

**Submission To The Parliamentary Inquiry**  
**Into Progress In The Scientific Research Of**  
**M.E.**  
**By The 25% Severe ME Group**

**CONTENTS**

1. Overview and Comments from some 25% ME Group Members (pgs 1-3)
2. Impact of the Chief Medical Officer's Report (pgs 3-4)
3. Dangerous Strategies (pgs 5-6)
4. Clinical Research (pgs 6-14)
5. Survey Results and Analysis (pgs 14-29)
6. Conclusion (pgs 29-39)
7. References (pgs 39-42)
8. Appendix 1 (pgs 42-53)

**“One of the biggest medical scandals in history”**  
**A survey of those most severely affected by ME/CFS.**

**Submission to the Parliamentary Inquiry into progress in the scientific research of M.E.  
by the 25% Severe ME Group**

**Greg Crowhurst**

**December 15<sup>th</sup> 2005**

*“This will be revealed as one of the biggest medical scandals in history”* declared a severe ME sufferer. This Report, based on an email survey of sixty- four severely ill, classical, Ramsay-defined ME/CFS sufferers, with a “multiplicity of symptoms” including, muscle phenomena, circulatory impairment and cerebral dysfunction (Ramsay 1988), was conducted at short notice in December 2005 especially for the Parliamentary Inquiry, by the 25% Severe ME Group.

“The too facile assumptions that such” an illness “can be solely attributed to psychological stress is simply untenable”, pointed out Ramsay.

The 25% Group is the only organisation in the UK specifically representing the interests of those who are most severely affected by ME/CFS.

*“It is bad having severe ME but not as bad as being treated as a time wasting malingerer by the medical profession and the Department of Works and Pensions”*, remarked one respondent. Another sufferer’s experience testifies to just how devastating severe ME is, yet like so many of the stories in this study, it is also a moving account of great courage, perseverance and determination.

*“I am 33 years old, and because of my illness I have no education beyond my GCSEs, no job, no qualifications, no partner, no children, I live with my parents, and have a very limited social life.*

*Yet I am incredibly self-motivated and positive, and spend almost all my available energy working towards getting better. I have a fantastic family, a few good friends (I became ill when I was 17, and most of my friends 'evaporated') and a good team of carers. The interesting thing is that none of them have ever offered to do a charity event on behalf of M.E. research. I can only guess, but I imagine that if I had cancer, M.S. or one of the other more 'acceptable' illnesses, people would have been running marathons and jumping out of aeroplanes at the drop of a hat. Understanding of my condition is improving all the time, but there seems to be no public awareness of the need for research.*

*Perhaps part of the problem is that the more ill we are, the more invisible we become -- hidden away at home and unable to participate in life. The elements of my illness which are the biggest handicap, are also the biggest hurdle in terms of public perception. We are too ill to be out there and be seen to be bravely struggling on with life. It is an unfashionable and boringly chronic illness. Yet because it IS such a long-term condition, there is a wealth of experience out there, which could be used to inspire and support scientific research”.*

In 2000 a survey of 25% Group members revealed that

- 55% of respondents had been ill for more than 10 years
- 50% of them had taken more than 2 years to obtain a formal diagnosis of ME/CFS
- 25% of respondents described themselves as bedridden
- 57% had been either housebound or bedridden for more than 6 years
- As regards appropriate medical advice or treatment, 29% reported that none had been offered during the course of their illness
- Only 25% of respondents felt that their condition was improving, or had improved from an even more chronic level
- 38% described themselves as totally dependent on others
- 48% reported no regular assessment or management of their condition.

Fundamentally, our members are very ill and very isolated indeed; little however has changed for them in the five years since the survey above. Our latest research paints a bleak and often horrifying picture, for a seemingly all-powerful, multi-million-pound-funded UK school of psychiatrists, determined for whatever political or commercial agenda to make ME a mental health issue, continues to wield its wildly inappropriate influence.

Just how powerful that psychiatric lobby's influence is and the impact it is having on real lives, is illustrated by the following examples :

- a medical team recently informed one severely ill sufferer that ME/CFS is a *“sort of phobia”*
- a sufferer was told by their *“NHS acupuncturist “ that “ ME/CFS patients .. are not really ill”*
- a sufferer reports being *“subjected to derision and dismissal with repeated accusations of ‘anxiety and depression’ ”*
- another sufferer states that *“My GP’s practice seems to have the opinion that ME is nothing, and that it is related to depression, and that if you are in bed, then you have “given in”*
- one of our members *“arrived at A&E ... when they took my medical history and discovered that I had ME they were reluctant to investigate into my new symptoms and on my medical notes they documented that I was psychosomatic and anxious and they kept sending me home and telling me to live with it. By my final admission into hospital my MP had forwarded my complaint to the PCT and proper investigations commenced in which it was discovered that I had a large amount of Gallstones in my Gallbladder, but despite the results of the ultrasound they were still saying that the new symptoms that I was suffering with were unrelated to the Gallstones and that it was my ME and irritable bowel syndrome. My MP carried on fighting for my case and in December 2004 the hospital finally surgically removed my Gallbladder which resolved the problem. In January 2005 I obtained a copy of my histology report on my Gallbladder which revealed that my Gallbladder was in a very bad way and chronically inflamed and compacted with Gallstones.*

Unavoidably, much of this report is overshadowed by issues concerning the psychiatric lobby, for its baneful existence is probably the greatest obstacle that sufferers face, standing accused as it does of :

- ignoring the *“world-wide literature on the severity and chronicity of ME”* (Williams 2005);
- falsely assuming that ME is a somatoform (psychiatric) disorder (Sharpe 1999)
- being unduly influenced by the medical insurance industry (Marshall, Williams and Hooper 2000) (Marshall & Williams 2003)
- being engaged in *“persistent and frequently covert attempts to subvert the international classification of this disorder.”* (Hooper 2004)

A respondent describes how *“This illness makes life hard enough as it is. It is so much worse that, whilst there is the ability to investigate this illness, that opportunity is being deliberately ignored. The choice the medical profession is making to treat a physical illness with psycho-nonsense is never going to cure anybody.”*

Another sufferer sums up the situation: *“If the psychiatrists continue to influence research and funding into ME we will never receive appropriate treatment or recognition for the severity of the illness. The many biomedical discoveries into abnormalities in ME patients are ignored by psychiatrists who inform the world (including our GPs and all medical staff we come into contact with) that we are suffering from a somatisation disorder...If the government continues to be informed about ME by a wholly inappropriate sector of the medical profession then many thousands of severely ill people will continue to be seriously ill and not taken seriously.”*

ME/CFS, which can occur in both sporadic and epidemic forms, has been described in the medical literature for about 70 years. Cycles of severe relapse are common, as are further symptoms developing over time. Around 30% of cases are progressive and degenerative and sometimes ME/CFS is fatal. (National CFIDS Foundation). Two recent reviews have concluded that "Substantial improvement is uncommon and is less than 6%" (Anderson et al. 2004); and "Full recovery... is rare" (Cairns & Hotopf, 2005).

As Simon Lawrence (2005), co-ordinator of the 25% Group explains: "The continuing argument as to whether ME/CFS is a physical illness or not, is one which is only perpetuated in some quarters. The reality is that the WHO classifies ME/CFS as a neurological condition (and has done since 1969) and this is the stance accepted by the British Government. Of particular concern to the 25% Group is the way in which this very complex disease, which affects every system in the body, is conceptually reduced to its principal symptom of overriding fatigue, and takes no account of neurological, immunological or endocrinological factors.

It leads the reader to believe that ME/CFS is, in the main, a psychological disorder; no proof for this view exists, and the majority of patients utterly refute this idea."

### **Impact of the Chief Medical Officer's Report**

The Chief Medical Officer (DoH 2002) acknowledged that people with severe ME/CFS in the UK currently receive "seriously inadequate health care".

A sufferer recounts a typical experience: "*I have been turned away by a neurologist, who did no tests, his comments were 'you need to get out more'. I am severely affected and 80-70% bedbound, 90% housebound. I am desperate to be free of dreadful pain and illness, and go out and live my life. I cannot find the words to express how frustrating it is when the suggestion is that I am in bed ill out of choice. ....I have been told by an ex-friend that I might be attention seeking, and that if they don't give me attention when I am ill, then that is best for me. I have even been told by a GP that if I meet someone and fall 'in love', I might find all my symptoms disappear"*.

Another sufferer tells how: "*I am not monitored by anyone. I only see my GP if I have an unrelated problem, eg. a chest infection or need an alteration to my existing drugs. I have not been seen by a consultant for 8 years. I have never been seen by anyone specialising in ME, apart from a psychiatrist whom I do not accept as an ME specialist as my illness is not a mental health or behaviour problem."*

In 2004 a survey of 25 % Group members revealed that:

- Of those who had had a community care assessment, 61% felt that their care package was inadequate
- Some of the reasons why members had not received a care package included: "Care package was opposed by the applicant's Consultant Psychiatrist" and "No medical evidence was provided by applicant's GP to support claim"
- Several subjects reported only receiving an adequate care package following High Court Judgements in the claimants' favour
- Nearly half of those studied had not received an assessment from an Occupational Therapist, although the need for home adaptations was rated fairly high, the greatest need being for mobility equipment
- 58% of respondents were completely unable to attend their GPs surgery, yet over half of these people said that they never receive home visits from their GP.

Clearly the CMO's Report has made very little difference to these sufferers' lives and that is no surprise. In 2002 the Countess of Mar predicted that the impact of the Report would be to compound :

- **Inaction** in not investigating the patient's illness or not providing any treatment – for the Report's emphasis was on management, not treatment
- **Ignorance** by promoting inappropriate and possibly harmful interventions
- **Denial** of the true nature of ME.

She noted at the time how the CMO Report was met by a “deafening silence”- and three years later that silence is still ringing out, according to sufferers:

- *I think the Report was unhelpful in that it did not draw a distinction between ME and Chronic Fatigue, trivialised ME (focusing on fatigue and pain when there can be other, much more serious and debilitating symptoms) and concentrated on CBT and Activity Programmes like they were a ‘cure’. They are not and can even be harmful. It also did not call for research into the physical causes of ME and treatments which are suit the severely affected and children.*
- *I thought the publication would bring about a new era for ME sufferers but it did not. I still meet Doctors, GPs and medical people who say that it’s all in the mind, which is sad when you have been living with the condition for nearly 6 years*
- *It’s now nearly 4 years since the publication of this report. In reality though it seems to have made little if any real difference though to people with ME. There has still been no public funding of biomedical research into this illness. Contrast this with the millions that have been handed over to a “select” group of psychiatrists to perpetuate their own flawed theories in the PACE & FINE trials as they continue to play their statistical games with other peoples lives.*
- *My GP hasn’t read it and I can’t see any evidence locally that anything has changed.*
- *I have not seen my GP since 1996.*
- *GP not that diligent. He won’t visit me at home so, like many M.E. sufferers, if I cannot get to the surgery, I am at distinct disadvantage.*

The CMO Report was criticised by MERGE (2002) for:

- The narrowness of its remit, which “ensured that the focus is on containment and coping, rather than on solving the clinical conundrum, namely, what actually causes the illness and what steps can be taken to elucidate the cause.
- Not unpacking the vague and too-wide diagnostic construct “CFS”
- Recommending Cognitive Behavioural Therapy and Graded Exercise Therapy, based on “less than conclusive evidence” and despite the fact that the “specific efficacy of neither is convincingly supported by the systematic review evidence, and nor is the pragmatic efficacy supported by survey reports from CFS/ME patients.”
- Not systematically analysing the significance of the large body of research literature outlining the numerous biological abnormalities, pathophysiological mechanisms and the range of clinical signs and symptoms exhibited by CFS/ME patients
- Presenting to “the media, the public, and opinion formers that the best that can be done is to manage symptoms, most prominently with psychological strategies.”
- For recommending inappropriate management strategies for the severely affected who remain a “neglected challenge”.

