thanks for the support letter for when I recently went into hospital for an operation. Your letter certainly had the anaesthetist doing some research and was very useful to the nursing staff. I am home now and recovering. ME-wise, of course it has caused a rebound as expected, but it is nice being home.

We wish you well with your recovery, Gwen.

For the benefit of 'Pathways' readers, Gwen's letter brought three points to the hospital's attention. Firstly an ME/CFS patient takes about twice as long to recover from anaesthesia as most patients and may suffer a rebound as a result of the surgical procedures. Secondly, with ME/CFS there may be problems with HPA axis impairment which the anaesthetist needs to know about and be prepared for. Thirdly the Sheffield hospitals have nursing guidelines which we printed out and Gwen took with her to the hospital.

A copy of the Sheffield hospitals' nursing guidelines for ME/CFS is printed under the 'News from Fairlawns' feature later in this Pathways.

Information Received from HSBC

HSBC are our bankers and occasionally we receive information from them. Here are two features that should be relevant to everyone.

Boiler Room Scams - what they are and what to look out for

What is a Boiler Room?

Boiler Rooms are businesses that use high-pressure sales techniques to sell 'sure thing' investments with the promise of massive returns. In fact, what they're selling is worthless stock in often unquoted companies that are either overvalued, or simply don't exist at all.

How they work

Boiler Room operatives generally cold-call their targets, using phone numbers from publicly available shareholder lists. Because it's against the law to cold-call investors in the UK, they tend to be based abroad (often Spain, Switzerland, or the US) where they're beyond the jurisdiction of the Financial Services Authority (FSA). They can approach anyone, anywhere.

Boiler Room techniques

A Boiler Room can look and sound legitimate. They may mention companies you've heard of, give themselves a UK address or phone number, and have a professional looking website. They're notoriously persistent, and can hound a victim for months in the hope of a sale, catching out even seasoned investors. According to the FSA. Boiler Room Scam victims lose on average £20,000. Remember, as a general rule, if an opportunity sounds too good to be true, then it almost certainly is.

What to do if you're called.

If you think you're being targeted by a Boiler Room, the FSA's advice is not to worry about being polite, just hang up. You should then dial the FSA contact centre on 0845 606 1234 with as much detail as you can remember. You'll find more information about Boiler Rooms on the FSA website www.fsa.gov.uk. If there are any other problems, please contact your bank.

Cheques dated after 30 June 2011 will no longer be guaranteed

A guaranteed cheque is simply a cheque that is guaranteed up to a certain amount. It has to be signed in front of the person receiving it, who writes the card number on the back of the cheque in accordance with the scheme rules.

How this affects you

If you accept guaranteed cheques, you can still accept cheques, although payment won't be guaranteed. This means that if your customer doesn't have enough money in their account to cover the cheque, it may be returned to you unpaid, for which there is a charge. There are plenty of alternatives - debit cards, credit cards, charge cards, electronic payments and cash. A lot of businesses already accept plastic card payments.

If you write guaranteed cheques

This means that you can continue to write cheques after 30 June 2011, they're just not guaranteed. There are plenty of alternatives - debit cards, credit cards, charge cards, internet and telephone banking, Standing Orders, Direct Debits, bank transfers and cash.

Why the Cheque Guarantee Card Scheme is ending

Since guaranteed cheques are being used less and less, the Payments Council decided to close the UK Domestic Cheque Guarantee Card Scheme on 30 June 2011. This will affect customers (whether individuals or businesses) of all banks across the UK.



ME/CFS & The ESA 50 3/11 Section 10 Query.

I have had queries from various members about exactly how the questions in section 10 should be answered, what should be written. The relevant section on the ESA 50 from is on the right. The relevant section of the law is:

Statutory Instruments 2011 No. 228, Social Security, The Employment and Support Allowance (Limited Capability for Work and Limited Capability for Work -Related Activity) (Amendment) Regulations 2011, coming into force 28th March 2011

10. Consciousness during waking moments.

- (a) *At least once a week, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration.* 15
- (b) *At least once a month, has an involuntary episode of lost or altered consciousness resulting in significantly disrupted awareness or concentration.* 6
- (c) *None of the above apply.* 0.

The ESA handbook(4) issued to Medical Services gives the following guidance:

...."Altered consciousness" implies that, although the person is not fully unconscious, there is a definite clouding of mental faculties resulting in loss of control of thoughts and actions..."

Based on the above, and with my intimate knowledge of ME/CFS, if someone has ME/CFS then the 'significantly *disrupted awareness or concentration*' bit must apply. For two reasons firstly most people with ME/CFS need to sleep sometimes when they would normally be awake. If you keep awake and don't sleep, your concentration will be impaired because you will nap or day dream. Secondly, there is brain fog or brain fog which can impair thinking or reaction. I have a number of carers and nurses that have contacted me and asked if 'absences (Petite mal)' are a part of ME/CFS. The answer is of course no, because 'absences' are from an epilepsy, whereas brain fog is not. However to a healthcare worker they appear the same. Most of the people I see suffer something like this on a daily basis—which would imply ticking the first box —weekly. The most recent copy of the relevant benefit and work guides (copy available to members only) suggests this issue may also apply to people who suffer disabling migraines as impaired concentration will certainly be a problem.

However, and quite rightly, a number of members have pointed out that by doing this it implies that they may be unfit to drive. The answer is not simple. Absences usually have a medical definite cause and happen without the patient's awareness. Most absences are reported by carer and health workers to the surprise of the patient. The two most common, epilepsy and diabetes are scheduled, and by law must be informed to the DVLC. There is no such scheduling for ME, CFS or Fatigue. I have dealt with this issue in previous Pathways. The advice I give to members is to discuss with their doctor and then inform DVLC about ME/CFS. Everyone I've dealt with to date gets a letter back saying that there is no restriction on their driving. If you have ME/CFS, you are aware that you are tired or having brain fog—and so can choose not to drive to make yourself safe. The choice is akin to driving under the influence or drink or drugs. The following are the thoughts of various members.

Sarah: "What I mean by brain fog, is poor short term memory, difficulty learning new things, or mental stamina and concentration – there may be difficulty reading a book or following a film story or following a line of argument, difficulty finding the right word and thinking one word, but saying another."

Lyrika: "In my interpretation brain fog usually means disrupted concentration rather than impaired consciousness. It is likely that some people have both states but I think they should be kept separate since, as you point out, the water soon gets deeper. It is not a medical term but is commonly used in ME circles to describe the difficulties people may have in thinking processes."

NICE: "Cognitive dysfunction, such as difficulty thinking, inability to concentrate, impairment of short-term memory, and difficulties with word-finding, planning/organising thoughts and information processing."

Part 1 – Physical functions continued

10. Staying conscious when awake

Please tick this box if you do not have any problems staying conscious while awake. ☐ Now go to question 11 in Part 2.

While you are awake, how often do you have fits or blackouts? This includes epileptic fits and absences, and diabetic hypos.

Weekly ☐
Monthly ☐
Less than monthly ☐

Use this space to tell us more.

DO NOT EVER TICK THIS BOX

AFME: "...problems with thinking, reduced attention span, short-term memory problems, word-finding difficulties, inability to plan or organise thought and loss of concentration."

Anonymous Internet: "Brain Fog is a term used to describe a loss of mental acuity. It has, to the best of my knowledge, no clinical name. It is a form of cognitive dysfunction, although this term encompasses any of a range of cognitive deficits. It presents as absent-mindedness or forgetfulness, a difficulty in concentrating, and, occasionally as a lack of spatial awareness or dysmetria. I have seen it described as a 'mental cataract' preventing you from seeing things clearly. It can give rise to periods of 'staring seizures' where you space out and then drift back."

At the recently held ESA 50 materclass and after discussion with Sally from Clouds, our model answer is to tick the weekly box, and include the following in the narrative box:

I do not suffer from fits or blackouts, but I have two problems where episodes of altered consciousness on a daily basis which I think may apply.

Firstly, I suffer on a daily basis due to 'brain fog'. This is a temporary inability to make decisions and react to input from the world outside. This is a disorienting disabling cognitive impairment which can happen from a few seconds to several hours minutes. Among the problems is inability to recognise people and lack of short-term recall. I go on to automatic pilot, and behave like a robot.

Secondly On a daily basis I have sleep problems in that I have the need to sleep during the day. If I don't allow myself to sleep, I just will drop off to sleep without warning. I could not go out, even if I wanted to. When this happens I need to go to bed, and there is no choice in the matter, and it cannot be put off. I can't walk or move around inside or outside safely until I have slept.

