Caring for M. E.

September 2012

Miss Janet Gilbert **D.O.B.**

missjgilbert@gmail.com

Allergies

many skin products;
cream/deodorant/soap
Monotrim (antibiotic)
Elastoplast
Eating peppers
Cow's milk – can only eat limited amount

Useful contact numbers

Mum's mobile number

Sarah Lawrence (sister)
home phone number
work phone number

Dr Thirkell (Heathgate surgery)
Social Worker

Advice lines

Working as a carer & direct payments	Independent Living 01508 491210
M. E. Association	0844 576 5326
Carer's support line	

(pic. Of Saidee and me)

Hello!

I have written this manual in the hope that it will help you in your job of looking after me.

The picture on the front is by Emma Harper, a 16-year-old girl who suffers from M.E.. Many people comment that I look well and do not support me as I need with my severe disability. This picture shows what M. E. feels like inside long before we look pale and tired outside.

My long-time carers have told me that in the beginning they found the details and particular needs of an M. E. sufferer worrying and onerous. But they do add that, once they got used to it, the consistency of my needs and predictability of my routine actually makes the job quite easy!

The descriptions and statements in this piece of writing are based on my experience and my understanding of articles and research I have read.

Thank you for taking time to read this.

From,

Janet Gilbert

About M.E.

The name

M.E. stands for myalgic encephamyelopathy, which describes malfunctions in the brain, brain stem and muscles. It is a term that has been used for a half-century and tries to pin down a disabling and exhausting condition. A more modern label, Chronic Fatigue Syndrome, is used for many people and can include those with M.E..

For me the defining symptom of M.E. is the excessive exhaustion after very small exertion and, if one persists, extreme deterioration and disability. The American M.E. Society phrased it like this:

> “The defining characteristic of M.E. is that patients relapse with physical exertion and develop disease progression with continued physical exertion. Hence, the defining characteristic is exercise intolerance, post-exertional muscle weakness, generalized weakness, faintness, and pain; and post-exertional relapsing of symptoms. In some cases symptoms remit with rest, and in other cases they do not”

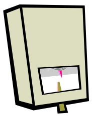
What has gone wrong?

No one knows for certain. Research is going on and some of the results make sense of what I experience. Increasingly a part of the brain called the hypothalamus is mentioned. The hypothalamus controls all the chemical messages in the body. For example serotonin which puts us to sleep; cortisol which makes us alert; acetylcholine which dilates the veins; and many others. All these have been found to be causing problems. You can imagine the impact, of these going wrong, on the way my body operates.

For example: Think about Standing up

We do it without thinking, yet imagine trying to stand a ruler up on end, and you can see that your body and brain are performing magic and working very hard. One example of this is how your body and brain stops gravity keeping all the blood in the feet and getting it to the brain and heart. This goes wrong in ME so that standing up makes us ill. There is research that shows that people with severe ME have heart failure if they remain standing because the ME biology can't do whats needed. This failure is called ORTHOSTATIC INTOLERANCE.

(I have written a separate section which describes the biology of ME and the ongoing research for you to read at another time.)



A doctor has used the picture of a thermostat, which controls all the heating in the house: you set it to turn on the heating at 20°. But it is faulty and although the house is still warm at 22° it thinks it is 20° and turn the heating on! In the same way although there is no germ attacking my body my brain still turns on the immune system so I am fluey. These malfunctions affect all parts of my health.

The basics

M.E. affects people with different severity and symptoms and will vary in intensity for each person day by day. If a person with M.E. has no symptoms at rest, can work full-time but will have mild symptoms following physical or mental exertion they have 10% loss of normal energy. I am classified as 100% loss of energy because I have severe symptoms on a continuous basis. I am bedridden constantly. I am unable to care for myself.

It is thought that 60% to 80% of people suffering from M.E. Find some improvement in their health often taking 3 to 5 years, a few will return to living a mostly normal life. However there is a significant minority that do not recover and, after 20 years, I fall into this category.

There is no cure for M. E. at present. I have tried many “cures” and therapies over the years without benefit. I take various tablets to manage symptoms such as pain and sleeplessness.