One sufferer sums up the situation:

*“The report’s failure to differentiate between fatigue states and ME has continued to influence understanding & handling of the condition. Research and treatment of the disease has been similarly affected in that any government funding for these ventures have only gone to towards psychiatrically based projects.*

*As a result of the above, and taking into account my own & others experience of the condition, I have to conclude that the CMO report has had little positive effect on our situation and has probably made a previously bad situation worse.”*

## Dangerous strategies

Other criticisms of the CMO's Report at the time of publication were:

- That it promoted CBT and GET as a treatment which benefits patients across the board, even though there is no evidence that it benefits patients with signs of immune activation or muscle disease, or for that matter, infectious or neurological symptoms. (Goudsmit 2002)
- That for a disorder classed under Neurological Diseases by the World Health Organisation (ICD-10: G93.3), "there was only one neurologist and he was on the ad hoc committee. On the other hand, there were five psychiatrists/therapists, at least one of whom had earlier dismissed ME as a 'belief system'. And although there was an immunologist on the influential Key Group, there was no one who has studied the virology of ME. (Goudsmit 2002)
- That it ignored patient evidence by recommending that Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) are the "most promising treatments" available at present" despite submitted evidence from over 4000 patients showing CBT and GET are positively harmful. (Harrison 2002)

A sufferer recounts the often horrifying impact of this "treatment" regime on those with severe ME:

*"All of my 'help' is useless:*

*I am offered anti-depressants (I am not depressed)*

*I am offered 'Behavioural Therapy' (I have no incorrect illness beliefs).*

*I am offered 'Graded Exercise' (Which even in small moderation, relapses me).*

*EVEN WHEN I DO THESE ALL AGAINST MY WILL. As an inpatient in Hospital, my medical records are falsified, and it claims I am 'obstructive' to my own recovery, as these psychosomatic principles have no effect on me. This is then claimed to be MY fault, not the fact that I am not mentally ill, and therefore do not 'recover' from M.E via mental illness interventions".*

The same sufferer goes on to tell how:

*"I was refused medical drugs for chest pain and orthostatic intolerance (a feature of M.E) unless I agreed to be LOCKED in a mental institution in LONDON (National Hospital For Neurology & Neurosurgery) Summer 2004.*

*I participated in ALL activities I was asked to do, despite being mostly bed-bound.*

*I was not given food, and had to resort to hiding food in bags, and urinating in water bottles and hiding them under the bed (as I was refused to be pushed to the toilet).*

*Despite this treatment, I continued my 'Behavioural Therapy at this Hospital and did everything they asked. On reading my medical records, it stated 'had not engaged with the treatment protocol, and self-discharged'. All lies and fabrication of the truth*

*This is what 'Behavioural Therapy' is for an M.E patient in 2004 in the NHS".*

There were many other such horror stories:

- *All nurses I have encountered, bar one whose daughter had ME, have treated me with contempt, lack of understanding and actual neglect during a hospital stay as they had "far worse off patients than you" to care for.*
- *Even now, after engaging in another battle with the local health authority because I was confronted with a doctor (previously) who would not even discuss a report with me which had*

*been produced and provided by the ME Specialist I saw, I feel the new doctor, at times, is merely paying lip service to the fact I got put on his list via the local health authority, rather than by his choice. This, lately, has caused him to develop an “attitude” with me and I keep biting my tongue when confronted with such an attitude. Not only is it appalling behaviour but I believe he is trying to see how far he can push me and then he can feel justified in saying to the local PCT he wants me to be removed from his surgery list.*

- *When I was first ill (8 years ago) my condition started to improve a little and my GP suggested I get back to exercising. It wasn't really graded exercise – he said I should “get on my bike and get my heart pumping again.” I did this along with some aerobic exercise thinking this would get my fitness back. I then became severely affected and have been for the past 8 years – whether this was because of the exercise I don't know.*
- *A hospital psychiatrist put in my notes that she suspected anorexia as I was very underweight - my inability to chew solid food due to muscle weakness and oesophageal spasms were classed as anxiety related. If they had been classed as the physical problems they were, I would have been put on a high protein liquid diet (or even been tube fed which would have been a Godsend) and given muscle relaxants to stop the spasms – both of which would have been invaluable. Once I was back home, my GP prescribed the muscle relaxants I needed (at my request) and I easily gained weight on store bought high protein shakes. Yet the anorexia notes are still in my hospital file and place a stigma on me which colours any future dealings with hospital medical staff, despite me proving that anorexia was not the issue – a physical difficulty was, and despite an earlier psychiatric report which stated I had no behavioural problems. No matter what evidence to the contrary, the psychiatric label prevails.*
- *I have been shut in an AIDS ward for 7 weeks and the staff have been told to “Limit Patient contact” and “Write down everything he says” despite being mentally sound, and never sectioned. This was in an Immunological ward. Astonishing that this should happen in the NHS after so much is known about M.E*
- *My GP's practice seems to have the opinion that ME is nothing, and that it is related to depression, and that if you are in bed, then you have “given in”. When I have tried to explain to my GP how ill I feel, or try to explain different symptoms, I feel I am not believed or that I am exaggerating...A family member asked me about my illness, and when I tried to explain what I was feeling, and how difficult it made my life, she dismissed every thing I said, and ended the conversation by saying that I “should be locked up. And that I was not fit to be out, and I should be locked in the Psychiatric unit immediately”*
- *My GP gave me a leaflet his practice had received from Simon Wessley's unit at Kings College Hospital in London. I read it and said that the condition it described had no similarities to what I was experiencing. He suggested I go for an initial assessment anyway which I did – at great cost to my health. On arrival I was horrified to find that the ‘CFS’ unit was in the psychiatric department KCH and at that time, security doors protected it. I was also concerned that I was attending a ‘CFS’ unit since this label did not describe my complaint. It came as a shock to be seen by a psychiatrist who displayed little or no understanding of what I told him. My symptoms, most of which are included in the Canadian Criteria, were dismissed or ignored. At the end of the consultation he suggested a course of CBT and said I should take up exercise and get some hobbies. Six months later I was called for a course of CBT which I declined. The therapist became aggressive and defensive when I explained why.*

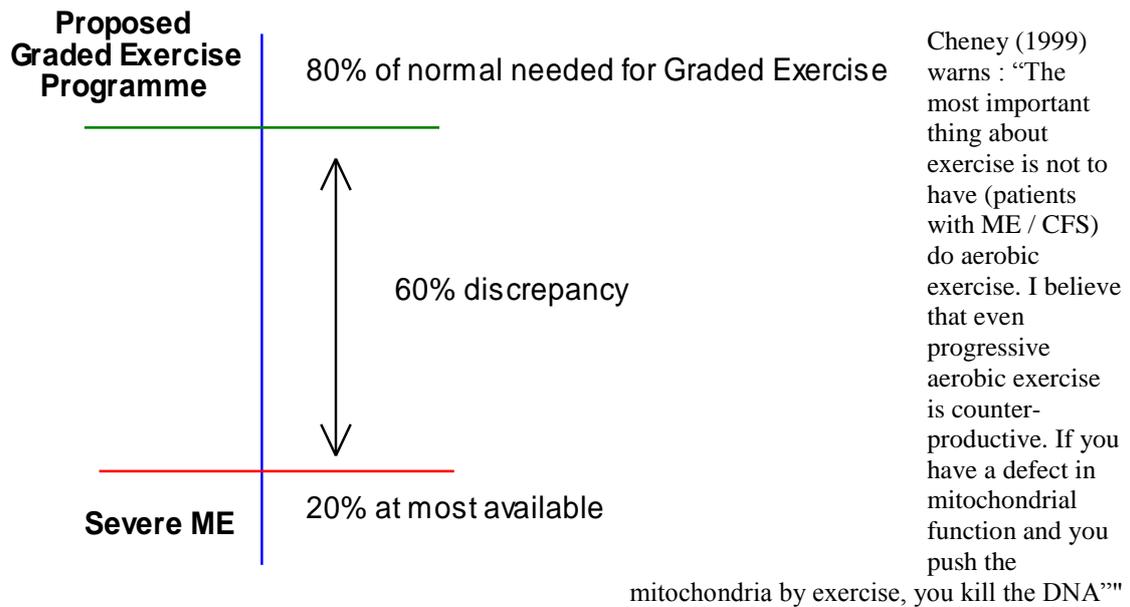
### **Clinical Research**

In a 2004 survey, members of the 25 % Group found:

- cognitive behavioural therapy (93% unhelpful) and psychotherapy (90% unhelpful)
- Worsening of condition with graded exercise therapy (tried by 39% of members, and 82% made worse by it)

These results are confirmed by this latest survey in which only one person who had tried CBT and GET reported that it was helpful

According to Loveless (Munson 1995) the ME/CFS patients whom he saw had far lower scores on the Karnofsky performance scale than HIV patients even in the last week of their life, indicating a probable functional ability of between 10 and 20 % of normal. This figure is highly significant for as Ho-Yen (1994) states, a patient “with (ME/CFS) should be advised not to increase their activities gradually until they feel 80% of normal”. This is illustrated below:



In 1994 Peterson stated that "In my experience, (ME/CFS) is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages". In a 2001 survey of US medical professionals (n=8100) 75% of survey respondents believed that ME/ CFS is at least as disabling (53%) or more disabling (22%) than other chronic diseases such as lupus, multiple sclerosis or rheumatoid arthritis. Australian researchers found that in severe ME/CFS the degree of impairment is more extreme than in end-stage renal disease and heart disease and that only in terminally ill cancer and stroke patients, is the sickness impact profile greater.

Wright (2003) outlines how the body of the ME/CFS sufferer: "is subject to a high degree of oxidative stress, probably the most damaging state in biology". A recent MERGE-funded study (2005) has shown for the first time in ME/CFS patients raised levels of F2 –isoprostanes, which are a standard indicator of oxidative stress and are also associated with clinical symptoms such as joint pain and post exercise illness. As Komaroff (2000) stated: "In summary, there is now considerable evidence of an underlying biological process in most patients (which) is inconsistent with the hypothesis that (the illness) involves symptoms that are only imagined or amplified because of underlying psychiatric distress. It is time to put that hypothesis to rest." Indeed Kennedy et al (2004) have proven that patients with ME/CFS have an underlying detectable immunological abnormality that is consistent with an activated inflammatory process such as a persistent or reactivating infection or a toxic state.

Professor Kenny De Meirleir of Brussels states: “For me as a clinician, “CFS” is no longer a mystery but a treatable auto-immune disorder. We have given it its place between lupus, diabetes Type 1 and multiple sclerosis. We explain all the symptoms of “CFS”, which we now call “AFS” (autoimmune fatigue syndrome) by cellular and immune abnormalities”.

### Immune system problems include:

- Abnormalities found in the 2-5 synthetase/RNase L anti viral pathway. As Professor Robert Suhadolnick (2004) affirms: “the higher the RNase L activity, the lower the patient’s ability to function”. Cheney (1999) explains: “What does RNase-L do? It chews up human messenger RNA inhibiting every enzyme in the body. Hence CIFS patients end up on their backs”
- Low molecular weight RNaseL in ME/CFS patients, this aberrant form of RNase L is up to six times more destructive than the typical form. This helps explain why ME/CFS sufferers are very sick; the question for Dr Cheney is “How are these people surviving?”
- In this illness, the RNase L activity shifts to the more destructive lower weight form and does not shut off. It stays activated much longer, resulting in pronounced cellular metabolic dysfunction.

### Endocrine system problems include:

- abnormalities in the output of hormones which help explain problems with cognitive functioning , central processing of information and sleep initiation
- abnormalities in cortisol and DHEA, leading to a chronic depression of cortisol and DHEA (which is not seen in depressive illnesses.) This means that bodily homeostasis (balance) cannot be maintained in the presence of any form of biological stress and goes a long way towards explaining the exacerbation of many of the symptoms in ME/CFS
- depletion of central opioid tone in ME/CFS, which may explain some of the pain that sufferers experience
- a reduction in adrenal gland size, which may be a result of the body trying to downregulate the stress signals it is receiving from the brain. This may also account for many of the symptoms of ME/CFS such as functional hypothyroidism at a cellular level even though blood level thyroid measurements are normal, and low levels of pituitary hormone output, for example Growth Hormone, caused by oxidative stress, which may be the cause of the fatigue.

### Nervous System problems include:

- an excess of sympathetic over parasympathetic tone means that a constant biological stress is present in the body
- simply stated, a body that cannot respond to any form of biological stress be it environmental, infective, physical or psychological
- a wealth of studies (about 85%) confirm autonomic nervous system (ANS) dysfunction in up to 90% of CFS patients, with resulting effects on many vital functions (blood pressure, pulse rate, breathing and body temperature)
- DeLange (2005) found a significant 8% reduction in brain gray matter volume, related to the level of physical activity in ME patients and Okada (2004) reported an average 11.8% reduction in gray matter volume which paralleled the severity of the fatigue of the patients.

As Wright (2003) puts it: "given the bi-directional flow of information between the nervous, endocrine and nervous systems we are presented with a perfect example of Chaos Biology."

Holgate and Kerr et al (2005) have recently found that patients with ME/CFS have reproducible alterations in gene regulation and that " there are more gene abnormalities present (in ME/CFS) than are found in cancer sufferers." (Williams 2005)

Variants of the term "M.E." were first used following a series of repeating epidemics starting in May 1955 in the Royal Free Hospital , London (Hyde 1998) Recognised as a specific disease entity by The

Royal Society of Medicine in 1978 and by the World Health Organisation since 1969 as an organic neurological disease, ME/CFS is currently classified under ICD code G93.3. Virtually no research has been carried out however on those who are most severely affected by ME. What few trials there have been, tend not to deal with the house and bed-bound. As Abbot (2004) points out: "very few studies exist, and all define "severe illness" in different ways, complicating interpretation of the findings. And specific laboratory-based or experimental studies on severe sufferers are as rare as hens' teeth."