What is unclear to me is how the DWP will react. It is becoming increasingly clear that some of the 'Health Professionals' dealing with medicals and assessments are not able to fully place this issue in context, so it cannot be relied upon. It is possible that it will need a tribunal to sort out what and does not apply in regard to this issue. In the meantime, if you have an ESA 50 or (any other DWP form), don't fill it out yourself, use a welfare rights advisor. There are plenty about and their service is free to most people.

Here is what some members have submitted on their ESA 50's:

10. Staying conscious when awake

Please tick this box if you do not have any problems staying conscious while awake.

☐

While you are awake, how often do you have fits or blackouts?

Weekly

☒

This includes epileptic fits and absences, and diabetic hypos.

Monthly

☐

Less than monthly

☐

Use this space to tell us more.

10. Staying conscious when awake

Please tick this box if you do not have any problems staying conscious while awake.

☐

While you are awake, how often do you have fits or blackouts?

Weekly

☒

This includes epileptic fits and absences, and diabetic hypos.

Monthly

☐

~~Altered consciousness~~ Less than monthly

☐

Use this space to tell us more.

Migraines require me to lie in a darkened room and sleep for up to 2 hours after taking Sumatripten. At present I am having migraines weekly and they last from 1 to 5 days. I feel very 'vague' for the few hours after the medication.

With ME/CFS I have occasions when I don't know what has been said to me, I have an absence for a few seconds then I realise I have completely 'switched off', this gets worse the more fatigued I become.

When CFS/ME symptoms worsen, brought on by increased mental, physical or emotional activity I have very disturbed nights, I wake dreaming 3-4 times a night, can be restless which increases daytime pain, or lay awake for up to 4 hours all of these cause sleepiness during the day. I have to return to bed during the morning for up to 2 hours or have a sleep at lunchtime.

Community Support Notices

From Sally Chamberlain Clouds Community Counselling Service Ltd. (Thorne)

Who are we?

Clouds Counselling Service is a person-centred Counselling Service for the Communities of East Yorkshire. The Service is FREE. All our Counsellors are volunteers, and are Diploma trained or in the final year of study towards their Diploma. They aim to provide a Professional Service at all times. In addition they have specialists in Hypnotherapy, Time Line Therapy and Neuro Linguistic Programming, also specialist Counsellors for Addictions and working with young people.



Aims

To empower clients to increase their sense of well being and enhance the quality of their life also their participation in the community. To enable the client to overcome emotional barriers. To respond to the needs of the individual reflecting the needs of the community by offering these choices:

- 1) One-To-One Counselling
- 2) Bereavement Service
- 3) Learning Courses
- 4) Support Groups / Support Workers
- 5) Autonomous Community Groups

Future Developments

Clouds is expanding its Practice so that even more of the most vulnerable people in society can be helped. We are interested to hear from local businesses that would like to support and champion Clouds for the excellent work the volunteers do. We also offer our Services to businesses to help with employee relations, staff welfare and Human Resources best practice.

If there is anything that you would like to see our Service provide please call and let us know.

Client Message Line: 07962 907053

Clouds Counsellors are members of the BACP and are bound by its Ethical Framework for Good Practice in Counselling and Psychotherapy and subject to professional conduct procedure for the time being in force.

From Helen Butler SYCIL: The Health Through Warmth Hardship Fund

The Foundations Independent Living Trust has secured separate funding through npower's Health Through Warmth initiative. This is a restricted fund to pay for insulation and heating works where the person in receipt of payment is suffering from a housing-related health issue. Illnesses that fit into the following categories will be considered as eligible for HTW funding assistance. Respiratory diseases, Cardiovascular disease (for example, heart disease and stroke), Diabetes (particularly type 1), Arthritis (osteo and rheumatoid, requiring regular treatment and review), Reduced mobility, including risk of trips and falls, Cancer, Terminal illness, Mental illness (depression and receiving treatment, schizophrenia, manic depression). For further information please contact the Leger ME office.

Clouds Community Counselling Service Ltd.

One-to-One counselling is available at:

Hedgerows. Moorends
Mondays & Tuesdays

TMRP. Bridge Street. Thorne
Monday to Friday

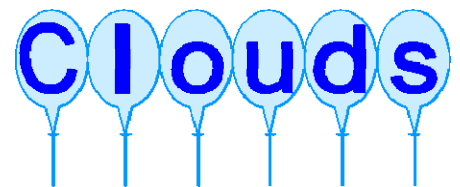
The Croft Children's Centre Dunscroft
Tuesday & Thursday Mornings

Hatfield Community Arts College
Tuesday Mornings

Hungerhill School
Friday Mornings

If you need to talk to us the Client Message Line is:

07962 907053



News from Fairlawns. (Sheffield ME/CFS clinic)

Here is a useful document if you are going into hospital. This guide was outlined at a recent Local Patient Involvement Group Meeting at the Clinic.



Sheffield Teaching Hospitals **NHS**
NHS Foundation Trust

CHRONIC FATIGUE SYNDROME (CFS) / MYALGIC ENCEPHALOMYELITIS (ME)**Nursing Care Guideline No. 155**

DEFINITION:- Range of symptoms including: fatigue, malaise, headaches, sleep disturbances, difficulties with concentration, muscle pain.

Severity

- **Mild CFS/ME patients** are mobile and can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure activities.
- **Moderate CFS/ME patients** have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education and need rest periods. Their sleep at night is generally poor quality and disturbed.
- **Severe CFS/ME patients** are unable to do any activity for themselves, or can carry out minimal daily tasks only (e.g. face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and noise.

GOAL: - That the patient is appropriately managed to provide diagnostic and therapeutic options, individualised to meet their needs.

GUIDELINE TO NURSING ACTION:-

- A. Liaise with medical staff to ensure shared decision making between patient and members of the health care team. **Always take into account the patient's level of expertise in their condition.**
- B. Acknowledge the reality and impact of the condition and the symptoms of the patient (refer to **NICE Guideline 53** as detailed below).
- C. Take account of the patient's age and the severity of their condition.
- D. Explain treatment options, as advised by the medical team and advise the patient of their right to withdraw or refuse any component of planned care without this affecting the provision of other aspects of care or future choices about care.
- E. Provide contact details for sources of information and support for CFS/ME as detailed below.
- F. Establish a supportive and collaborative relationship with the patient and their carers.
- G. Refer to Physiotherapist/Occupational Therapist and encourage patient to maintain activity and exercise levels if possible, **unless** advised that it is necessary to increase rest periods to stabilise condition. **Discuss with the patient.**
- H. Advise patient to minimise daytime sleep periods where possible.
- I. Emphasise the importance of a well balanced diet, including regular intake of slow release starchy foods in meals and snacks. Monitor nutritional intake and refer to Dietitian as necessary.
- J. Discharge: Ensure plans are tailored to the patient's condition through shared decision making with health care professionals, the patient and family/carers.

PREFERRED OUTCOME:- To provide support and information to allow the patient to adopt the treatments and strategies to manage their condition.

Evidence Link:-

National Institute for Health and Clinical Excellence (2007) Guideline no. 53, Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management of CFS/ME available at: <http://guidance.nice.org.uk/CG53>
Nursing Care Guidelines 133,134, and 135 regarding nutrition, poor appetite and referral criteria to dietitian
Other references are available at: <http://www.supportme.co.uk/library.htm>

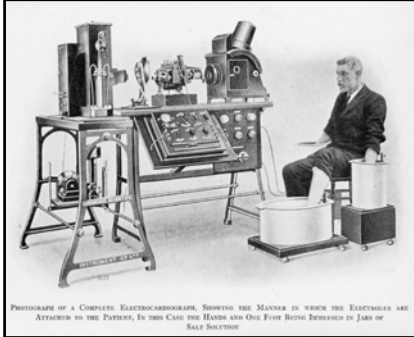
More information about CFS/ME:-

Action for ME, website at: www.afme.org.uk
Association of Young People with ME, website at: <http://www.ayme.org.uk/>
NHS Direct online website for general searching at: www.nhsdirect.nhs.uk
NHS Expert Patient Programme website at: www.expertpatients.nhs.uk
The ME Association website at: www.meassociation.org.uk
The Young ME Sufferers Trust website at: <http://www.tymestrust.org/>
Sheffield ME Group: telephone number 0114 2536700

*CFS/ME Service for
South Yorkshire and
North Derbyshire,
Fairlawns,
621 Middlewood
Road,
Sheffield, S6 1TT,
Tel 0114 2292937 or
07968 376750.*

The Electrocardiograph.

I think everyone from school will recall that the heart is a bag of specialised muscle acting as a double pump circulating blood. The heartbeat can be felt as a pulse or throbbing or may be heard. Before the advent of modern medicine the ancients (*cf* Chinese) were well aware of changes in the heartbeat, and its health implications. In historical times the invention of the stethoscope enabled doctors to hear heart sounds from which they could draw diagnostic conclusions. Now electronics have become involved.