It is often said to me that I look well. It may even be that you see me do something that I have said I cannot. For example I will say I do not read. This is true: if I read the consequences are devastating. So when I say I cannot do something I may mean the results of doing it will be destructive.

The most important aspect of M. E. is this deterioration after exertion.

The best picture of what is going on is of the **bank account**!

An elderly couple has £100,000 in the bank. They are paid £10,000 interest each year. This is their income and covers their daily expenses. But they decide to go on a £10,000 holiday to Florida. So for this year they spend £20,000: 10,000 more than their income, leaving only £90,000 in the bank. The problem comes when they are only paid £9,000 interest. So they are £1000 short on their daily expenses. And so a spiral of eating into their capital, to cover lessening interest begins.

This is like M.E.. I already have very little in the energy bank and very small interest payments. If I use more than I should I eat into my capital and the amount of energy available to me day-to-day shrinks, which makes matters worse. I can get to the point of having nothing in the bank and then I am paralysed.

If you wait until I seem tired and ill to conserve my energy levels it is already too late because I have already had to tap into my capital.

What is it like?

It is like the second day of **having flu** when you ache all over, have a sore throat, are exhausted by a little trip to the bathroom, and you feel either very hot or very cold.

It is like having a **brain stuffed with cotton wool**. Some of my thought processes are damaged so that memory and concentration are affected; I tire rapidly and "compound thinking" which requires juggling more than two thoughts is almost painful.

The brain processes also **malfunction** with **information from the senses.** For example, imagine two radios, tuned to different stations at their loudest volume, sitting on your shoulders all day. This is a kind of torture, fatiguing and obviously makes it difficult to listen to people etc. All my senses are inflamed in this way - and particularly eyesight and touch.

It is being continually **thirsty**. It is **burning pains** in my neck, hands, feet and in arms and legs. It is **nausea** and **poor digestion**. It is plummeting blood sugar. It is **allergies -** for me particularly of the skin. It is constant **headaches.** It is **nothing working** reliably in my body. It is have **being emotional** but not having the energy to be happy or angry or worried or upset. On bad days it is difficulty breathing and swallowing; at my worst it is **paralysis**.

It is continual and profound exhaustion. It is being weary 10 minutes after waking. It is heaviness and weakness of muscle after doing so very little. It is life confined by lack of energy and overreaction of my body systems.

What does it mean for daily life?

It makes details terribly important. Getting it right is not just about me being comfortable or uncomfortable. Getting details right is about me being more or being less disabled.

- For example if I am too hot, because my Bedding has not been arranged as I need it, I am less mobile
- For example if I am asked too many questions in the morning I may be unable to move to use the commode in evening
- For example if there are two people in my room doing different things my brain goes into visual overload and I become confused and tired.

Pacing

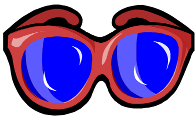
There are many ideas about managing M.E. (some of them even cause long-term damage to sufferers.) One of them is called "pacing". This is a common-sense idea, which breaks the activities of the day into small portions. One calculates for anything that takes energy: eating; talking; washing and dressing; watching television; more obvious exertions; and for me, being awake! These sessions of activity are interspersed with proper rest.

So a pattern of activity and rest is formed; protecting the energy supply and rationing it out to the end of the day. I am dependent on this timetable; it enables a higher quality of life. Ignoring it means my condition deteriorates severely. So it is important that things happen punctually so that I get the proper amount of rest in the right places and also food for energy

Proper rest means body and brain relaxed, without pain or distraction so at the end I am as refreshed as possible. To achieve this my bedding must be comfortable (especially with regard to temperature) and I use pillows to support my body. (See the sections on the bed)

How I manage my mental restrictions and the oversensitivity of my senses.

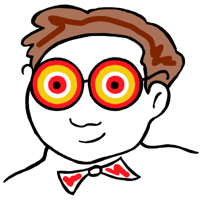
Although none of my senses are comfortable to live with, sight and sound are particularly disabling.



SIGHT: the problems I have with my eyes start with oversensitivity to light. Even winter sunshine is a problem. This is why I wear dark glasses. It is important that you put these on me quickly as is practical. In the summertime we keep my bedroom curtains closed. In the spring and autumn they are open about a foot unless the day is very bright. In the winter if there is no sunshine it could be fully open.