ME / CFS is characterized by (Mark 2005):

1. malaise following even modest physical activity
2. delayed reaction to physical and/or mental activity (up till 24 hours and more)
3. abnormal length of convalescence (out of proportion to level of activity)
4. varying and fluctuating symptoms during the day, but also in the course of days, weeks and months.

Above all, the defining characteristic of ME/CFS is cellular metabolic (Sieverling 1999) and acquired central nervous system dysfunction (Hyde 2003)

As Crowhurst L (2005), a severe ME sufferer, explains: "When you say "fatigue", what do you think of? You think of just being very tired. The muscle fatigue I experience is completely devastating fatigue that leads to a multifunctional inability to move. That goes beyond ordinary normal awareness and interpretation of the word "fatigue". This is what I think people do not understand. It's not that my muscles are tired, or very tired, or even very, very tired; they don't work. That is the fatigue we are talking about in severe ME and I don't think most people realise that. I certainly didn't know it, even though I had the condition, because no one explained it to me. This isn't the tiredness that comes from depression and non-activity; this is the paralysing, non-functioning disability caused by a range of malfunctioning physiological systems within the body and is not something that is controllable or relinquished by intention or by increased activity. Increased activity is impossible when your muscles do not function. "

Shepherd (2001) warns that as much care should be taken in prescribing exercise as in prescribing pharmaceuticals for ME/CFS patients do not respond to exercise in a manner that is expected of healthy people (Streeten et al 2001) This is illustrated in the table overleaf :

### The impact and the dangers of Exercise in ME/CFS

- It takes the ME/CFS sufferer an inordinate amount of time to recover from exercise (van de Sande 2003)
- A characteristic worsening of symptoms following exercise is a major feature of ME/CFS (Cheney and Lapp 2000)
- Patients cannot increase their activity levels every week, even gradually, as they tend to reach a plateau and going above that invariably causes a relapse (Goudsmit 2001)
- ME/CFS patients receive less blood and oxygen to the brain after exercise (Goldstein 1993) and their maximum oxygen uptake is approximately only half that of sedentary controls. This could indicate the heart is functioning at a sub-optimal level and that exercise could be dangerous (De Beceker et al 2000)
- Either a cardiac or peripheral insufficiency could be embedded in the pathology of ME/CFS patients (Inbar et al 2001). Williams (2004) states : "many people with ME / CFS may have a serious heart problem "
- In ME/CFS, the patient's body temperature normally decreases in response to exercise - the opposite of normal (Goldstein 1993) The severity of post-exertional symptoms ranges from mild to severe, or may be life-threatening (seizures and cardiac events). The onset of post-exertional symptoms may be very sudden, but more often are delayed by 12 - 24 or 48 hours (or longer) and may then persist for hours, weeks or months afterward (Bassett 2005)
- The response of ME/ CFS patients to incremental exercise associates a lengthened and accentuated oxidative stress together with marked alterations of the muscle membrane excitability. These two objective signs of muscle dysfunction are sufficient to explain muscle pain and postexertional malaise reported in patients (Jammes et al 2005)
- Orthostatic intolerance, low circulating blood volume and blood pooling in the legs often play a role in post-exertional malaise and fatigue (Streeten 2001)

Just how dangerous aerobic exercise can be for the severe ME sufferer is illustrated by this respondent's tragic story :

*"I was an in-patient in a psychiatric ward of a London hospital. I was the only patient who did not have a mental health problem, and although my CBT therapist had had plenty of experience of working with M.E. patients, I was the first to be admitted as an in-patient. I only saw my therapist once a week, and the psychiatric nurses had no understanding of my illness at all. There was a huge amount of stress, and I was treated very badly by some of them. I received both CBT and GET, but the graded exercise seemed to be given priority. I worked with a physiotherapist, who also had no experience of M.E. I began to seriously deteriorate, and 4 months in, suffered a major relapse. I had a kind of undiagnosed 'stroke', collapsed, and became incapable of looking after myself.*

*When I went to the hospital I could walk 100 yd., feed, wash and dress myself. When I left I could not weight bear at all, had no leg muscles to speak of, and needed two people to transfer me on and off the toilet and in and out of bed. I had little use of my hands and was totally bed bound. I could not tolerate sitting upright against the pillows, conversation was beyond me, and I could barely manage to feed myself by picking up food in my hands -- cutlery was out of the question. Nine years later I have improved, but I'm still bed bound".*

Sufferers -- who are desperate for physical research and treatment -- are very aware of and extremely angry about the impact of the predominant psychiatric paradigm upon their life:

- *It has destroyed my life. Now 22 years in severe ME state with no appropriate treatment for a neurological illness.*

- *....terribly bad -- makes my situation twice as hard – now I have to deal with the illness and the negativity of the medical profession and media. I have been ignored by the medical profession on the whole, and at other times ridiculed and verbally abused. This has all caused me untold stress and suffering.*
- *It annoys me intensely. Psychiatric treatment would be totally inappropriate for me. I know perfectly well that my symptoms are physical and neurological (rather than psychological or psychosomatic) and consider this bias extremely unhelpful; I feel that more resources should be channelled into research to seek a clinical cure.*
- *It ruins lives. If you do not respond to CBT and Graded Activity you are given up on. The medical profession, and lay persons, think that ME is just pain and fatigue and we are all depressed, even in the face of evidence to the contrary. The only treatments offered aim to correct these symptoms, and any other symptoms are classed as psychosomatic. Because of this serious, debilitating and potentially life threatening symptoms are left untreated causing unnecessary suffering.*
- *I feel that I have to constantly explain myself. I think most people understand and believe I've got a real physical illness...but there's still this idea that there may be a psychiatric component to it. I feel that if I had another more recognised neurological illness like MS I wouldn't have to continually explain things.*
- *THEIR ATTITUDE HAS been an absolute bane on my health and well-being. I have had problems with doctors, benefits, and my permanent Health Insurance thanks to the psychiatrists' attitude towards ME and appalling treatments suggested.*
- *The suggestion that this illness has a psychological basis fuels many of the misconceptions about this illness. I am very ill, and I have had to suffer comments from people that are extremely upsetting i.e. 'I need to be dragged outside for my own good'. Or 'fresh air is the answer' or 'A change of environment is needed'.*
- *Since contracting ME over 10 years ago I have experienced misunderstanding, neglect, rudeness, ridicule, ignorance and what can only be described as downright cruelty from almost every area of society (medical profession and some ME charities & their officials included).*
- *The benefits system seems to work on the basis that sufferers have no physical illness & are psychiatric cases. As has recently happened in my own case. This decision is made by an Examining Medical Practitioner who spent less than an hour in my home. He concluded that as he could see no clinical signs then I must have a gross illness behaviour problem. The tribunal panel were hostile, nasty and confrontational and totally believed the EMP saying I was a wholly unreliable witness.*

“It seems we are constantly having to fight on different fronts concerning how ME sufferers are treated when it comes to the medical profession or the benefits agency” writes Simon Lawrence in the (Winter 2005) Newsletter of the 25% Group.

Current Disability Living Allowance (DLA) guidelines on CFS/ME may easily usher in wrongful assumptions on the part of assessors, leading them to believe:

- that Cognitive Behaviour Therapy (CBT) and Graded Exercise are an effective cure
- that those unable or refusing to participate in inappropriate psychiatric "treatment" regimes or who are not getting better following them are somehow inadequate and at fault
- that sufferers do not have the right thought processes or the correct attitude to getting better / returning to work.

As one respondent stated:

*“If you do not respond to Graded Activity, the Benefits Agency seem to think you are either malingering or depressed and benefits are refused. The Agency, and in particular their Medical*

*Examiners, seem oblivious to the problems and symptoms of severe ME and all seem under the impression that everyone with ME recovers in under 5 years. If you are still ill after that it either isn't ME or you are mentally or behaviourally ill in some way.*

The truth is that those with ME can be so ill and not get better; they can be so ill, not just for a few weeks, but for years on end, for decades even, without remit, without any relief, while psychiatric research accrues every single penny of Government funding for itself in a fruitless attempt to research and implement an inappropriate, harmful behavioural and exercise regime:

- *Giving GET and CBT to people with ME is like trying to prescribe treatment without first investigating the disease – madness! We need proper biomedical research to find out the cause(s) of this illness and to investigate fully what it does to the body. GET and CBT have been found to be at best unhelpful to those with ME at worse, harmful.*
- *It means that I live in fear of professional involvement because I want to be treated for my physical illness and am afraid that*
  - a) *they will not believe I am really ill*
  - b) *they will not understand the symptoms I suffer or accept they are real*
  - c) *they will give me inappropriate treatment*
  - d) *they will say I am lying about my disability*

*(I have experience of all these things in the past from various professionals)*

- *Any treatment for psychiatric problems that are not there are likely to kill me!*
- *It means that I am simply offered no treatment whatsoever. I am just left to get on with it.*
- *After I came home from the hospital where I received CBT/GET therapy, a physio came to see me once a week. The first one was absolutely appalling, and used to drag me up off the bed and hold me upright, even though I was too ill to cope with this, and my body was collapsing under me. It was a 'fight' really, with her believing that if I wasn't allowed to sit down, the muscles in my legs would improve, and I would gradually begin to weight-bear.*

Sufferers are far too ill to protest, and too ill to ever undergo the so called behavioural remedies being developed in their name, but will never successfully treat anyone with real ME, as one sufferer explains:

*"I have been ill in different phases for 15 years. I have worked it out for myself that you can only "exercise" within very narrow limits. It is simply not the case that you can exercise your way out of this illness. If it were that simple most people with ME who were previously very fit and active, would have long since recovered."*

Another sufferer describes how, despite an "extensive psychiatric evaluation" which resulted in a report saying 'she is severely physically disabled', 'has no mood or behavioural problems' and 'is coping remarkably well given very difficult circumstances', she was still offered "CBT and counselling and my symptoms of severe nerve pain, nausea, difficulties with speaking, sight, swallowing and eating, seizure like brain activity, intermittent paralysis, contractures in hands and feet etc were left uninvestigated and untreated."

This sufferer states how: "I could see the sense in graded exercise and how it could help someone to comeback from an illness and aid in their recovery but unfortunately with ME this treatment does not work and just sets you back".

Today, UK mainstream medicine --- ignoring the mountain of biomedical evidence to the contrary--- seems to subscribe to the Three Myths that:

<b>ME/CFS : THE 3 MYTHS</b>
<b>ME/CFS is a “medically unexplained condition”</b>
<b>ME/CFS is due to “aberrant illness belief”</b>
<b>ME/CFS is best "treated" by a combination of behaviour and exercise therapies</b>

*“It is totally unacceptable that I should be put through this distress because of ignorance about the severity and reality of my condition and disability, as a person really suffering with severe ME”* asserts a sufferer.

*“We wish of course that we could recover from the illness, and resume a normal life, with a little graded exercise/activity and a positive mindset. It would be the perfect solution without having to resort to drugs and the risk of side effects. But it simply doesn’t work for those correctly diagnosed with ME and in some cases can actually make matters even worse”*, says this respondent.

*“I no longer see medical professionals because it is so hard to tell who is biased and who is not until it is too late. The absolute worst are so called ME specialists as they do not admit that they think ME/CFS is a behavioural disease and they put on the charm offensive, they are such liars and cheats”* another sufferer complains.

*“ME patients not given proper consideration when the diverse range of symptoms are classed as being "all in the mind". As a consequence my own condition deteriorated to my requiring 24hr care with a rota of three nurses and my husband to care for me”* this sufferer stated, showing how dangerous ill-informed treatment can be.

*“CBT in particular is understandably appealing to the DoH as it’s an apparently cheap option to deal with an expensive problem. But it appears to be a red herring dressed up as a cure by those who seek to deny the physical reality of the illness”* points out this sufferer.

Hyde (2003) outlines how: "ME illness in adults is associated with measurable changes in the CNS (central nervous system) and autonomic function and at times injury to the cardiovascular, endocrine, and other organs and systems. Munson (2000) states how "Many startling abnormalities have been found in ME/ICD-CFS patients in almost every bodily system, such as extremely low blood volume, enzyme pathway disruptions, cardiac disturbances, and malfunction of the hypothalamus-pituitary-adrenal axis. One remarkable study, utilizing specific brain scan techniques, found the effects of ME/CFS on the brain to be strikingly similar to AIDS dementia. Earlier research discovered punctuate lesions in ME/CFS brains resembling those of Multiple Sclerosis patients. Dr Paul Cheney found that in dual chromatography analyses, many ME/CFS patients actually had more derangement of the brain, on a biochemical level, than Parkinson's or Alzheimer's patients.