In the 19th century it became clear that the heart generated electricity. The first to systematically approach the heart from the point-of-view of electricity was Augustus Waller, working at St Mary's Hospital in Paddington, London. In 1911 he was still able to see little clinical application for his work. The breakthrough came when Willem Einthoven, working in Leiden, The Netherlands, discovered the string galvanometer, which was much more precise than the capillary galvanometer that Waller used. Einthoven assigned the letters P, Q, R, S and T to the various deflections, and described the electrocardiographic features of a number of cardiovascular disorders.

For his discovery, he was awarded the 1924 Nobel Prize for Medicine.

The Electrocardiograph (ECG) was one of the earliest forms of electronic medical diagnostic technique to be introduced, and has added insights into heart physiology. Most electronic gadgets these days have some sort of diagnostic facility. The ECG can be thought of as a device for displaying the diagnostic facility provided by the heart.

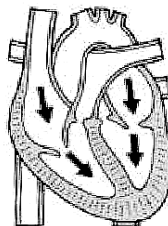
The ECG works mostly by detecting and amplifying the tiny electrical changes on the skin that are caused when the heart muscle "depolarizes" during each heart beat. This signal has an intensity of about 1/1000 of a volt. (A typical watch battery has about 1½ volts). At rest, each heart muscle cell has a charge across its outer wall, or cell membrane. Reducing this charge towards zero is called depolarization, which activates the mechanisms in the cell that cause it to contract. During each heartbeat a healthy heart will have an orderly progression of a wave of depolarisation that is triggered by the cells in the sinoatrial node, spreads out through the atrium, passes through "intrinsic conduction pathways" and then spreads all over the ventricles. This is detected as tiny rises and falls in the voltage between two electrodes placed either side of the heart which is displayed as a wavy line either on a screen or on paper. This display indicates the overall rhythm of the heart and weaknesses in different parts of the heart muscle.

The pumping action of the heart has three main phases for each heart-beat. Each beat is brought about by electrical waves that emanate from

the heart's own pacemaker, the sinoatrial node. The electrocardiogram tracing also shows the phases of the cycle.

Diastole

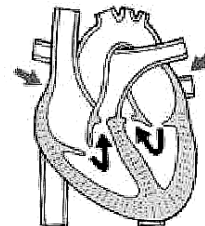
During this resting phase, the heart fills with blood. Deoxygenated blood flows into the right side of the heart; at the same time, oxygenated blood flows into the left side.



In diastole, the heart muscle is at rest. Towards the end of this phase of the heart cycle, an electrical impulse begins to emanate from the sinoatrial node.

Atrial systole

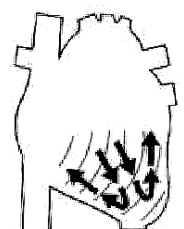
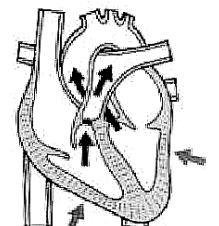
In this second phase, the two atria (upper chambers of the heart) contract simultaneously, squeezing more blood into the two ventricles, which become fully filled.



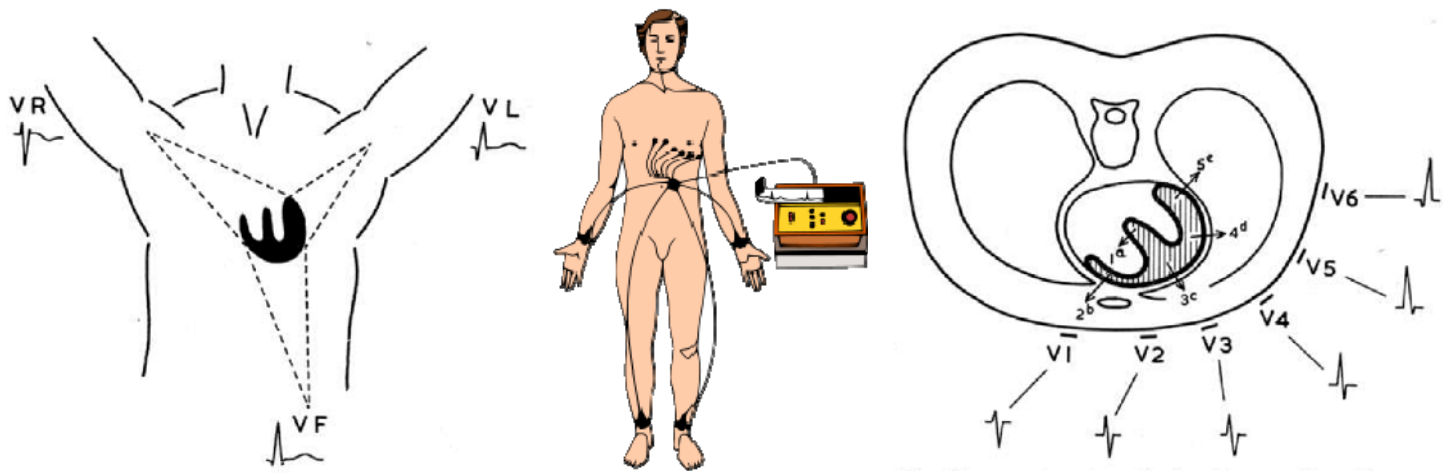
Atrial systole is brought about by the impulse from the sinoatrial node spreading over the atria. The impulse soon reaches another node, the atrioventricular node.

Ventricular systole

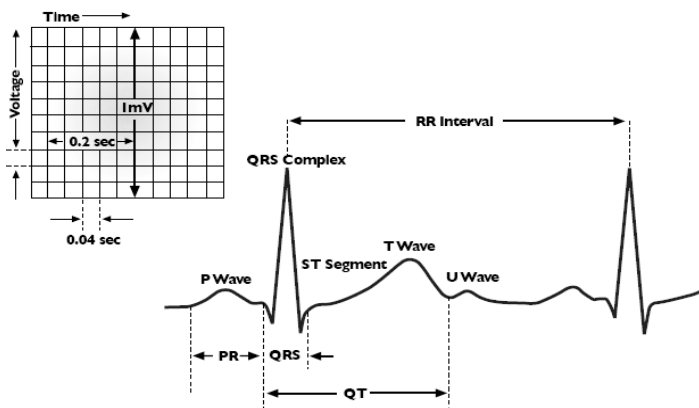
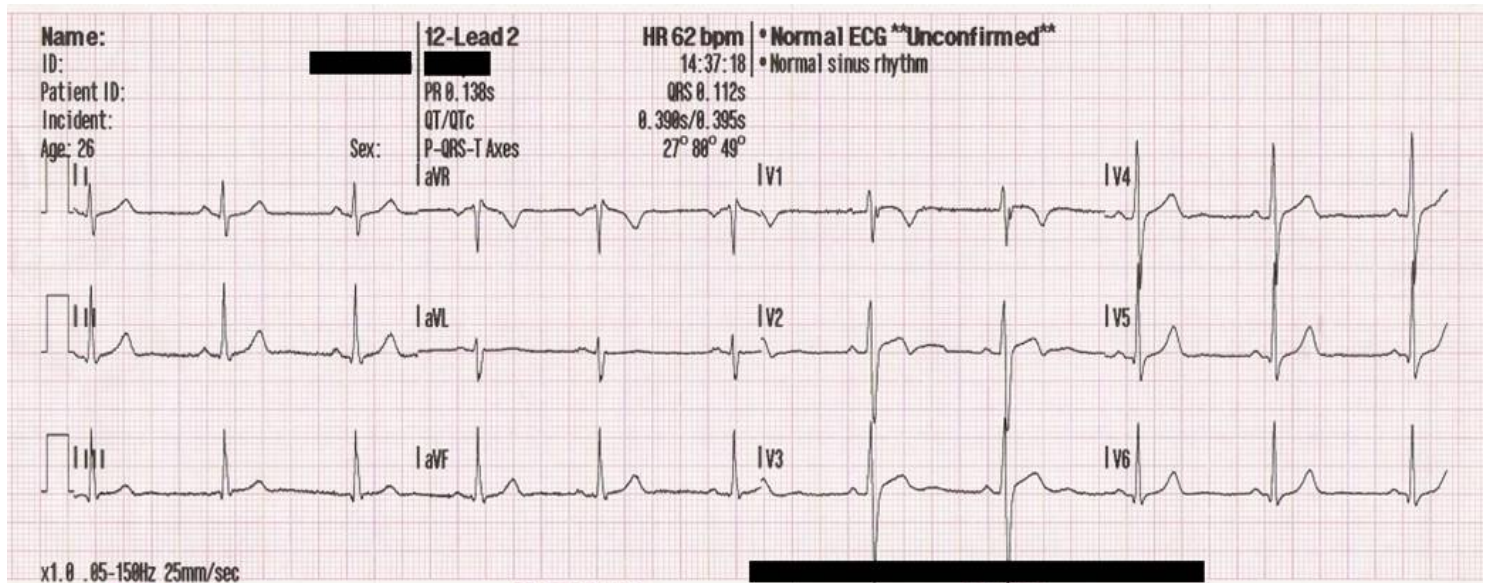
The ventricles contract to pump deoxygenated blood into the pulmonary artery and oxygenated blood into the aorta. When the heart is emptied, diastole begins again.