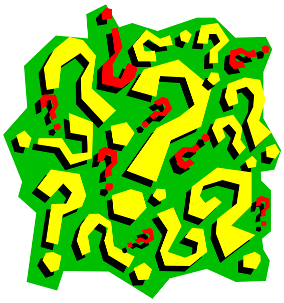
The other problem is that my brain does not process input from my eyes normally: it does not ignore things noticed before and allow them to become part of the background; it tries to process all movement it sees; some process like reading are complicated and exhausting.

I manage this by not reading; by limiting (videoed) TV to about four hours a week, watched in bits and pieces. I also try to keep my environment visually simple. This is impossible with so much going on around me so I have quiet areas from which **clutter** must be moved. Please be aware where you put things and be aware of clutter that can be put away.



SOUND: this is not just loud noise because any sound provokes brain exertion. Any sound takes brain processing and absorbs energy. Repetitive or layered sounds such as rustling plastic bags are really tiring. My brain is sometimes overwhelmed so that I can be slow understanding what is said to me.

I wear ear plugs constantly but still I hear a great deal. Please do your best to minimise the sound you make; although I do recognise that you need to work! E.g. wearing soft-soled shoes/letting go of the kitchen cupboard doors when closing so the soft-close hinges can work/keeping doors shut.



TALKING AND QUESTIONS: Having people around me is very demanding. My brain has to process a lot of information from sight and sound. Visits from carers every day as well as family coming and going. I need those around me to be aware that conversation drains my energy supply drastically.

Please be aware of this. I enjoy people's company but I cannot afford the energy to chat all the time. It will help me if you will keep a limit on talking so my brain can rest when you are with me. It is also easier for me if you keep things brief and sentences short! Do not wait until I appear exhausted. Also, do not wait for me to manage this; it may be necessary to tell me to shut up for my own good!

Answering questions and giving instructions or explanations seems to demand complex brain processing and compound thinking. I am exhausted very quickly. This means you need to take the initiative and decide what needs doing. I prefer the wrong decision to being asked a question.

This goes against the natural way of working, I know, but it is essential. One technique that does help is to make a statement of your intention: don't say, "Do you want the blind up?" Say, "I'll open the blind."; don't say, "Shall I turn you over?" Say, "I'll turn you over now." This gives me the opportunity to comment but doesn't seem to need the same brainpower.

I may also give you clues. For example: if I say I am tired I mean that my energy levels are getting dangerously low and I need you to conserve my energy and be extra careful.

MANAGING TEMPERATURE: My own body temperature is unpredictable so I need my environment to adapt. I also rely on cold to manage headaches, feeling fluey, burning pain in my extremities etc. My sense of hot and cold is not the same as yours so you need to think about this even when you are not too hot and cold.

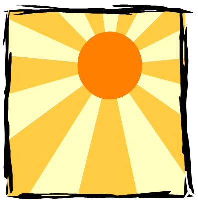
Normally speaking I am most comfortable at a temperature of 15° to 17° (there is a thermometer on the bedside table)

In winter this is fairly easy to achieve.

If you need to lower the temperature you can consider a) turning off the radiators b) opening the window c) making Janet's bedding and clothing less warm.

If you need to make the room warmer you can consider a) closing the window b) turning on the radiator c) adjusting Janet's bedding so it is warmer or giving her a cardigan.

When you choose to make things warmer please check the temperature again because after an hour the room gets uncomfortably warm.



In summer it is impossible to get the temperature 15° to 17°. We do the best we can.

-If the outside temperature is below 20° opening the window and adjusting Janet's bedding will be adequate.
-If the temperature is above 20° close the window and turn on the air conditioner.

We keep **wheat bags in the freezer**. My carers put them behind my neck. They are an essential support but also the cold is very important. You will need to replace them all the time.

MANAGING THIRST: please give me a drink of water if it more than 30 minutes since my last drink. Please make sure that the water jug has plenty of water in it. Please make sure the plastic beaker is nearest the bed so that I may reach it comfortably.