As microbiologist Dr. Elizabeth Dowsett explains: ‘There is ample evidence that M.E. is primarily a neurological illness, although non-neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised’

Some sufferers tried to describe the severity of their symptoms:

- *“Chronic fatigue, to the point of exhaustion. Severe migrainous headaches, with which I wake up - often lasting up to 5 days – light, noise sensitive, nausea, vomiting, loss of appetite.*
- *Tinnitus, Severe menstrual problems, Nerve pain, Bone pain, Back pain, Severe headaches continuous to acute, Post exertional Malaise – excessive weakness, Myalgia – muscle pain, Fibromyalgia - Neck and shoulder muscle pain, Mood swings, Chronic Insomnia, Hypersomnia, Sleep disturbances/nightmares ,Multi Chemical Sensitivity – MCS ,Cognitive dysfunction, concentration and attention span loss, Anomia – difficulty to give objects a name,*

*Dysnomia – inability to give objects a correct name, Memory loss, Food intolerances and insensitivities, Pain. Loss of co-ordination and comprehension, Intolerance to certain smells, environmental pollutants, aerosols, cleaning products, Difficulty walking, Difficulty standing, Fluid retention, Oedema/swelling of face, hands, feet and ankles, Tight chest, Facial neuralgia, High blood pressure, Slow speech, Visual disturbances, Unexplained hair loss, Neck creaks and cracks, neck stiffness, Eyes/vision: double, blurry, pain, increased floaters, increased motion sickness, Light-headedness, wooziness, difficulty walking, clumsy bumping into objects, irritability*

- *Poor circulation, my hands and feet are always cold. Sweats day and night – which is linked to chronic infection. Migraines that are worse than migraines and different pain to any other headache Nose Bleeds. Spinal cord inflamed and painful day and night. Twitching of muscles. Soreness, aches and pain in limbs. Legs give way, rashes on body, shingles. Lack of muscle tone. Find it difficult to find the right words in conversation. Breathlessness. Urinary Tract infections*
- *EXHAUSTION AFTER NORMAL ACTIVITY is a prime symptom- “general malaise” doesn’t seem strong enough to cover this, and people don’t realise the absolute depth of exhaustion experienced.*
- |                           |                           |                                                                       |                                                                                                                                                                                                            |
|---------------------------|---------------------------|-----------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>WEAKNESS</i>           | <i>EXHAUSTION</i>         | <i>FATIGUE</i>                                                        | <i>MALAISE / DEBILITY</i>                                                                                                                                                                                  |
| <i>Poor Co-ordination</i> | <i>No Strength</i>        | <i>Knee, hip, back, shoulder &amp; upper arm joint stiffness/pain</i> | <i>Easily tipped into exhaustion &amp; relapse by physical, mental or emotional exertion, taking days to recover. Unpredictable how much exertion will be deleterious, or how serious or long-lasting.</i> |
| <i>BRAIN</i>              | <i>Poor concentration</i> | <i>Poor comprehension</i>                                             | <i>Word finding problems</i>                                                                                                                                                                               |
| <i>Slow thinking</i>      |                           |                                                                       |                                                                                                                                                                                                            |
- *Permanent exhaustion with recovery times after any effort or movement increasing with each year that passes—ie. for the first 10 years, recovery time would be 2-4 days whereas over the last 12 years, recovery time has gradually increased to 7-20 days.*

### **Survey Results & Analysis**

The table shows just how ill the severely affected who took part in this study are.

“GPs don’t realise the severity of and distress caused by the symptom” declared a respondent.

*“I spent 4 days in hospital last April and the doctors/nurses seemed to have no/very little understanding of ME/CFS – when I explained my symptoms they seemed uninterested, and didn’t really take the ME seriously or as relevant to my gut problems. Very frustrating. Same with the NHS dietician – she had no understanding of ME and wasn’t very supportive at all”* writes this sufferer.

*“I have also, during 1996-2003 been subjected to some very invasive surgical procedures, involving general anaesthetic which, had (someone with knowledge of M.E.) been available on the NHS in my area, they would, I am sure, have recognised some of the symptoms with which I suffer, and the surgical exploration therefore would not have been necessary”* this sufferer observes, stressing how important it is to understand the symptoms of ME/CFS.

Bassett (2005) explains : “ Myalgic Encephalomyelitis is a loss of the ability of the Central Nervous System (the brain) to adequately receive, interpret, store and recover information which enables it to control vital body functions (cognitive, hormonal, cardiovascular, autonomic and sensory nerve communication, digestive, visual auditory balance etc). It is a loss of normal internal homeostasis. The individual can no longer function systemically within normal limits. Confirmation of this hypothesis is supported by electrical tests of muscle and of brain function (including the subsequent development of PET and SPECT scans) and by biochemical and hormonal assays. Newer scientific evidence is increasingly strengthening this hypothesis.”

The diagnosis ME/CFS is controversial. In 1994, the United States Centers for Disease Control and Prevention (CDC) published a working case definition called the Fukuda criteria, which has become internationally accepted (Fukuda *et al* 1994). However, the CDC criteria were primarily intended for research purposes and not for clinical definition (Carruthers *et al* 2003). Because the CDC emphasises fatigue as the sole compulsory criterion, it has attracted criticism for allowing disparate fatigue conditions, for example, post-traumatic stress disorder, depression and conditions that improve with exercise (Spurgin 2003) to be diagnosed as CFS/ME; the CDC definition is increasingly viewed as too broad and indistinct to be useful (Carruthers *et al* 2003).

The Fukuda criteria led to misunderstanding in both research and treatment modalities by making "fatigue" a compulsory symptom but by downplaying or making optional the disease's hallmark of post-exertional malaise and other cardinal ME/CFS symptoms. This led, says Spurgin (2003) "to inconsistent research results and inappropriate treatment protocols, like cognitive behaviour therapy (CBT) and graded exercise therapy (GET) which caused many patients to become worse."

In 2003 The Canadian Expert Consensus Panel published a medical milestone, the first clinical case definition for the disease known as myalgic encephalomyelitis/chronic fatigue syndrome, upon which the chart below is based. This definition was a vast improvement over the CDC's 1994 Fukuda criteria.

At its AGM in 2004 the members of the 25% Group voted unanimously to adopt the Canadian Definition as their criteria for membership of the Group.

In sharp contrast to the Fukuda criteria, the Canadian clinical case definition makes it compulsory that in order to be diagnosed with ME/CFS, a patient must become symptomatically ill after exercise and must also have neurological, neurocognitive, neuroendocrine, dysautonomic, and immune manifestations. In short, symptoms other than fatigue must be present for a patient to meet the criteria.

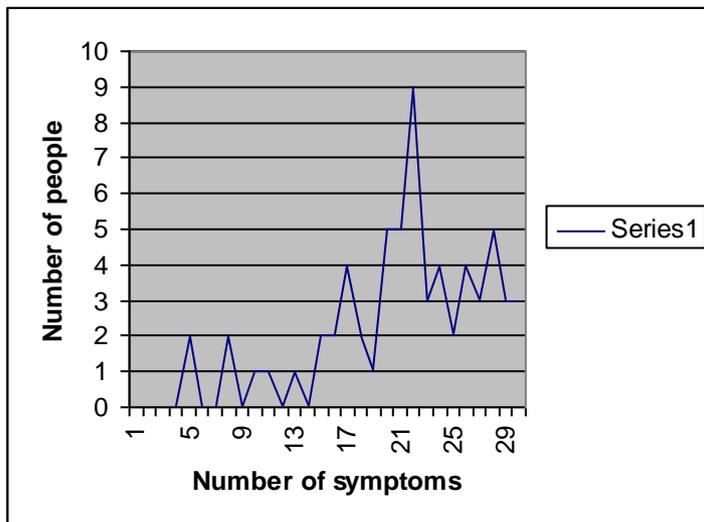
Some of these symptoms are reproduced in the following chart, along with the number and the percentage of sufferers experiencing each symptom:

<b>LIST OF SYMPTOMS (Adapted from the Canadian Definition - Carruthers B et al (2003) Myalgic encephalomyelitis/chronic fatigue syndrome : clinical working case definition; diagnostic and treatment protocols. Journal of Chronic Fatigue Syndrome 11, 1, 7-115)</b>	<b>Number of sufferers experiencing this symptom</b>	<b>Percentage of total</b>
<b>Tender lymph nodes</b>	<b>44</b>	<b>69%</b>
<b>Sore throat</b>	<b>48</b>	<b>75%</b>
<b>Flu-like symptoms</b>	<b>60</b>	<b>94%</b>
<b>General malaise</b>	<b>63</b>	<b>98%</b>
<b>Development of new allergies</b>	<b>38</b>	<b>60%</b>
<b>Hypersensitivity to medications and/or chemicals</b>	<b>46</b>	<b>72%</b>
<b>Loss of thermostatic stability</b>	<b>60</b>	<b>94%</b>
<b>Heat/Cold intolerance</b>	<b>53</b>	<b>83%</b>
<b>Anorexia or abnormal appetite</b>	<b>11</b>	<b>17%</b>
<b>Marked weight gain</b>	<b>29</b>	<b>45%</b>
<b>Hypoglycaemia</b>	<b>30</b>	<b>47%</b>
<b>Loss of adaptability and tolerance for stress.</b>	<b>53</b>	<b>83%</b>
<b>Worsening of symptoms with stress and slow recovery and emotional lability</b>	<b>57</b>	<b>89%</b>
<b>Postural hypotension (low blood pressure)</b>	<b>33</b>	<b>52%</b>
<b>Vertigo</b>	<b>42</b>	<b>66%</b>
<b>Light-headedness</b>	<b>52</b>	<b>84%</b>

<b>Extreme pallor</b>	<b>43</b>	<b>67%</b>
<b>Intestinal dysfunction</b>	<b>50</b>	<b>78%</b>
<b>Bladder dysfunction</b>	<b>38</b>	<b>59%</b>
<b>Heart Palpitations</b>	<b>35</b>	<b>55%</b>
<b>Respiratory irregularities</b>	<b>30</b>	<b>47%</b>
<b>Confusion</b>	<b>39</b>	<b>61%</b>
<b>Difficulty with information processing</b>	<b>54</b>	<b>84%</b>
<b>Perceptual/sensory disturbances</b>	<b>42</b>	<b>66%</b>
<b>Photophobia</b>	<b>41</b>	<b>64%</b>
<b>Hypersensitivity to noise</b>	<b>56</b>	<b>87%</b>
<b>Pain</b>	<b>60</b>	<b>94%</b>
<b>Transient Paralysis</b>	<b>31</b>	<b>48%</b>
<b>Pins &amp; Needles</b>	<b>47</b>	<b>73%</b>
<b>Numbness</b>	<b>44</b>	<b>69%</b>
<b>Nausea &amp; Vomiting</b>	<b>38</b>	<b>59%</b>

Significantly, 71% of respondents, according to our research, experience 20 or more symptoms each; the highest number of symptoms experienced was 30 .

This confirms that the research is a voice for the severely affected:



The symptoms reflect a complex range of:

**AUTONOMIC MANIFESTATIONS**, for example : Orthostatic Intolerance: e.g., neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension, vertigo, light-headedness, extreme pallor, intestinal or bladder disturbances with or without irritable bowel syndrome (IBS) or bladder dysfunction, palpitations with or without cardiac arrhythmia, vasomotor instability, and respiratory irregularities.

**NEUROENDOCRINE MANIFESTATIONS**, for example: loss of thermostatic stability, heat/cold intolerance, anorexia or abnormal appetite, marked weight change, hypoglycemia, loss of adaptability and tolerance for stress, worsening of symptoms with stress and slow recovery, and emotional lability.