Ventricular systole is brought about by waves of electrical activity carried from the atrioventricular node to all parts of the ventricles by means of special fibres.



The placing of the leads changes the signal, and enables various cross-sections to be viewed. On modern equipment the multiple several traces are done at the same time automatically. In the example below all the leads are attached to the patient, with three trace streams taken for 3 beats. The leads are then switched electronically to give a total of 12 traces.



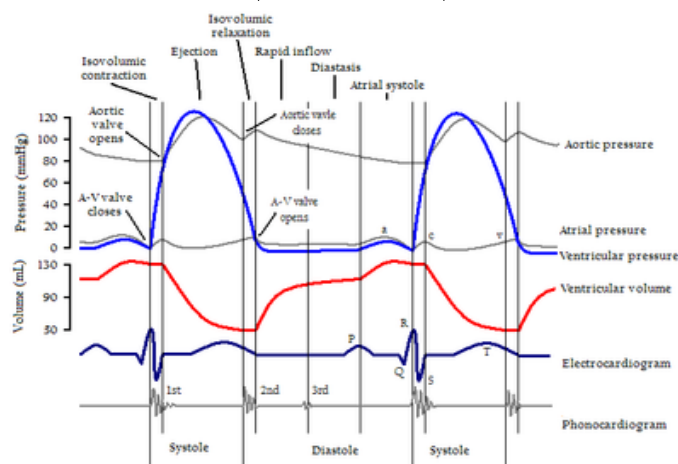
P wave: The P wave is the electrical signature of the current that causes atrial contraction. Both the left and right atria contract simultaneously. Irregular or absent P waves may indicate arrhythmia. Its relationship to QRS complexes determines the presence of a heart block.

QRS: The QRS complex corresponds to the current that causes contraction of the left and right ventricles, which is much more forceful than that of the atria and involves more muscle mass, thus resulting in a greater ECG deflection.

Q wave, when present, represents the small horizontal (left to right) current as the action potential travels through the interventricular septum. Very wide and deep Q waves do not have a septal origin, but indicate myocardial infarction.

R and S waves indicate contraction of the heart muscle. Abnormalities in the QRS complex may indicate bundle branch block (when wide), ventricular origin of tachycardia, ventricular hypertrophy or other ventricular abnormalities. The complexes are often small in pericarditis.

T wave represents the repolarization of the ventricles. The QRS complex usually obscures the atrial repolarization wave so that it is not usually seen. Electrically, the cardiac muscle cells are like loaded springs. A small impulse sets them off, they depolarize and contract. Setting the spring up again is repolarization, getting them ready for the next heartbeat.

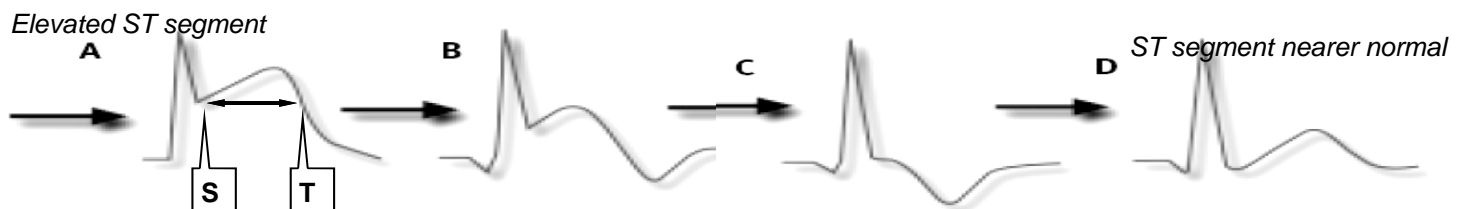


The Use of ECG in Myocardial Infarction (MI) - a Cardiovascular Emergency.

Any sudden unexplained chest pain is a medical emergency, and needs an immediate 999 call. The stakes are high. About half of patients taken into hospital survive, and of these about one third will die within 12 months. Immediately on arrival the paramedics will attach a portable ECG machine. Depending on what they see, they may start emergency treatment immediately. On arrival at casualty, an ECG similar to that on the previous page will be recorded, and a monitoring ECG will be attached on transfer to a ward. The shape of the ECG shows the sort of heart attack it may be, and changes over several hours as the heart attack progresses. This aids a quicker diagnosis and the choosing of the most appropriate treatment.

A non STEMI (ST elevation myocardial infarction) will show up on the ECG, and indicate a partial obstruction to heart blood-flow. In unstable angina (UA), the blood flow in the heart muscle is partially obstructed by spasm of the smooth muscle that controls blood through the heart muscle. This is usually reversible within the short term with the help of drugs. A Non-ST-segment myocardial infarction (NSTEMI) is caused by a partial obstruction of blood-flow within the heart muscle, usually due the 'unstable plaque' leaking from an artery wall. ST-segment elevation myocardial infarction (STEMI) is when the embolus/clot is totally occlusive to blood. This is a serious one, and this involves 'clot busting' drugs as soon as possible.

Below: Recovery of a STEMI over time & treatment to the nearer normal trace.



This is the most common example of the use of the ECG. Obviously the treatment and interpretation of such information is best left to the expert doctor's eyes. There is a well known number of protective measure you can personally take by changing your lifestyle.

Putting ECG/MI issues into context for ME/CFS sufferers.

As part of the diagnostic workup in hospital, an ECG should have been taken to eliminate any heart problems that may be the cause of fatigue.

Very often I hear of ME/CFS patients being admitted to a casualty as an emergency, and nothing being found, they are usually classed as NSTEMI similar to unstable angina. A STEMI ECG would be serious and a cause for concern.

ME/CFS patients are at a higher risk of a heart attack and stroke, mainly because of limitations of exercise ability. A daily dose of 'baby' Aspirin 75mg daily is reputed to reduce the risk by 20%, and is heavily promoted within the NHS. There are alternatives for those who cannot take aspirin such as those who also have asthma.

People who take fish oil supplements e.g. cod liver oil, maxepa, vegEPA may have increased protection because these oils contain EPA and are reputed to have a cardio-protective effect. The EPA causes an increase level of triglycerides in the blood. If your doctor is not aware of this fact it can result in his being puzzled and prescribing inappropriate medicines.

Current medical opinion promotes heart attack-prevention by prescribing anti-cholesterol drugs like Statins (e.g. simvastatin) and fibrates. If you do take anything like this, please ask your doctor to test your blood creatine phosphokinase (CP or CPK) regularly. There is a serious side effect called rhabdomyolysis which ME's seem to be prone to. If you take B3, nicotinamide or NAD type food supplements at the same time as a statin or fibrate you need to tell your doctor.

The NHS CKS Website

The NHS **Clinical Knowledge Summaries** (formerly PRODIGY) are a reliable source of evidence-based information and practical 'know how' about the common conditions managed in primary care. CKS is commissioned and paid for by NHS Evidence, a service provided by the National Institute for Health and Clinical Excellence. CKS is aimed at healthcare professionals working in primary and first-contact care. There is an increasing tendency for GPs to give patients this following printout on diagnosis

Chronic Fatigue Syndrome (according to CKS June 2011)

Anyone can get CFS, although it is more common in women than in men. It usually develops in the early 20s to mid-40s. Children can also be affected, usually between the ages of 13 and 15.

How serious is it?

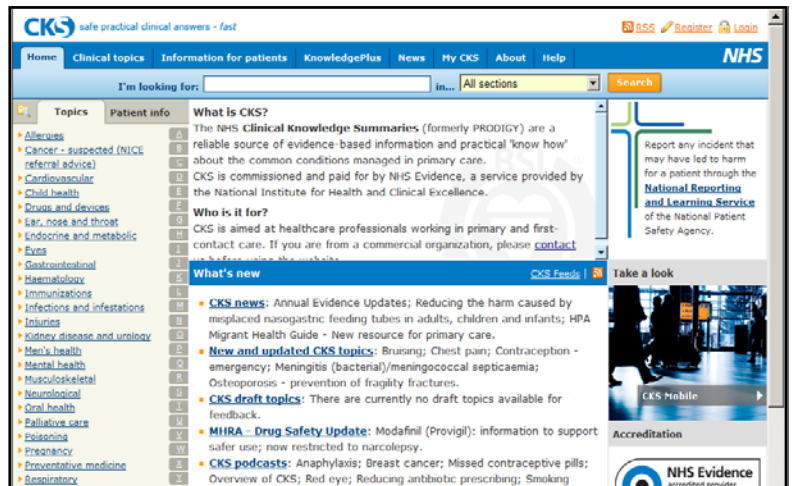
Most cases are mild or moderate, but up to one in four people with CFS have severe or very severe symptoms. These are defined as follows:

- Mild: you are able to care for yourself, but may need days off work to rest.