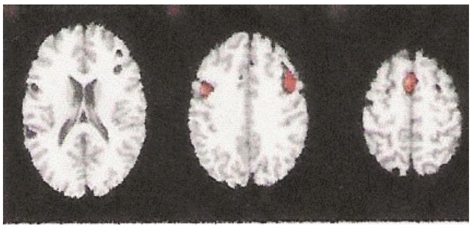
LATEST RESEARCH IN ME
as understood by Janet

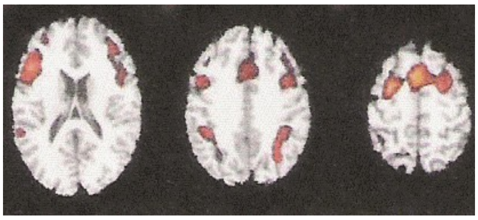
WHAT GOES ON IN M.E. HEADS?

M.E. People experience "brain fog", problems thinking, and also with processing input from the senses properly. Why?

Research* that scanned the brains of healthy people and M.E. People may give a clue. Red indicates activity.

SPOT THE DIFFERENCE





Both groups are adding up the same numbers. Both groups get the right answers. But the M.E. group's brain scan shows more and larger areas of red. The brain is working harder.

This explains why questions and other complex thinking exhaust M.E. People. And if the activity is the same for sensory input it explains why sound or movement can bring paralysis and spasms to those with M.E.

LANGE ET AL 2005

DR KERR'S RESEARCH INTO GENE EXPRESSION 2007

Gene expression looks "gene activity", that is the way genes are behaving.

This research found 88 genes in people with ME that are behaving differently from healthy people. The areas they looked on the DNA were to do with the immune system and mitochondria (the batteries inside cells).

Importantly they may have the first evidence to explain why one person with ME has very different symptoms from another. The Gene expression was able to predict from the gene activities abnormalities in each person the symptoms and severity they would have.

HEART PROBLEMS

Research by A Perkerman, PHD called “Abnormal Impedance Cardiography” pr may help explain why some ME people are more severely affected than others.

The study tested the behaviour of the hearts of a group of severely affected CFS/ME sufferers and a group that were less severely affected, looking at stroke volume and cardiac output.

It found that severe sufferers have an abnormally low cardiac output, significantly this was different for the finding for the less severely affected.

The study excluded the possibility that this was a consequence of inactivity by including a group of healthy but inactive controls

Excerpts from the paper:

“The patients with severe CFS had significantly lower stroke volume and cardiac output than the controls and less ill CFS patients.

Post-exertional malaise and flu-like symptoms of infection differentiated the patients with severe CFS from those with less severe CFS (88.5% concordance) and were predictive…. of lower cardiac output”

In short, at times, the hearts of patients affected severely by CFS/ME are doing an inadequate job. This leads to problems in other major organs.

Why do we get more disabled after activity?

This is the symptoms that makes ME different from other fatigue illnesses. It is what disables us, because we learn that to push outside the confines of our “activity envelope” is counterproductive – we are able to do less!

A study published in 2009 by Dr S Myhill looked at “CFS and mitochondrial dysfunction”

We are made up of lots of different cells - heart, blood, muscle nerve cells etc. All these cells are different because they all have a different job of work to do. To do this job of work requires energy....the way in which energy is supplied is the same for every cell in the body. . Energy is supplied to cells by mitochondria which I think of as little engines which power every cell in the body -like an engine takes petrol and turns it into energy for a car.

So mitochondria takes chemicals inside the body, adds extra fuel eg glucose and phosphates and so the cells have energy to work. The cycle of providing new energy should take about 10 seconds If the mitochondria is slow then stamina is poor and then body struggles – activity cannot be sustained.

Even worse, the body responds to the lack of energy by going into emergency mode and using all available glucose to create lactic acid which burns and makes muscles heavy and leaves no glucose left for normal energy production – and that normal energy is needed to repair the body and so produce fuel for activity efficiently.

No wonder it takes days to recover from minimal activity!

A SUMMARY OF THE

MEDICAL DIAGNOSIS CRITERIA FOR ME

FROM GUIDELINES CALLED,

“THE CANADIAN CONSENSUS GUIDELINE