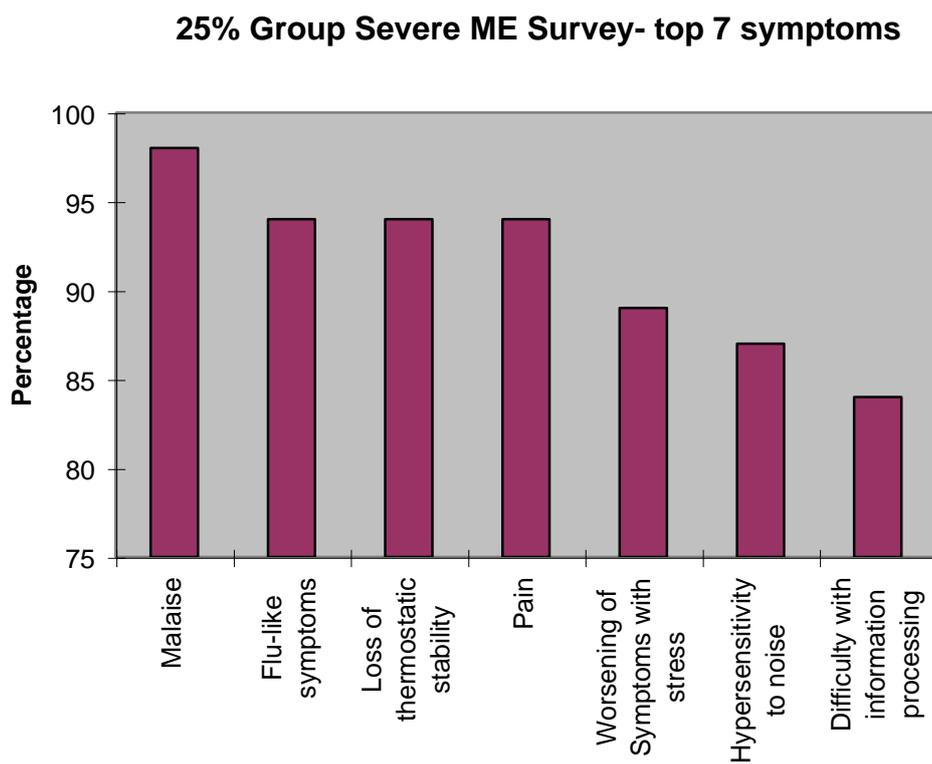
**IMMUNE MANIFESTATIONS**, for example: tender lymph nodes, sore throat, flu-like symptoms, general malaise, development of new allergies or changes in status of old ones, and hypersensitivity to medications and/or chemicals.

**NEUROLOGICAL/COGNITIVE MANIFESTATIONS**, for example: confusion, impairment of concentration and short-term memory consolidation, difficulty with information processing, categorizing, and word retrieval, intermittent dyslexia, perceptual/sensory disturbances, disorientation, and ataxia. There may be overload phenomena: informational, cognitive, and sensory overload -- e.g., photophobia and hypersensitivity to noise -- and/or emotional overload which may lead to relapses and/or anxiety.

The top seven symptoms experienced by the respondents were:

- **Malaise**
- **Flu-like symptoms**
- **Loss of thermostatic stability**
- **Pain**
- **Worsening of symptoms with stress**
- **Hypersensitivity to noise**
- **Difficulty with information processing**

This is illustrated in the chart below:



Clearly respondents are not just suffering from “medically unexplained fatigue”. A consideration of these real physical symptoms gives an insight into the seriousness of the illness and confirms the relevance of the Canadian Definition for the severely affected.

98% of respondents report malaise and 94% report “flu-like” symptoms, in other words: a loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional fatigue, malaise

and/or pain, and a tendency for other symptoms to worsen, a pathologically slow recovery period (it takes more than 24 hours to recover) .

As Laura Hillenbrand, ME sufferer & best selling author of the book and film “Seabiscuit” says: “This illness is to fatigue what a nuclear bomb is to a match. It’s an absurd mischaracterization.”

Sufferers, it should be stressed, feel generally ill all the time as well as disabled: *“physically unable to move, cognitively impaired, emotionally and physically stressed. Any one of these symptoms would send a normally healthy person to the hospital for tests, but people have on average 21 of these symptoms , and they are just not offering us the right tests”* said a severe ME sufferer.

“The disabling weakness and exhaustion a patient with ME/CFS experiences is so profound that ‘fatigue’ is probably an insult” Cuzzo (1989) noted.

A sufferer comments: *“It is difficult enough for the person with severe ME to be able to identify clearly the different symptoms that are operating and thus to understand what is going on in their body. Initially I was in such pain, shooting, stabbing, burning pain that spread to every part of my body, that coping with that alone was all-consuming and in a sense this masked the whole range of other symptoms that were developing or were already present. Fatigue was not the primary noticeable symptom.”*

94% of respondents report “loss of thermostatic stability”. This means that people’s temperature will rise and fall. They will feel hot and cold inappropriately. *“My hands and feet are always cold whatever the weather. I have shivers when it is hot and have to lie under a blanket because I cannot get warm or I sweat buckets, particularly at night and need my nightdress changing sometimes 2-3 times a night. My body temperature never seems to relate to outside conditions.”* describes a sufferer.

94% of respondents report “pain”: “This is a severe symptom which is difficult to treat and is usually due to dysfunction of the thalamus, an important sensory relay station in the brain stem. Failure to produce natural painkillers (e.g. endorphins and encephalins), may be an additional factor.” (Dowsett). There are many levels of pain suffered in ME and they can occur simultaneously: *“I have not been out of pain for 12 years now and that pain is never ending”*, says one sufferer, *“and all over my body, even my eyeballs, my eyebrows and the soles on my feet hurt. I find it hard to bear being touched. There is muscle pain, nerve pain, burning, itching, throbbing pain. It goes on continuously with no relent and no drug helps it, in fact most drugs I have tried make me more ill.”*

Another sufferer writes: *“Strong pain killers do little more than dull the muscle and joint pain I constantly experience all over my body.”*

25% Group member Megan Ò Criogàin (2002) expresses the physical agony of severe ME in a poem :

Pain gnawing  
Unrelenting pain  
Unremitting on body and mind  
This bag of bones was not designed  
For pain gnawing  
Unrelenting pain  
Burns through the soul  
Reaps a heavy toll  
This pain gnawing  
Unforgiving pain.

89% of respondents report “worsening symptoms with stress”. This, says Dr Dowsett, probably “arises from injury to the brain stem which normally controls the production of cortisol (a steroid required for stress control) via the hypothalamus, pituitary and adrenal glands. In the absence of an efficient response, even minor stress can cause catastrophic collapse in these patients. NB. Because of the many and varied symptoms arising from encephalitic damage to the brain, all symptoms reported, however bizarre they may seem, must be taken as possible evidence of organic disease.”

*“Yet current health provision, the policies and practices of the DWP, organisations that are supposed to be supporting the ill and disabled”, says a sufferer, “are doing everything in such a way that increases stress and decreases health – increases illness. Why not work out ways of helping that value and honour the person’s illness, disability and level of health? They are working against optimising health for people with severe ME.*

89% of sufferers report noise sensitivity; 84% report cognitive difficulties, with problems in processing information. It is well established, even among groups positing a psychological cause for ME/CFS, that objective cognitive changes have been found; Vercoulen et al (1998) found that test subjects could be correctly classified as CFS based on the cognitive test results.

Cognitive changes are not due to psychiatric co-morbidity (Vercoulen et al 1998 Backwood et al 1998 ) SPECT cerebral blood flow studies of persons with CFS show decreased blood flow in several key areas such as frontal lobes and brain stem which are different from both healthy controls (Barnden et al, 2001 Costa et al, 1995) and depressed subjects (Schwartz et al, 1994; Fischler et al, 1996). PET scan studies have reached similar conclusions (Tirelli et al, 1998).

There is so much more involved in this illness than “fatigue; additional symptoms were also listed by respondents in addition to the symptoms on the chart itself (which for the purposes of the questionnaire were restricted to only 31 symptoms).

In fact Bassett (2005) comments how: “More than 64 distinct symptoms have been authentically documented in ME/CFS. (Hooper & Montague 2001). At first glance it may seem that every symptom possible is mentioned, but the seemingly random list of symptoms in fact form unique and distinct patterns – they are anything but ‘random’ for those with knowledge of the illness and/or of how the illness effects the body’s various systems. As ME/CFS expert Dr David Bell M.D. explains ‘The pattern of symptoms is so reproducible in the usual case that patients are able to diagnose ME/CFS in others in an instant.’(1995). Montague and Hooper further comment that: ‘In ME/CFS, different people have different symptoms but the general pattern and evolution of major symptoms are remarkably coherent.’”

These are the additional symptoms reported by respondents:

sleep disorder  
disproportional slow recovery  
left-sided paralysis  
swallowing difficulties  
swollen eyeballs  
blurred vision  
inability to write  
word finding problems  
insomnia  
tinnitus  
severe menstrual problems  
excessive weakness  
mood swings  
hypersomnia  
multi-chemical sensitivity (MCS)  
concentration & attention span loss  
anomia (difficulty giving objects a name)  
dysnomia – inability to give objects a correct name  
memory loss  
food intolerances and insensitivities  
pain left eye, watery and glue like  
loss of co-ordination and comprehension

difficulty walking  
 oedema/swelling of face, hands, feet and ankles  
 tight chest  
 high blood pressure  
 slow speech  
 increased motion sickness  
 clumsy- bumping into objects  
 poor circulation  
 sweats day and night  
 nose bleeds  
 spinal cord inflamed and painful  
 twitching of muscles  
 legs give way  
 rashes on body, shingles  
 muscle weakness  
 urinary Tract infections  
 inability to read  
 body feeling heavy  
 acid reflux  
 difficulties swallowing  
 loss of vocal power  
 rhinitis  
 lack of stamina  
 inability to sit for long  
 inability to stand for long  
 repetitive thoughts, "runaway" thoughts  
 anxiety  
 complete inability to multitask  
 brain fog  
 need for bed rest and sleep  
 strange pains and creep crawly feelings  
 chest/cardiac pain  
 POTS (Postural Othostatic Tachycardia Syndrome)  
 Auditory/olfactory hallucinations  
 Itching  
 Extreme reaction to movement and bumping

A severely affected person's description of her problems with reading gives an example of how many of the symptoms work together to create great difficulty in ordinary actions, taken for granted by most people:

*"Reading, which seems like such a simple thing in principle, is so hard in practice because of the following difficulties:*

- *First of all there is the pain in my eyeballs, they itch and burn and throb. Sometimes they are numb and feel swollen. The eye doesn't keep its tear film intact so my eyes are constantly dry and irritated. The muscles do not stay in focus so it is physically difficult to look and see clearly the word on the page. It is painful even to look at them*
- *Then there is the difficulty of focussing attention and making sense of what the words actually mean*
- *There is the problem of processing the information*

- *There is also the tiredness in my head that people call 'brain fog'*
- *There is also severe head and eye pain and acute migraine-like headaches, to cope with*
- *And there is the aftermath of attempting to read which can result in a total shutdown and worsening of symptoms. The words can seem to move around the page. I might read the words but make no sense of them and cannot even bear to look most of the time*
- *This is the level of understanding required when approaching someone with severe ME. You need to accept that a person who says they cannot read, really cannot read and, as a professional, you should have some understanding of the complex reasons why that might be so in severe ME, especially if your job is to assess that person. I remember feeling belittled by a DLA Doctor who asked me if I could read and then did not give me the respect or have the understanding to listen to my answer."*

The chart below is designed to help one appreciate what might really be happening in the severe ME/CFS sufferer's body:

<b>Severe ME/CFS : Experience &amp; Symptoms</b>	
<b>Person's Experience</b>	<b>Some Possible Symptoms (Marshall et al 2001, Bassett 2005)</b>
I can't think	Cognitive impairments ( <b>impaired attention, memory and reasoning</b> ) are among the most frequently reported and least investigated components of CFS/ME.
I can't understand	<i>Processing problems, brain fog, intermittent partial or complete memory loss, recurrent stupor or stroke-like episodes, tremors, aphasia, ataxia, discalcula, .</i>
I can't cope with noise	<i>Hyperacusis, loss of adaptability and worsening of symptoms with stress</i>
I can't speak	<i>Word , number and thought sequencing difficulties , information absorbing difficulties, difficulty with voice production, paraphasia – incorrect word selection.</i>
I can't sleep	<i>Reversed sleep pattern disturbance, hypersomnia, vivid &amp; disturbing dreams</i>
I can't eat	<i>Food intolerances, difficulty with swallowing, choking, abdominal pains, problems with diarrhoea</i>
I can't sit up	<i>Muscle weakness, severe pain, palindromic arthropathies.</i>
I can't walk	<i>Pain, muscle fatigue, paralysis, persisting dysequilibrium and ataxia, cardiac arrthmia, angina-like chest pain</i>
I can't telephone	<i>Noise sensitivity, no energy, muscle weakness, loss of memory, concentration, intractable pain</i>
I can't write	<i>Pain, weakness, numbness, parasthesia, cognitive impairment, agraphia (inability to locate the words for writing), neurological changes in motor skills (handwriting, walking gait, vision, etc</i>