- Moderate: you may have reduced mobility, and your symptoms can vary. You may also have disturbed sleep patterns, and sleep in the afternoon.

- Severe: you are able to carry out minimal daily tasks, such as brushing your teeth, but occasionally you may need to use a wheelchair. You may also have difficulty concentrating.

- Very severe: you are unable to carry out any daily tasks for yourself and need bed rest for most of the day. Often, in severe cases, you may experience an intolerance to noise and become very sensitive to bright lights.



The CKS website

Outlook

CFS may last for years. Most people improve over time and some people recover and are able to resume work and normal activities. However, others will continue having symptoms or may relapse, and some remain housebound. The outlook for young people is more optimistic.

Symptoms

If you have chronic fatigue syndrome (CFS), there will be times when your symptoms improve. You will be able to do many normal, everyday activities. However, at other times your symptoms can flare up and get worse. This affects your daily life.

Fatigue: The main symptom of CFS is severe fatigue (tiredness) following mental or physical activity. This does not go away with sleep or rest, and limits your usual activities. Fatigue is mental as well as physical. Some people describe it as overwhelming. You may feel that:

- It is a different type of tiredness from what you have experienced before.
- After sleeping you do not feel refreshed.
- It is not due to exhaustion.
- It is not simply a loss of motivation, which people with depression often experience.

Exercising can make symptoms worse. This is called post-exertional malaise. The effect of this is sometimes delayed. For example, if you were to play a game of sport, the resulting fatigue may not develop for a few hours afterwards, or even the next day.

Other symptoms There are other common symptoms as well as fatigue, although most people do not have all of them. They include:

- Muscular pain, joint pain and severe headaches.
- Poor short-term memory and concentration.
- Difficulty organising your thoughts and finding the right words.
- Painful lymph nodes (small glands of the immune system).
- Stomach pain and other problems similar to irritable bowel syndrome, such as bloating, constipation, diarrhoea and nausea.
- Sore throat.
- Sleeping problems, such as insomnia and disturbed sleep.
- Sensitivity or intolerance to light, loud noise, alcohol and certain foods.
- Psychological difficulties, such as depression, irritability and panic attacks.
- Less common symptoms, such as dizziness, excess sweating, balance problems and difficulty controlling body temperature.

Causes

The cause of chronic fatigue syndrome (CFS) is unknown. There are several theories. Some experts think that a viral infection such as glandular fever can trigger the condition. Tiredness is normal after a viral infection, but this does not explain why symptoms persist and get worse. It is more likely that CFS is caused by a combination of physical and psychological factors, which also affect how severe the condition is and how long it lasts.

Contributing factors: The main factors thought to increase the risk of developing CFS are:

- Inherited genetic susceptibility (it is more common in some families).
- Viral infections such as glandular fever, which weaken the immune system.
- Exhaustion and mental stress.
- Depression.
- A recent traumatic event, such as bereavement, divorce or redundancy.
- Childhood trauma (see Useful links).

Exacerbating factors; The following factors are thought to make CFS worse:

- recurring viral or bacterial infections,
- not being active enough, or being too active,
- stress,
- poor diet, and
- being socially isolated and/or feeling frustrated and depressed

Diagnosis

There is no test to diagnose chronic fatigue syndrome (CFS). Many people consult their GP because they think they have CFS, but only a small minority are diagnosed with it. CFS is not diagnosed in people who simply feel tired all the time. There are other symptoms that help to confirm the diagnosis. Your GP will ask you about your medical history and carry out a physical examination. You may have blood tests and scans to rule out other conditions, such as anaemia (not enough red blood cells), an under active thyroid gland or liver and kidney problems.

NICE guidelines for diagnosing CFS Guidelines (2007) from the National Institute for Health and Clinical Excellence (NICE) state that doctors should consider diagnosing CFS if a person has fatigue with all of the following:

- a clear starting point,
 - persistent and/or recurrent,
 - unexplained by other conditions,
 - a substantial reduction in activity level,
 - characterised by post-exertional malaise and/or fatigue (feeling worse after physical activity),
- and one or more of the following symptoms:
- difficulty sleeping, or insomnia,
 - muscle and/or joint pain without inflammation,

- headaches,
- painful lymph nodes that are not enlarged,
- sore throat,
- cognitive dysfunction, such as difficulty with thinking,
- physical or mental exertion that makes symptoms worse,
- general malaise or flu-like symptoms,
- dizziness and/or nausea, or
- Palpitations, without heart disease.

This diagnosis should be confirmed by a clinician after other conditions have been ruled out and the above symptoms have persisted for four months in an adult and three months in a child or young person. For more information see the NICE guidelines

Treatment

There is no cure for chronic fatigue syndrome (CFS), so treatment focuses on the symptoms. The effectiveness of treatments depends on how CFS affects you. Early diagnosis, balancing rest with activity, medication to control certain symptoms and self-help measures can all help. Simply diagnosing CFS and giving specialist advice about how to deal with it can help. CFS may last for years. However, most people do recover ^{*1} or at least adjust their lifestyle to improve their symptoms.

Common treatments

Cognitive behavioural therapy (CBT) aims to change the way you think, behave and feel. By talking to a professional, you may identify the thoughts and feelings that are causing certain behaviours. CBT helps you manage the emotional impact of your symptoms (see Useful links for more information). For some people, it is one of the most effective treatments for CFS.

Medication Antidepressants can be useful for people who have depression with CFS. Over-the-counter painkillers can help to ease muscle and joint pain and headaches. Stronger painkillers can also be prescribed by your GP, although they should only be for short-term use ^{*2}.

Graded exercise therapy (GET) involves a structured activity management programme that aims for a gradual increase in aerobic exercise, such as swimming or walking. Patients have their exercise programme adapted to their own physical capacity. GET should only be carried out by a trained specialist with experience in CFS. Patients are advised not to exceed the exercise duration or intensity they have been given. Randomised controlled trials evaluating GET found it had an overall beneficial effect on fatigue. However, studies have shown higher drop-out rates here than for CBT.

Lifestyle advice

Pacing is an important way of controlling CFS symptoms. It involves a balance between activity and rest and avoiding large bursts of exercise that may set you back. Learning how to make the most of your energy helps increase the amount you can do.

Other self-help techniques.

These include the following recommendations:

- avoid stressful situations,
- avoid alcohol, caffeine, sugar and sweeteners,
- avoid any other food and drinks that you are sensitive to,
- eat small, regular meals,
- spend time relaxing,
- be aware of how your energy levels change, and rest or be active accordingly

**1 In the twenty years or so I've been dealing with ME/CFS total recovery only occurs in a few cases. This is an anomaly on the NHS standard data sheet which does not record long term outcome.*

**2 The need for long term pain control in the majority is my experience.*

Dr. Charles Shepherd: ME Now & Next?

From an address to Stockport ME Group on 8th April 2011 and reported by Angela Glendinning, Member of ME Observatory (epidemiological Research) Steering Group, Member of the Feasibility Study into Post Mortem Tissue Archive Steering Group, and Director/Trustee of a Charity (The ME Association) that funds biomedical research through the Ramsey Research Fund

Dr. Shepherd started by telling us of his own experience of suffering with ME. He had had a fulfilling job as a hospital doctor, was fit and well, was able to play squash, and then he suffered a bout of chicken pox in the early 1980s, and the ME started from there. He has been Medical Adviser to the MEA for some time now and has worked for people with ME over many years.

Dr. Shepherd divided his talk into four main headings:

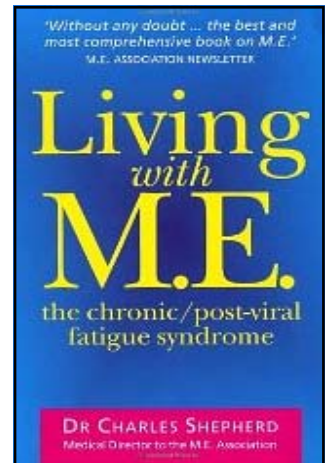
1) Research: Where Are We Now And Where Are We Going.

Dr. Shepherd stressed the need for research as crucial. There are three stages in ME, known as the 3Ps - predisposing /genetic factors which may contribute to someone being more susceptible to getting ME; precipitating/triggering factors such as an infection (infections are usually the culprits, whether viral or bacterial); and thirdly perpetuation. What is it that keeps it going? It is this third factor that medics cannot agree on. There are two main models to try and explain this, the psychiatric model and the biomedical model. The psychiatric model fits in with psychological treatments, and research up to now in this country has been dominated by this model. The biomedical explanation asserts that there are ongoing problems in the immune, the central nervous and endocrine systems.

There has up to now been very little impetus from the Medical Research Council to fund research into the biomedical model, with research along those lines being done largely by charities. A working group was set up in 2008 chaired by Professor Stephen Holgate, Professor of Immunopharmacology at Southampton University. Dr. Shepherd was invited to sit on this working group and the aim of the group was to advise the MRC on future research strategies. The result is that £1.5 million has been made available as research grants to suitable applicants for strictly biomedical research. A list of areas to be looked at has been agreed.

Dr. Shepherd talked about the Ramsay Research Fund (RRF), which was set up in memory of Dr. Melvin Ramsay who was a doctor at the Royal Free Hospital in London at the time of the ME outbreak in the hospital in 1955. The RRF is setting up a bio-bank at University College Hospital, London. Blood samples will be collected from people with ME who form part of the ME Observatory patient database and this might help to narrow down which medical criteria they fall into e.g. Canadian Consensus, Fukuda etc. Professor Peter Behan who is a well known researcher in the ME field is doing a study on people who fit into the Canadian criteria. The bio-bank should be set up by July and there will be a tissue bank as well. The RRF is also funding a study into mitochondrial function in muscles being done by Professor Julia Newton at Newcastle University, with the results now being analysed, and Dr. John Gow at Glasgow Caledonian University has been funded to carry out gene studies.

Dr. Shepherd mentioned the PACE Trials and the recent announcement of the results and said that the pacing results were not really convincing and that the MEA had not been in favour of the trials while they were being carried out. The worry is that NICE will want to adopt this form of pacing, but fortunately the guideline will not now be reviewed until August 2013. He mentioned the Lightning Process (LP) and the XMRV (retrovirus) research and felt regarding the former that the trial of LP should not be done on children when it hadn't been done first on adults, and he felt with the latter that the jury is still out on XMRV as studies subsequent to the original Lombardi et al research done in 2009 did not show up the virus. Further research on XMRV is needed.



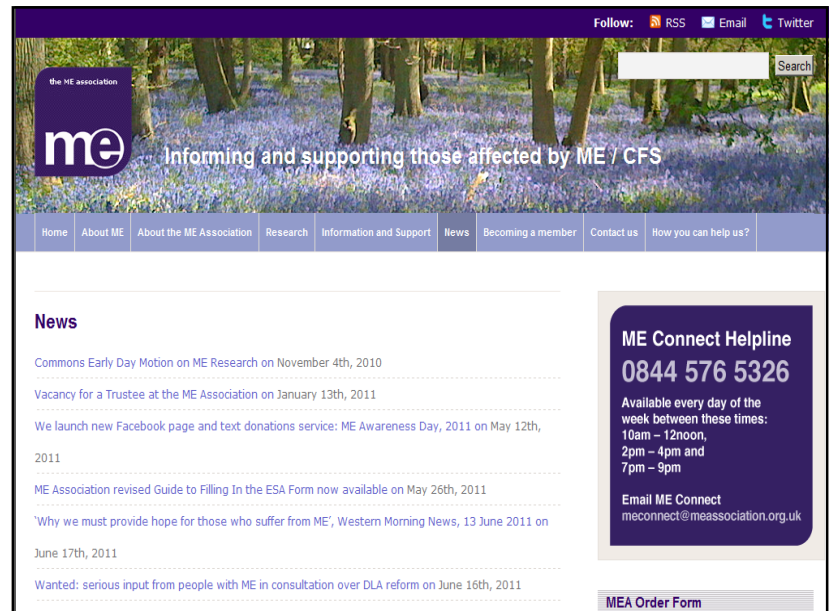
Dr. Charles Shepherd is the Author of Living with M.E. This is THE text book for ME/CFS

2) Management of ME/CFS

It is important to get a proper diagnosis and investigations done. As the cause is still unknown there are no cures or effective drug treatments. A range of drugs can help e.g. painkillers, sleep medication. Orthostatic intolerance is often a factor in ME and is caused by the malfunctioning of the CNS. The Tilt-table test is done to test for this. A survey was done by the MEA into what treatments people found most effective, and a lot of treatments were covered, including complimentary therapies. Proper pacing and energy/activity management is also important. Dr. Shepherd isn't convinced about a lot of complimentary therapies, but felt that Acetyl-L-Carnitine might be of benefit. He did mention Vitamin D deficiency, and felt that you should really be tested for this as taking too much Vitamin D is harmful. The ME Association (MEA) does a booklet on clinical guidance known as the Purple Book which is available from the MEA.

3) Welfare Rights & Benefits

Benefits reform is being undertaken to drastically reduce the number of people on benefits. The new Employment and Support Allowance (ESA) is difficult for ME sufferers to get because of the way in which the form has been designed. It does not account for the fluctuating nature of ME. Since the introduction of the original descriptors for the Work Capability Assessment, legislation came into being on 28th March 2011 which revises these descriptors and has resulted in the removal of some of the original ones. Included in the ones removed is the one concerned with cognitive dysfunction e.g. short term memory loss, poor concentration etc. which is relevant to people with ME. A bid during a House of Lords debate to get this bill annulled failed. Dr. Shepherd is a member of the sub-group for Professor



The ME Association Website

Ten good reasons for joining The ME Association

1. We know ME is a physical illness. No one should be telling you that "it's all in the mind".
2. Throughout the year, we campaign for better care for everyone with the illness. This cannot come without greater understanding.
3. We work to secure improved health services for people with ME and benefits which are easier to obtain by those too ill to work.
4. We fund research into the physical nature and causes of the illness and effective treatments.
5. We run ME Connect, Britain's premier helpline for ME. This is open every day of the week, including Sundays and Bank Holidays, on 0844 576 5326.
The lines are open 10am--12noon, 2--4pm and 7--9pm.
6. Britain's best-known ME campaigner, Dr Charles Shepherd, is our honorary medical adviser and a trustee of The ME Association. He is backed by a panel of paediatric, dental and psychology experts.
7. Dr Shepherd contributes to our quarterly 'ME Essential' membership magazine, required reading for many thousands of people with the illness and their carers.
8. All new members receive a copy of our medical guidance brochure
ME/CFS/PVFS: An Exploration of the Key Clinical Issues. Where appropriate, we ask that this be passed on to the member's GP or other healthcare professional.
9. When joining by annual Standing Order, new members can select ME charities in the UK.
10. WE listen to what YOU tell us.

Harrington who has been compiling a report on the issues to be taken into consideration on how ME affects people. If you are refused benefit it is worth while appealing as the success rate is quite high. The appeals process is independent of the Department of Work and Pensions. The DWP is tending to rubber stamp what Atos, the company doing the work capability tests, decides. The MEA does provide a guide to filling in the ESA form and information on ESA is provided in the ESA section of the Disability Alliance Handbook.

4) THE ME Association:

Dr. Charles Shepherd is the Hon. Medical Adviser to the ME Association. Dr. Shepherd mentioned that the MEA continues to provide information and support for sufferers, and there is literature you can buy from them, plus a listening and information line called ME Connect, number is 0844-576-5326. The website for the MEA is www.rneassociation.org.uk

Recipe Corner

Spiced Berry and Yoghurt Layered Puds

Made with frozen mixed berries and thick Greek yoghurt, this is a quick and easy low fat dessert – a refreshingly summery alternative to the usual calorie laden winter puds!

(For a more adult version, replace the apple juice with red wine).

Serves 6, Ready in 45 minutes plus chilling

- 400g bag frozen mixed berries
- 75g (3oz) caster sugar
- 55ml (2fl oz) apple juice
- 1 mulled wine spice sachet
- 1-2 tsp vanilla extract
- 500g carton Greek yoghurt
- 6 ready-made brandy snaps

1) Place the frozen berries in a deep pan. Stir in the sugar and apple juice and add the mulled wine spice sachet. Gently heat the fruit, stirring all the time, until the sugar has dissolved.

2) Simmer gently for 10 mins until the fruit has thawed completely and the liquid is syrupy. Set aside and leave to cool for 30 mins. Remove the mulled wine spice sachet and discard it.

3) Stir the vanilla extract into the yoghurt. Lightly crush half the brandy snaps. Layer the fruit compote, vanilla yoghurt and crushed brandy snaps in 4 tall serving glasses, ending with a layer of yoghurt.