I can't get to the toilet	<i>Muscle dysfunction and twitching, orthostatic intolerance, Extreme post-exertional muscle fatiguability, recurrent nausea and profound, incapacitating malaise. Light-headedness and/or syncope (fainting), lower than normal blood volume, hypotension, loss of thermostatic stability,</i>
I can't wash myself	<i>Poor coordination, pain in muscles, joints, head, back, limbs, chest and stomach</i>
I can't stand up	<i>Orthostatic intolerance, muscle fatigue, weakness, difficulty with breathing, sudden attacks of breathlessness, dyspnoea ; the more severely affected are unable to stand unsupported for more than a few minutes.</i>
I can't cook	<i>Transient paralysis, pain, brain fog, poor coordination and balance, dizziness, volitional problems and/or cognitive slowing, loss of fine motor skills.</i>
I can't read	<i>Dry eyes, pain, blurred and double vision, difficulty in focusing , swollen and painful eyelids, word blindness, alexia (problems with reading)</i>
Colour hurts my eyes	<i>Neuralgia, disorders of colour perception,</i>
Touch hurts me	<i>Hyperesthesia, light touch can be acutely painful</i>
People's energy affects me	<i>Severe lack of energy to cope, prosopagnosia - not being able to recognize faces, facial agnosia, impairment of concentration, difficulty with visual and aural comprehension, an exaggerated response to even small amounts of additional input.</i>
Light hurts me	<i>Photophobia, perceptual and sensory disturbances, special instability and disorientation, abnormalities of sensation.</i>
Food hurts me	<i>Food intolerance, IBS, problems with maldigestion or malabsorption of food, histamine intolerance, esophageal spasms , difficulty swallowing, esophageal reflux, changes in taste and smell, bloating, abdominal pain, nausea, indigestion or vomiting , intense gallbladder pain,</i>

Often the only choice for sufferers is to avoid the medical profession, because of its negative attitudes and inappropriate, negative treatment, as one sufferer describes:

*I participated in Graded Exercise therapy via the 'National M.E Centre', Romford, Essex.*

*This lead to a relapse, at home, and made me unable to sit upright for 1 year due to pressure in my head, and chest pain. I then relapsed and ended up in my local NHS Hospital in a cardiac care unit.*

And another sufferer tells how:

*After exploration into Dr S's methods (treatment with antidepressants) I declined to attend. Firstly my condition bears no relation to that of the one described as Chronic Fatigue & secondly, I'd been prescribed several antidepressants when I first became unwell. They produced near catastrophic consequences & I had no wish to repeat this experience!*

As this sufferer points out:

*Having a career in professional management, (before forced to give up work through ill health), as part of management development, I touched on CBT within the psychology of training so knew a little about its application/benefit. Not a cynic, I felt I was sufficiently self aware however to recognise that CBT was not the answer to the “very physical” symptoms with which I battle as part of M.E. and felt it was not the best form of treatment for me.*

It is very important to understand that internationally, cognitive behavioural therapy and exercise are viewed as a coping strategy, to help people to "adjust to the limitations of the disease. It does not attempt to convince them (as in the UK, where it is used as a "treatment") that there is nothing physically wrong with them." (Marshall & Williams 2005), as this sufferer explains:

*There is also rumour (on good authority) that local health “politics” are afoot to transfer M.E. patients, such as myself, who are presently seeing a Consultant on an “out of area referral basis” over to these local clinics, pushing them to agree to the CBT, Pacing, GET therapy instead of existing treatment for very real “physical” symptoms.*

Overshadowing all this is an ongoing attempt by the psychiatric lobby to simply deny the illness by subtly changing its name, as Martin Walker (1998) observes : “Under cover of the most ubiquitous term ‘fatigue’, they had wiped out an illness by classifying a symptom.”

The descending ladder of abstraction is from:

**M.E.**

**Chronic Fatigue Syndrome**

**CFS/M.E.**

**CHRONIC FATIGUE**



As this sufferer explains:

*I am also told to my face and in my medical records, that as Chronic Fatigue Syndrome is now called CFS/ME in England, that now my illness, (M.E) is now called CFS/M.E....I am now told by my G.P, and by Doctors in Hospital, that Chronic Fatigue is Chronic Fatigue Syndrome, and Chronic Fatigue Syndrome is CFS/M.E*

The terms ‘fatigue’ and ‘chronic fatigue’ were not associated with this illness at all until the name was changed from ME to Chronic Fatigue Syndrome (CFS) in 1988 in the US, some say for political reasons (Johnson 1996). This has caused great confusion, for as Spence states: “‘ME’ at the start of the 21st century has come to be seen as little more than a ‘lay term’ used by patients and patient organisations, while chronic fatigue syndrome (CFS) has been adopted by the doctors and scientific journals. Today, the composite term ME/CFS represents the uneasy, not to say stormy, marriage of these two strange beasts”.

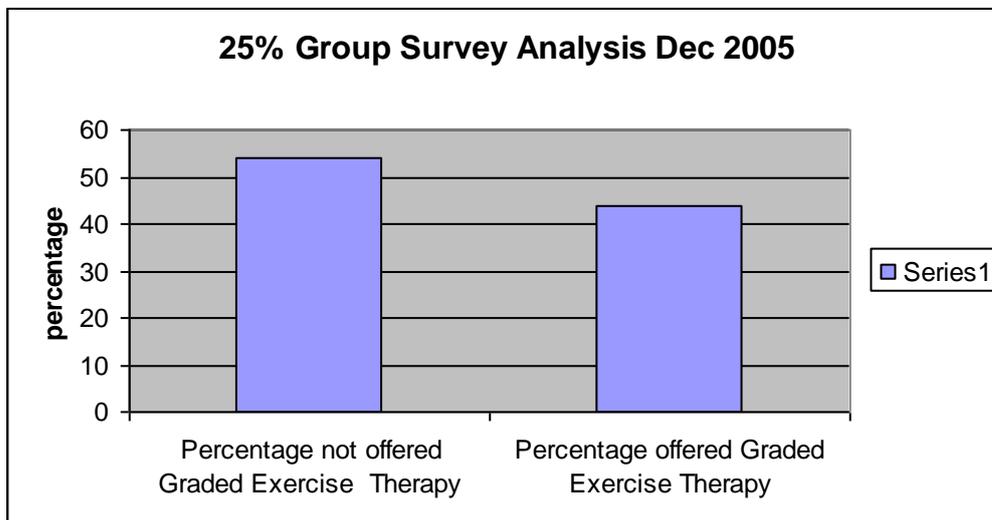
As Kennedy (2004) points out, this confusion has led to a "common misapprehension among doctors" which is to confuse Myalgic Encephalomyelitis, for which Chronic Fatigue Syndrome is merely another name, with Chronic Fatigue, a different condition. ME/CFS is classified in the WHO ICD-10 as a neurological disease (G93.3), whereas chronic fatigue is classified in ICD-10 as F48 (a mental disorder). It appears from anecdotal evidence that this is a common misapprehension among doctors... Some psychiatrists have been (incorrectly) using the two terms interchangeably for some time"

The condition is a complex one and there is an urgent need for a generic template ME/CFS care pathway. In the meantime it is crucial to listen to and respect the patient when he or she describes his or her symptoms, even if the symptoms are not fully understood. As Wall (2000) says: ‘My injuries are invisible, subtle in neurones, enzymes, cytokines, the intricate inner circuitry of the body that still eludes concise theories, that require scientific minds to make a leap of faith, to become, as it were, believers.’

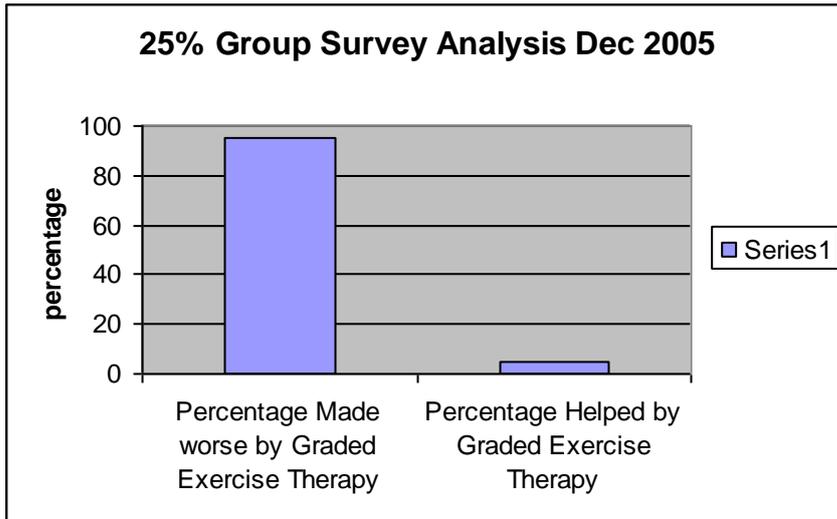
It is misleading to consider CBT, GET or pacing as treatments – they are management or coping strategies (Jones 2004). While strategies such as pacing appear to make sense, the situation in severe ME/CFS is complex. Crowhurst (Crowhurst L 2004) says: ‘My body moves towards paralysis and increased pain the closer it gets to the sleep state, even “resting” my body will move towards an inability to function: I won’t be able to move my fingers, legs, arms, walk, breathe easily, so the notion of pacing, which is based on rest, isn’t adequate because rest brings dysfunction and disability closer.’

Our survey results (below) demonstrate just how inappropriate it is to try and “treat” ME/CFS, a neurological illness, with psychiatric interventions.

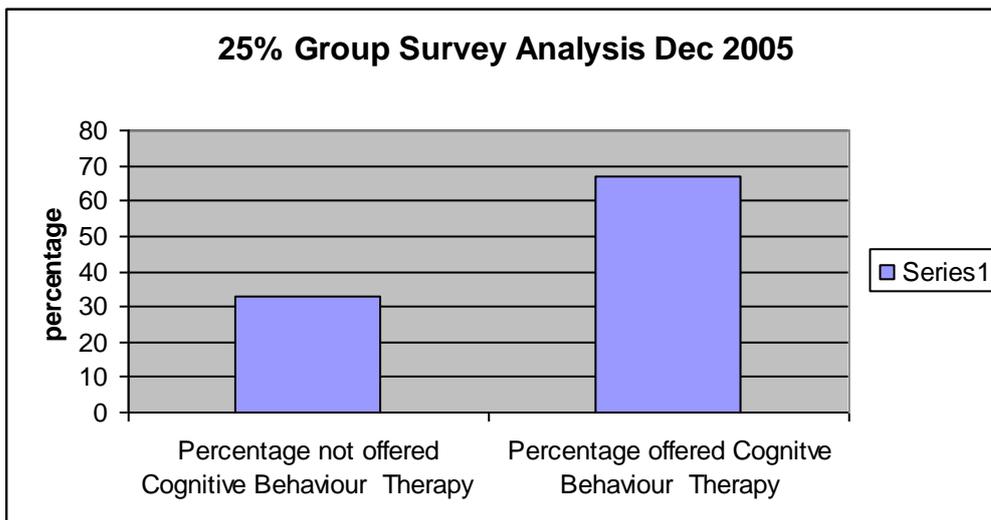
44% of respondents were offered Graded Exercise Therapy :



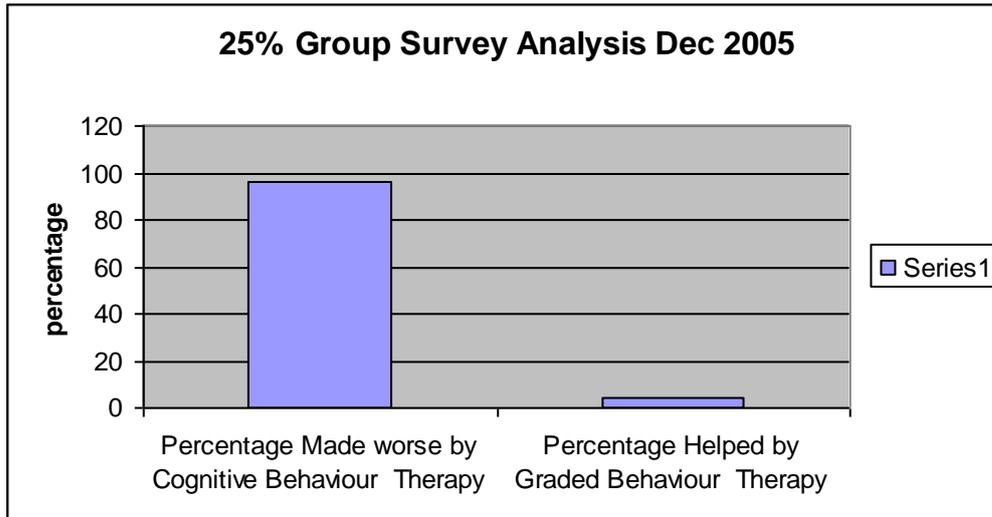
Of the 44% who were offered GET 64% tried it and 95% reported that GET had a negative impact on them:



67% of respondents were offered Cognitive Behaviour Therapy:



Of the 67% who were offered CBT 42% tried it and 96% reported that CBT had a negative impact on them :



The one sufferer who found GET and CBT helpful, heavily qualified their supporting statement:

*This (CBT & GET) had a positive effect in that it helped me develop coping strategies to deal with the day to day problems of ME. In no way was it put forward as a cure & I have never had the impression the therapist very firmly believes I have a genuine physical illness.*

Often the only option sufferers have left is to try and cope with the illness the best way they can :

Living & Coping with Severe ME/CFS (Crowhurst & Crowhurst 2005)
Be aware of the subtly of the illness : <i>when you can, when you can't and when you might.</i>
Know how you are in any one moment so you can cope with it
Learn how to be accepting of yourself in whatever state of illness you are in without giving up hope that it might/will/can change, at least on a micro-level, if not in an external obvious way.