4) Cover and chill in the fridge for at least 1 hour. Break the remaining brandy snaps into pieces and use to decorate the desserts. Serve immediately.

TIP: For a hot version, allow the fruit compote to cool for just 10 mins. Warm a carton of fresh custard and use in place of the yoghurt.

Wind Down DIP



Chickpeas provide a creamy, low-fat base for this spinach-packed dip.

Makes 6 servings, Start to Finish: 25 minutes

In a saucepan, combine:-

- 5 cups of torn fresh spinach,
- one normal size can of chick peas,
- about 2 tablespoons of water,
- 3 tablespoons olive oil,
- 2 cloves of garlic thoroughly crushed (like mince)
- ¼ teaspoon salt.

Cook on a medium heat for 5 minutes and then let it cool. Carefully blend until the dip is smooth.

Serve with:- Whole wheat crackers or strips of raw veggies.

A Tip for Frugal Times

Polish Your Shoes with a Banana Peel

You can polish your shoes with a banana peel. It is a great way to reduce waste. Eat your banana and then reuse the peel to polish the shoes. The oils and the potassium in the banana polish and preserve your shoes. Compost the peel. You can have polished shoes without damaging your health or the environment, leaving behind zero packaging waste.



How to shine your shoes with a banana

- 1) Eat banana
- 2) Rub **the inside** of the banana skin against the surface of your shoes.
- 3) Get a soft cloth and buff up to a perfect shine.

It works, it really does!



Alternative Food Recipe Ideas from Sarah Myhill

These recipes are for increasing oils in the diet

Coconut oil chocolate

This is a very palatable way to eat coconut oil and get a nice chocolate buzz at the same time.

Warm up a pot (460grams) of coconut oil so that it just melts.

Stir in a pot (125 grams) of Green and Black's organic cocoa powder (more or less according to taste).

Sweeten with 10 grams of D ribose, (or fructo-oligosaccharides). It mixes easily.

Pour into a plastic ice cube container to make bite-size cubes, place in deep freeze. Consume direct from the deep freeze. Done like this it has the consistency of chocolate and is the perfect fuel source for CFS and foggy brain sufferers!! If you do not tolerate chocolate, then carob powder makes a good substitute.

I can't believe it's not cream

Two cups of sunflower oil (or rape seed oil or hemp oil), One cup of soya milk (or coconut milk, rice milk, almond milk), ¼ teaspoon liquid lecithin (can be soya or sunflower), 5 grams of D ribose, One teaspoon vanilla essence

Whizz up in smoothie maker. If too runny, add more oil. If too thick, add more liquid. Use as you would cream!

I can't believe it's not Ice Cream

Use the cream from above; Add frozen berries to the smoothie mix – this breaks up the berries and the mix freezes solid as ice cream as it is stirred.

Double Cream

Two cups of sunflower oil (or rape seed oil or hemp oil), One cup of soya yoghurt, ¼ teaspoon liquid lecithin (can be soya or sunflower), up to 5 grams of D ribose, One teaspoon vanilla essence

For really thick cream add a teaspoonful of linseed seed – these absorb any water and really thicken the cream! OR add in some coconut oil which gives a sweetness and, as it cools, thickens further.

Mayonnaise

One cup of soya milk (or coconut milk, rice milk, almond milk), 1 level tsp. mustard, lemon juice, garlic, and salt-to taste. Blend in blender and trickle in two cups of olive oil (or sunflower oil, rape seed oil or hemp oil) very slowly until the emulsion forms.

Vegetable juice smoothie

Juice the following:

1/2 lime, 1/4 medium cucumber, 1 stick of celery, handful of spinach, 1/2 inch of broccoli stem and/or a few broccoli florets, and anything else green!.

Place all above into a blender and add:-

¼ Avocado, Coconut oil 1 dessert spoon (10ml) (Coconut Oil must have been kept in the fridge in order to blend well), Lecithin 1 dessert spoon (10ml), Hemp oil 1 dessert spoon (10ml), Sunflower oil, 1/4, teaspoon (1ml), 2-4 Ice cubes

Blend everything until smooth. Pour and enjoy!

Berry Fruit smoothie

In a blender:- 2 handfuls of any berries – blueberries, strawberries, raspberries, blackcurrants etc, Handful of any chopped nuts – brazils, hazels, almonds etc, 2 tablespoons of soya yoghurt, Milk (soya or coconut or rice or almond milk), Coconut/lecithin/oil mix*, Ice cubes

Blend until smooth, pour and enjoy.

Oil	6 to 3
Peanut oil	very high!
Safflower oil -	152
Sunflower oil	68
Corn oil	54
Olive oil	10
Palm oil	10
Soybean oil	7.7
Hemp oil	3.8
Canola oil	2
Rapeseed oil -	2
Linseed oil -	0.3

* You should aim for 4:1 ratio, so if you cannot access hemp oil or there is an allergy problem, make up another mix. So, for example, 80% olive oil with 20% linseed oil would also give a 4:1 ratio.

Research Corner: ME Research UK on recovery

by Neil Abbot, ME Research UK,

The outcomes of ME/CFS can vary considerably between people. While some research reports say that 'recovery' is a real possibility for some people (about 20%), others say that recovery is rare though significant improvements can occur in about 40%. But is there any way of predicting what will happen to a particular patient? Are there any characteristics that can identify who is more likely to improve quicker?

A team from New Jersey Medical School has recently attempted to find factors related to the outcome of the illness. As reported in the *Journal of Nervous and Mental Disease* (2010), the researchers examined 94 women with ME/CFS, assessed the severity of their symptoms and physical impairments, and documented the presence of other illnesses. Over the next two and a half years, these women were contacted every six months and asked about their quality of life, physical functioning, disability and symptom severity. Importantly, instead of relying on judgments of improvement, the researchers estimated the perceived change in physical functioning using the standardised SF36 questionnaire.

Interestingly, two-thirds of the women reported significant improvements in their physical functioning over the follow-up period, although none could have been considered to have made a full recovery. These women also reported less work-related disability, less fatigue, lower levels of pain, fewer symptoms of depressed mood, and fewer non-specific physical symptoms. Unfortunately, there were no defining characteristics that distinguished these patients from the others who did not improve or who got progressively worse - there was no difference between the two groups in baseline level of physical functioning, severity of symptoms or rate of concomitant illness.

One finding does seem important, however. The ME/CFS patients who had a diagnosis of fibromyalgia as well as ME/CFS were three times more likely not to improve, and it may be that patients with the other sources of pain characteristic of fibromyalgia fare worse than those without this extra burden to carry.

Montezuma's proposition (or 'seriously, can chocolate really help?')

Chocolate is rich in flavonoids, and evidence from observational studies suggests dietary flavonoids may reduce the risk of mortality from coronary heart disease, cancer and stroke. Apparently, it was the Aztec Emperor Montezuma II who first noted the effect of chocolate on various symptoms, including fatigue; as he said, "A cup of this precious drink [cocoa] permits man to walk for a whole day without food." So, might high-dose chocolate improve the symptoms of ME/CFS?

In a recent small study (*Nutrition Journal*, 2010), researchers from Hull/York Medical School gave either high cocoa liquor/polyphenol rich chocolate (HCUPR) or a sham preparation consisting of cocoa liquor free/low polyphenol chocolate to people with ME/CFS to test its effect on 'severe' fatigue and disability. Individual 15g foil-wrapped bars (provided by Nestlé, which also did the analysis) were prepared, and participants were asked to consume one bar three times a day. In this 'cross-over' design, patients received eight weeks of either HCUPR or sham, followed by a two week 'wash out,' followed by eight weeks on the preparation they had not eaten previously.

In the 10 patients studied, there was a significant improvement in fatigue score after eight weeks of HCUPR chocolate (from 33 to 21.5), and when they were given sham chocolate the fatigue score worsened again (from 28.5 to 34.5). The score on the London Handicap scale also improved significantly after HCUPR chocolate (from 0.49 to 0.64) and deteriorated after sham chocolate (from 0.44 to 0.36). A similar pattern was observed for anxiety and depression, and average weight remained unchanged throughout the trial. The researchers say that improvement was likely to be due to the high polyphenol content within the active chocolate, and were surprised at the significance of the results given the small number of trial participants.

Lactate in the brain

Recently, an overview of Neurocognitive research into M.E./ CFS found that attention span, memory and reaction time were impaired - a finding consistent with the memory and concentration problems that patients themselves describe. Given that some neuropsychiatric disorders also show similar cognitive symptoms, there is a need to identify specific biomarkers to differentiate ME/CFS as a distinct biomedical disease.

Magnetic resonance spectroscopic imaging (MRSI) is a relatively novel technique that gives information about metabolic changes in the central nervous system. The patient is placed inside a powerful magnet which magnetises atoms in the body, causing them to line up. A short radio frequency pulse alters this arrangement and following this, as the atoms spring back into alignment, a magnetic resonance signal is produced. This signal can be analysed to determine the concentrations of various chemicals in the body tissue, and the information across a region can be collected together to form a two dimensional image.

Researchers in New York (NMR in Biomedicine, 2010) have used this method to measure levels of a metabolite called lactate in the cerebrospinal fluid (the liquid that surrounds the brain and spinal cord) in 19 ME/CFS patients, 31 people with major depressive disorder subjects (in whom impairments in concentration, sleep, and appetite are also found) and 23 healthy control subjects. Significantly, they found mean lactate levels to be higher in the ME/CFS group (0.92 units) compared with healthy volunteers (0.04), with the depressive disorder group having an intermediate level. Moreover, the researchers found a significant correlation between lactate and mental fatigue in ME/CFS patients but not in depressed patients or healthy controls. The scientists point out that high brain lactate levels are consistent not only with the reports of areas of low blood flow to the brain in ME/CFS patients but also with the reports of increased oxidative stress leading to mitochondrial dysfunction, anaerobic glycolysis and lactate production.

Sleep disturbances

In narcoleptic sleep disorders, individuals experience excessive sleepiness during the day, and may also fall asleep at inappropriate times. Treatments now consist of trying to improve the quality and depth of sleep in these individuals to restore their disrupted sleep pattern. But perhaps these therapies might also be helpful to people with ME/CFS?

The question is pertinent because, while problems with sleep are not the cause of most cases of ME/CFS, they are certainly a major contributor to the pain and suffering experienced. For instance, one investigation of the prevalence and severity of symptoms in 1,578 patients with ME/CFS found sleep disturbance reported by 91.9% of the group with a high level of severity.

Researchers from a Neurology Department in Michigan (Pain Practice, 2010) reviewed the case records of 118 patients who had been referred to their practice over a five-year period for a range of conditions, from neuromuscular disorders to complaints of weakness and myalgia. Diagnoses of ME/CFS or fibromyalgia were made retrospectively, after review of the case histories. All patients had undergone polysomnography (monitoring of body functions during sleep), a multiple sleep latency test (which measures how fast people fall asleep) and measurement of human leukocyte antigen (a protein known to be associated with narcolepsy). Based on these tests, 40% of patients met the criteria for a narcoleptiform sleep disorder, while many of the others had features that suggested the condition.

Approximately 70% of patients were subsequently treated with sodium oxybate, which is a general anaesthetic commonly used to treat narcoleptic sleep disorders. Of these, three-quarters experienced significant relief of their fatigue; 60% experienced some degree of pain relief; and more than half had relief of both their fatigue and pain. While sodium oxybate itself is not a long term solution to the sleep problems of ME/CFS patients - it has been associated with adverse effect and addiction - the findings point to the need for treatment aimed at disrupted sleep in a range of chronically ill patients, including those meeting the definition of ME/CFS.

North of Doncaster: Personal American Travel Diary by Trevor Wainwright

On 2006 April 5th “the last leg” I thought, looking out of the plane window as we left Memphis. There had been some trepidation at first - would my paperwork be in order? Previous attempts at a long holiday had met with failure, now I was almost there; Austin Texas for a poetry festival; another at Lamesa then that would be it - off across America. Everything had gone so smoothly I was in a daze. In Austin it was a moment of triumph as I walked down the terminal stairs to where two of the poets, Lee and Mike, were waiting. Car collected and they led me to my motel and a good night's sleep. The following day was spent getting used to Austin and how to use a Sat Nav, a poetry reading at night and the following day the Festival began in earnest.

Thom, my friend from Austin had been at an event elsewhere when I arrived. It was great to meet up again at registration and so began a hectic but enjoyable time of poetry events, all held at free trade cafés. They loved my accent and humour as when asked what had brought me to Austin I replied “767 from Amsterdam”. On two occasions we held midnight to dawn events and only three of us made it through both of them. I had written 9 poems on the way and would continue to write long into the holiday, often at events, and read them straight away.

Austin is such a laid back city, clean and green with a pride in its environment. It was a pleasure to see more of it, photograph it and write poems about it. After the festival and there were still more open 'mikes' after until we left for Lamesa on the 14th for another festival. Before then I would spent time exploring Austin, preferring to stick to the more rural areas such as Zilker Park and the Colorado River, although on Congress Avenue in an outdoor arcade is a piano on which it says “play me I'm yours” anyone can have a go and anyone can decorate it, when I passed a guy was playing John Lennon's “Imagine” and playing it well.

At Lamesa I would be prolific as we recited on local radio, old people's homes and a school along with workshops and a community centre event. I was virtually reading as soon as I'd written something.

On April 17th I said goodbye to all my new found friends and left with some trepidation, Thom had said “don't worry just start your adventure and go”. A days driving through a changing landscape to Texarkana where I would stop for the night before making my way to Memphis the following day. The drive to Memphis went well. I arrived about lunchtime as planned, this gave me time to visit the Hollywood café where Muriel played piano in the song *Walkin' in Memphis*. I got my first view of the Mississippi River - boy was it big. Back at the Hollywood I ordered a meal yes they had catfish, looking round while it came I looked at the pictures of Marc Cohn and Muriel, they seemed to have a great time doing their little number and to actually sit at Muriel's piano - well that was really something.

The following day I drove into Memphis and really did walk along Beale Street and Union Avenue and saw the gates of Graceland's but no ghost of Elvis. Later I would enjoy both a river trip and streetcar tour but not before walking once more along Beale Street watched over by W C Handy's statue, as musicians played on the sidewalks and in the park. I even managed to catch a glimpse of the Peabody Ducks.

That night it threw it down, rain almost horizontal. Later at a rest stop on the way to Chattanooga I would find out that it had actually been a tornado. The guy that told me said he and his group took shelter in the bathroom; we must have been on the edge. The initial plan for going to Chattanooga and Asheville was that there should have been a poetry 'open mike' at each but on getting to Chattanooga I found that these were no longer taking place, Asheville though was the best place for the Appalachian leg of my tour.

One of the beauty spots at Chattanooga is called Ruby's Cave, home to a 145 foot high underground waterfall in Lookout Mountain, although the water is clear and safe to drink it is advised against as it contains magnesium which is known to have laxative properties, not advised for long journeys. The waterfall is part of an underground cave system discovered by a caving enthusiast, Leo Lambert, who was looking for a way to re open Lookout Cave the original cave in Lookout Mountain which was closed during the construction of a railway. During the course of the excavations which began in 1928 they discovered a passageway 18 inches high and 4 feet wide, a long search of this passageway eventually led to the waterfall. On his next trip Leo took his wife and said he would name the cave after her.



It was mid afternoon when I got there so decided of the three main attractions it would be my choice, I wasn't disappointed.



Lookout Mountain actually did live up to its name, almost at the top is Point Park of strategic importance in the American Civil War in 1863 and the battle for Chattanooga. A visitor centre tells the story as do information boards through the park. The centre piece is a New York type memorial with a Confederate and Union Soldier shaking hands on the top. With cannons aimed at downtown Chattanooga the park also offers

fantastic views of the town and Moccasin Bend in the Tennessee River; it's a picturesque drive up there too, and ideal for poetic inspiration. It's another early start tomorrow when I head for Asheville and what I hope will be my Appalachian Adventure.



In Asheville I stopped at another Motel 6, it thundered again during the night also there was a noisy loco with its horn going off - other than that a good night's



sleep and an early start. Sat nav took

me via Knoxville it was quicker and much more scenic, high hills and rivers, bendy roads. It rained a bit on the way, now it's sunny, it's a nice place, very picturesque, there was a slight glitch getting here - an accident had closed the interstate and a diversion was in operation. Calling for fuel a guy at the filling station asked if I wanted help to get back on the interstate. I think the Texas number plate might have been a good indication. I said "yes please" and he gave me clear directions and they worked.



I did my laundry, at Asheville and that was it unless I needed to iron a shirt there was no more washing it was mostly shops and commercial premises where I was but it was a pleasant afternoon. I was able to relax and plan the next stage both the Blue Ridge Parkway and Skyline Drive, a total of 490 miles of scenic beauty where there is no commercial traffic; the biggest vehicle you'll see is a camper van. I booked two nights at different locations on the route I decided to trust to luck on the third night, at this time of the year there seems to be no problem. I'd bought a mobile whilst in Austin so I would be able to ring any motel whilst on my travels and my great American Adventure. In the next issue I cover the rest of the tour but a question before then, in the song 'Walking in Memphis' what was the little number Muriel and Marc did?