This is not easy, but it is a courageous strategy to try and live with the onslaught of symptoms. This sufferer describes how: *Because I have never had a GP with full understanding of ME – I have made a book for myself to manage the illness according to my symptoms.*

However this is far from good enough; a respondent points out how:

*“My physical condition has deteriorated in the last three years and I have not been able to access the treatment I have been offered because of the severity of my condition i.e. the treatment available is not appropriate to people with severe ME/CFS.”*

The Chief Medical Officer stressed how: “Care of people who are severely affected is an urgent challenge that must be addressed in appropriate and imaginative ways, drawing from service models

applied to other severe chronic disabilities. Healthcare and social service professionals are responsible for finding ways of supporting and guiding patients and their carers for the duration of illness, ensuring access to available support, keeping in contact, constantly re-evaluating the options, maintaining morale, enabling respite, and minimising consequences of prolonged disease.” His report outlined :

What clinicians can do:

- Listen to the patient, recognize and believe his or her individual experience.
- Acknowledge uncertainty and the impact that this has on the patient, family, and carers.
- Provide support and encouragement – e.g. during setbacks.
- Provide information on and discuss: the nature of the condition, approaches to self management, helpful therapies, and how to access other agencies and services.
- Agree a name for the condition.
- Give advice on symptomatic treatment.

CMO Report Annex p.12

When this actually happens, it is warmly welcomed by sufferers, although it needs to be the norm rather than the rare exception:

- *I opted to choose a clinician nearer to me geographically who adopted a more positive approach to treating physical symptoms as part of my M.E. rather than labouring on the (alleged) mental aspect of the condition*
- *My GP has been supportive which helps emotionally. He hasn't much to offer in the way of treatment or advice though. My ME Specialist is very good but I only get to see him every 18 months or so.*
- *I have had good experience with Occupational Therapists – I've seen 3 O/Ts over the years and they have all been sympathetic, understanding and have tried to help in any way they can. I've received help with relaxation techniques, nutrition and mobility aids – they've all been excellent.*
- *The support I receive from my GP is the same now as it was before the CMO's report. She is supportive, prepared to listen, but effectively powerless. GPs receive no information or training – which may paradoxically be a good thing - as she is able to read literature on biomedical research from MERGE, excellent diagnostic guidelines such as the Canadian Criteria, without being prejudiced by fatigue orientated material from the Department of Health. She also knows that not all patients “with ME/CFS” are the same.*

- *I have not been offered CBT. My GP doesn't believe it will make any difference as I have no "faulty illness beliefs", am well motivated, and have adjusted my life to working within my (very limited) energy levels.*
- *My GP is very helpful. We work as a team. Most other healthcare professionals are a dead loss and find the life restrictions caused by ME and the resulting MCS completely unworkable.*

A few examples of the practical ways that people with severe ME may be supported are listed in the table below :

<u>Symptom</u>	<u>Experience</u>	<u>Outcome</u>	<u>Service Response</u>
<b>Sleep Paralysis</b>	<p>Completely unable to move.</p> <p>Difficulties with breathing</p> <p>Difficulties with speech</p> <p>Difficulties with swallowing</p>	<p>Cannot sit up/move/get-out of bed/feed yourself/get a drink/get dressed/talk/go to toilet/wash yourself/answer the door/get the post</p>	<p>Provide physical assistance : Lifting/Supporting ( assisted walking)/Mobility/Dressing/Personal Care/Shopping/Cooking/Feeding</p> <p>Knowledge of what the person needs in advance.</p> <p>Sensitivity &amp; Awareness.</p>
<b>Light Sensitivity</b>	<p>Cannot bear bright light, maybe any light at all, even with eyes closed.</p>	<p>Need to wear dark glasses, have curtains shut,</p> <p>No lights on or low lights only</p>	<p>Acceptance</p> <p>Be prepared</p> <p>Work in low light situations and/or protect client from light if need light on</p>
<b>Headaches</b>	<p>They are not normal, they maybe constant or last for days, can be predominantly left-sided, may not respond to drugs</p>	<p>May be continuous, may vary in degree</p> <p>Difficulty in getting comfortable.</p>	<p>Be sensitive to noise and light issues.</p> <p>Awareness of the potential emotional distress of being in constant pain and the potential for the person to be irritable.</p> <p>Medication</p>
<b>Pain</b>	<p>Whole body may be too painful to touch</p> <p>Skin itching/hypersensitive</p> <p>Muscles burning/Screaming.</p>	<p>Too sore to be touched / helped/lifted</p> <p>Having to wear very loose clothes, or unable to get dressed at all.</p> <p>Irritability</p> <p>Impact on sleep</p> <p>Impossible to get</p>	<p>Pain awareness and extreme sensitivity.</p> <p>Knowing how to touch &amp; lift carefully</p> <p>Knowing how to "flow" with the person.</p> <p>Knowledge of pain, aids, equipment, drugs</p>

As this sufferer explains :

*“I take amitriptyline for sleep disturbance and homeopathic remedies for pain, and I take strong prescribed tablets for the gross migraines I get, which are like no other headache or migraine. I wear sunglasses at all times, because I have a very low tolerance to light – if I do not wear them – my ME symptoms are aggressive and I crash. Peace and quiet is a must as I am sensitive to noise and I do not have social life because being sociable is hard work, because I get so breathless and groggy talking – you can hear the tiredness in every voice of someone with ME. “*

### **Conclusion**

This report paints a desperate picture. Surely our respondent was right to call this a “medical scandal” of gross proportions.

Despite the real danger of Graded Exercise Therapy being harmful to the severely affected, 44% of respondents were still offered this intervention.

Every survey of sufferers (and this one is no exception) seriously calls into question the efficacy of GET and CBT: 96% and 95% respectively of respondents who tried it said that it had a negative impact upon their symptoms, yet as this report shows, this is often the only “treatment” on offer to sufferers and is the one being vigorously pursued by Government.

Significantly more than half of those offered CBT or GET refused the treatment; that is because, as the study has shown, people are very aware and are simply not willing to be made worse. However the bleak reality is that more than half of sufferers, each one on average experiencing more than 20 severe neurological, autonomic and endocrine symptoms, are just being left to get on with it, with no treatment whatsoever, some for decades.

This report has presented shocking evidence of abuse at the hands of the psychiatric lobby. Our members have reported being locked in secure psychiatric wards or AIDS units and their lack of response to “treatment” being taken as an indication of their misguided thinking.

It is time to acknowledge and address the main issues underlying the reasons for this abuse.

### **People with severe ME want:**

- The seriousness of this condition recognised.
- Serious money to be provided for research into the physical causes of ME, which at present is relying totally upon voluntary donations.
- Any research to definitely include the severely affected who are presently very neglected.
- Research to be carried out into the aetiology of the disease; that it is separated out from other fatigue and or depression based syndromes; that proper attention is paid during diagnosis to highly specialised blood tests; that an appropriate care package is offered to the patient including experimental drugs currently being used in the USA and other countries.
- Research into this illness to provide a clearer understanding of severity and prognosis. In the meantime, please believe us when we tell you how we feel.

- More support services and care with regular monitoring of people's condition, to discuss new symptoms, help assess new treatments found, plus general support for sufferer and carer.
- The continued offering of Cognitive Behavioural Therapy and Graded Exercise Treatment as frontline treatments for people with ME to be stopped. It is simply the wrong treatment for the vast majority of people with ME. We need research into the physical causes and better management of the illness. It is so frustrating to see research funds given to psychiatrists for graded exercise when this has actually harmed many ME sufferers, and nothing allocated to physical research.
- Local ME specialist and specialist nurses who can carry out home visits, who know that ME is a physical illness and have been appropriately trained.
- Training for all members of the caring professions.
- Drugs that may help some ME patients eg. "NEURONTIN" and "ENADA" to be universally available on prescription.
- A higher standard of practical, financial and medical help and easier access to these. To stop the following being true: *' My options are: deteriorate without the help I need or deteriorate faster trying to fight for this help and usually having to give up as I'm deteriorating so much.'*
- To clearly separate people who have Chronic Fatigue from those suffering from the World Health Organisation recognised, neurological illness that is severe ME/CFS and treat them differently and appropriately.
- Adoption of an appropriate diagnostic criteria, like the Canadian Definition, which acknowledges the autonomic, neuroendocrine, immune and neurological/cognitive dysfunction of this illness.
- Funding for appropriate tests, for example a PCR or polymerase chain reaction test, as well as other tests of a more routine nature carried out by patients' local micro-biology laboratory; SPECT scans and more research in this area generally, including the appropriate trials for potentially suitable drugs.
- Correct treatment to be assured (appropriate treatments may include anti-virals, anti-retrovirals and antibiotics).
- The severely ill, for whom there is no cure and a less than 6% chance of recovery, to be fairly treated and given an appropriate level of disability benefit, for a realistic length of time.
- Sincere and proactive promotion of the truth that severe ME/CFS is a profoundly disabling condition affecting multiple systems of the body and that people who have the condition are :
  - a) Not malingering
  - b) Not just tired
  - c) Not just not trying hard enough

and urgently require adequate and appropriate support.
- An apology for those with severe ME/CFS who at best are suffering in systems unwilling or unable to support them adequately or at worst are being physically harmed.

Finally we invited each respondent to say one thing to the Parliamentary Inquiry.

Here is what sixty four severely affected ME/CFS sufferers have to say; please bear in mind that the relevance of the entire psychiatric approach to severe ME is based on a single account of two wheelchair-bound sufferers who were actually able to attend a clinic in the first place (Abbot 2004) .

This research is based on 32 times that number of people.

**If you had just one thing to say to the parliamentary enquiry what would it be?**

**1.** The idea that ME needs psychiatric treatment needs to be reconsidered. In my view, any patient with severe ME will tell you that their symptoms are physical. If it were ‘all in the mind’ or I were feigning symptoms in order to have an easy life, surely I would be feeling ‘miraculously better’ for high days and holidays!!! In fact I have been unable to take any sort of holiday for over 20 years.

ME and CFS should be considered as separate illnesses when treatments are being considered. For example, I am sure there are instances where graded exercise could be very helpful in CFS whereas I know, as a severe ME sufferer, that in my case it would do far more harm than good.

In my experience, the medical profession at GP level has little understanding of ME’s effects and its wide range of possible symptoms. In many cases the view still seems to be taken that this is not a real illness just because its initial cause cannot be clarified. Believe me, for the ME sufferer it is a very real, physical illness and should be treated as such.

**2.** Graded exercise does not work.

**3.** If the psychiatrists continue to influence research and funding into ME we will never receive appropriate treatment, or recognition for the severity of the illness. The many biomedical discoveries into abnormalities in ME patients are ignored by psychiatrists who inform the world (including our GPs and all medical staff we come into contact with) that we are suffering from a somatisation disorder.

We are denied the benefits many of us depend on for survival because psychiatrists are used to inform DWP policy. If the government continues to be informed about ME by a wholly inappropriate sector of the medical profession then many thousands of severely ill people will continue to be seriously ill and not taken seriously.

This will be revealed as one of the biggest medical scandals in history.

**4.** I became ill 15 years ago and have learned to live with my symptoms but my life has changed beyond recognition. My initial treatments were delayed by generally poor understanding of the condition and insistence that it was in essence psychological. It is absolutely essential that new sufferers be diagnosed and treatment started without delay,

**5. BELIEVE this illness is REAL & PLEASE get funding for research.**

**6.** I have a disabling long term condition that is very hard to manage without support. I need to be able to access suitable practical help/services at short notice...to help me stay independent and in my own home. I need welfare benefits suitable for my needs, and paid on a regular reliable basis.

Many PWME are middle aged and single which require special services to be in place to avoid serious undiagnosed health conditions to develop needing expensive hospital treatment.

**7.** It is imperative that proper and extensive scientific research is established and continued in order to refute the psychiatric bias which blights the life of so many sufferers. After all, no one would choose to live like this, all we want is to be well. This bias permeates through government departments and bodies, making life even more difficult than it need be for people who are already very ill.

**8.** What about spending the money on biophysical research instead of giving all to psychiatrists!

**9.** Please, please, look in to the medical causes of this illness, I have lost 19 years of my life and so has my husband. I previously worked in the NHS looking after others, now I cannot even go to the bathroom on my own.

I had so much faith in the NHS when I became ill I thought they would help me get better, it took over five years to be given the name ME, I saw so many doctors and was treated badly.

I hoped for testing to be done, and informed NHS staff yet 19 years later I am still experiencing ill informed Doctors and health care professionals some who don't even know what ME is. We need help, and do not want to be forgotten.

**10.** It affects everything! ME is not understood, not taken seriously. I have not applied for some benefits that I should probably be receiving as I am worried one of the “conditions” will be that I am referred to the local “ME/CFS” clinic for CBT and GET. Needing any kind of hospital treatment is a worry, as very few hospital staff know anything about ME, they just see it as “fatigue” and take no account of the pain, food/chemical sensitivities, the impact on life generally. It also means that I receive no practical help – I live with my parents (both retired). Although I do not need nursing care, I could not manage either physically or financially to live alone, yet there is no provision for me to live anywhere other than at home, which is a real concern as my parents get older. How do I care for them if I can't manage to live by myself?

Unless the true nature of ME as a serious, debilitating, primarily neurological condition is properly acknowledged and understood, I don't see that things will improve and the help given by society generally, and the medical profession in particular, will improve.

**11.** Get health professionals to realise that ME is a serious NEUROLOGICAL ailment NOT a psychological self delusion.

Provide strong and positive backing into neurological research for ME so that some day this neurological illness won't halt peoples lives.

Look seriously into providing appropriate care for those with ME, the severity and length of disablement could be greatly reduced by practical support and positive action.

**12.** Get the benefits agency sorted out

**13.** Let's have money invested in investigating and diagnosing these illnesses PROPERLY. There are so many who have other illnesses who are also told they have ME because of the fatigue. We also need to know where the overlap with Lyme Disease lies as so many ME patients test positive for Lyme, live in areas where there are infected ticks, know they were bitten yet the NHS refuses to recognise it.

Why does mitochondrial dysfunction happen in this illness? Patients' cells look as if they are dying. That is not fatigue. The cells of normally fatigued or “burn outs” do not show this dysfunction. I have seen the charts of several test results and it is astonishing – AND WORRYING.

Why are our Advocates not putting these points over to the Government ?

Why are they still allowing the psychiatrists to dominate advocacy by replying and joining in with arguments on “opinions”. There are many diagnosed with “ME” who are helped by what the psychiatrists order, there are many who get better. But there are other illnesses.

We need to highlight the fact of the suffering, the cost to families of paying for treatments to keep their loved one alive. The Canadian Guidelines, although good, do not go far enough.

**14.** GOVERNMENT NEEDS TO REALISE:

ME / CFS IS A SERIOUS PHYSICAL ILLNESS.

IT NEEDS SERIOUS RESEARCH.

**15.** Please put as much money as possible into researching the causes and the most successful treatments of this illness. We want to get better and resume our lives as productive members of society.

**16.** ME is a real physical illness. The medical profession's refusal to accept that – despite a growing mountain of evidence worldwide – is destroying the lives of countless men, women, and children. This deplorable situation is primarily down to the criminal influence Prof Simon Wessely is allowed to wield over the illness.

It is my sincere belief, and as the webmaster of several web sites on ME and MCS I know it is the sincere belief of a great many others also, that Prof Simon Wessely and his high-profile followers, should all be tried in the International Criminal Court for crimes against humanity.

**17.** Please get people to take this condition seriously especially those in the healthcare system. Make getting and keeping benefits easier not harder (I realise there are those who claim fraudulently) but surely a consultant can be asked to express an opinion.

Seek expert research into the condition following the Chief Medical Officers pronouncement that this is a serious neurological condition that affect real people and hampers them enjoying life, family and work

**18.** ME/CFS is a serious and disabling physical condition – early diagnosis and appropriate treatment could preserve function and prevent deterioration, allowing sufferers to continue with an economically and socially useful life

Identifying the origin of the condition and effective treatments is the only way to prevent the waste of life caused by ME/CFS

**19.** Please take an open-minded and science-based approach to research and treatment (looking at the physical as well as the psychological dimension of the illness), provide adequate funding (to promote quality of life and ability of sufferers to contribute to society) and listen to patients.

**20.** Please fund research into this awful disabling illness. Even if a diagnostic test was developed that would be helpful to prove that the illness exists and I would be believed. If a cure or some kind of treatment were found that would be even better.

**21.** Please, please, please start funding research into the physical side of the illness instead of flogging a dead horse by continuing to research CBT and GET. The evidence is already there that CBT and GET don't work but there are research projects around that look very promising and they badly need funding.

**22.** Please do some research into the physiological causes and effects of ME/CFS. Forget the psychobabble.

There have been many studies showing abnormalities – research should be backing this up.

Examples of areas which need researching:

- research to show many people with ME may have chronic borreliosis. Many MEs are sending their blood to the USA for private testing and are getting positive results (when NHS tests are negative) and a significant number are slowly responding to treatment.

- research into why people with ME have abnormal ATP profiles – a private doctor has told me that the level of disability correlates very well with the degree of abnormality of ATP profiles. Most likely caused by environmental toxins.

- research into why people with ME have a low cardiac output and hence orthostatic intolerance.

**23.** The crucial importance of investing in research into the physical causes and underlying processes of ME, along with identifying the sub-groups. Without this, there is no chance of finding any treatments which offer substantive improvements

**24.** Please listen to the following people:

Those who chose not to belong to AfME. The membership numbers for this group are small in comparison to the overall number of ME sufferers in the UK. It is also evident that this organisations membership is mainly made up of people who experience health conditions that do not mirror ME.

Those who know that psychiatric explanations and approaches are not acceptable for what is a life threatening, life destroying, and neurological disease.

Those who understand the differences between fatigue states and ME.

Those who live with ME on a day-to-day, hour to hour basis rather than those who form their opinions about the condition on misinformed textbook or peer education.

Those who are truly fighting for a better deal for themselves and fellow ME sufferers instead of those who seek self-advertisement along with a desire to inflate egos, salaries, status etc.

**25.** This is an illness that costs lives. I have lost so far, a decade and a half of my youth. I have lost the chance of furthering my career, having a relationship, children, and income. Added to this are hours, days, weeks, months and years of suffering, in severe pain. I have been no less than appalled that in this day and age, I could lie in bed so ill for so long without any support, unless I find it myself. The nature of this illness, and the misconceptions about it, have made it all the more intolerable. To go through so much and to have so little understanding or even sympathy is really indescribable. My nightmare is far from over. I would gladly have chosen death, and may yet have to. I do not suffer from clinical depression, nor have I ever. I was a happy, social young woman, (working as a nurse) when I first became ill. My life has been ruined, now beyond repair. Please listen and help us.

**26.** Could you please start to treat this illness as you would any serious illness, although it has not yet had any fatalities attributed to it, considering some of the symptoms and the neurological implications it could on be a matter of time at this point in time who knows.

Even so this is a very real illness and it affects a lot of people to different degrees and doctors must stop it being lumped together with CFS. It is totally a different illness with many more symptoms and it must no longer be used as an umbrella illness for illnesses that don't fall into any other category but carry some of the symptoms.

This is a life destroying disease that wreaks havoc with peoples' lives and touches those around them; it has long lasting effects on both the patient and their families. Patients suffering from ME will never have a normal life again, they will be suffering from this disease for many years to come and with a very uncertain future, because no one knows what will happen to them and there is no one who is able to even give us some sort of idea of what the future may hold. There is no cure, not at least at the moment, so for most sufferers if not all, the future is one with pain and struggle and more pain and struggle, taking each day at a time with dependency on others becoming more and more apparent. So please take ME seriously; treat it as you do other types of similar disease such as MS. Our lives with ME are just as difficult but with no end in sight.

**27.** Read "Skewed", the book by Martin Walker it will tell you the true facts and what is really going on between the psychiatrists and insurance companies. Start listening and trusting ME sufferers, feed off their knowledge of the illness, as they are the best judges because they have the illnesses. STOP psychiatrists' greed for money and stop them having any relevance in this illness – after all you don't take a BMW car to a Ford garage for maintenance – do you? You take it to someone who is an expert and has experience with BMWs.

STOP letting psychiatrists guide insurance companies, benefits etc, it causes so much pain and stress for ME sufferers, and their health and well-being and years of fighting and struggling for what is theirs deservedly by right.

These so-called clinics for ME should be aborted, with a fresh concept with the right people involved that isn't going to put ME sufferers health and well-being at stake. Psychiatrists have tried to suggest in the past that MS was all in the mind years ago – so that they could make money. They have tried this with many illnesses including ME and they have all proved to be physical, NOT mental illnesses.

It took me 2 years to eventually get the benefits I should have had. Stop using psychiatrists and ignorant views on ME to seep into Doctors' notes on ME and the benefits agencies.

**28.** Stop bugging about talking about it and get something done. Listen to the sufferers and spend some money on something other than GE and CBT.

**29.** The stranglehold that the psychiatric lobby have had on resources and funding has effectively held back the progress of biomedical research in the UK. The plethora of psychiatric research papers that have been drip fed to the mainstream medical journals such as the BMJ and The Lancet has effectively mis-informed a whole generation of medical practitioners and prospective biomedical researchers.

It is an absolute disgrace that researchers carrying out potentially ground-breaking research, such as Dr Gow and the likes of MERGE, are having to scratch around for funding, when a select group of psychiatrists (seemingly in league with the insurance industry) only have to whistle to the MRC for funding.

I have not been offered CBT. My GP doesn't believe it will make any difference as I have no "faulty illness beliefs", am well motivated, and have adjusted my life to working within my (very limited) energy levels.

We wish of course that we could recover from the illness, and resume a normal life, with a little graded exercise/activity and a positive mindset. It would be the perfect solution without having to resort to drugs and the risk of side effects. But it simply doesn't work for those correctly diagnosed with ME and in some cases can actually make matters even worse.

CBT in particular is understandably appealing to the DoH as it's an apparently cheap option to deal with an expensive problem. But it appears to be a red herring dressed up as a cure by those who seek to deny the physical reality of the illness.

**30.** Get rid of the current psychotherapist panel and invest in research

Ditch the current guidelines

Readdress the ME/CFS protocols for referral

Offer a holistic treatment tailored to the individual on an open-ended treatment programme

**31.** Please take this illness seriously. Thousands of people are affected. It ruins lives, it's ruined mine – I used to be a happy, very active, young person with a good job and a great social life – I am now housebound (back living with my parents), with a painful debilitating condition which affects every part of my life. More money has to go into researching this very physical condition to find a cure or if not an effective treatment.

**32.** Stop thinking of it as a psychiatric illness

**33.** Listen, more closely, to what the national M.E. campaigning groups, are saying to you (the UK Govt) about this illness and treatment. They "represent" the sufferers and have no financial or political agenda to serve. If the Govt "listen" to the patients, a large percentage of today's voting population, instead of the psycho-babble which appears to be "driving" the research and treatment in today's health arena, sufferers, like myself, will feel more confident that they are going to get what they need.

**34.** I am fortunate in having a supportive GP as I know many people with ME are not so lucky. Even so my condition means that I have huge restrictions in what I am able to do as there are no treatments to help the main ME symptoms.

Imagine being able to think clearly for only one hour a day and being able to walk less than 20 yards. Imagine filling in a questionnaire like this and then having to rest for three days to recover. Life is difficult with ME.

**35.** Please get people to take this condition seriously especially those in the healthcare system. Make getting and keeping benefits easier not harder (I realise there are those who claim fraudulently) but surely a consultant can be asked to express an opinion.

Seek expert research into the condition following the Chief Medical Officer's pronouncement that this is a serious neurological condition that affects real people and hampers them enjoying life, family and work

**36.** There is some physical cause for ME that just hasn't been discovered yet, so research and funding are vital. Years ago the causes of TB for example weren't known, yet research persevered and they were discussed. Please DON'T DISMISS ME as "all in the mind" just because research has not caught up yet. ME patients desperately want to get well – so research and a more enlightened and informed approach are VITAL. See and actually talk to some ME patients – be open-minded, prepared to listen and learn.

**37.** Please take an open-minded and science-based approach to research and treatment (looking at the physical as well as the psychological dimension of the illness), provide adequate funding (to promote quality of life and ability of sufferers to contribute to society) and listen to patients.

**38.** I believe the ignorance about M.E is due to it being an illness at cellular level in the body -- the scientific and medical professions have been unprepared for a disease such as this occurring.

It's a great pity that this ignorance has prevailed for so many years since sufferers, on the whole, could and want to, contribute a lot to society. Many, like myself have been in full time, state funded, education, until 23 years of age and have then taken ill in their early thirties. This means we've been taxpayers for only a fraction of the time we should have been and instead, are dependent on benefits for around 30 years or so of our lives. Taking the cost of the education into account, we are having a very negative effect on the economy.

On top of this, sufferers can become very expensive for the health service, M.E often leading to earlier than average cancers, as well as other diseases caused by a dysfunctional immune system.

**39.** Please research severe ME (bedridden patients) and please stop putting money into psychological interventions (CBT, Activity Programs, Behavioural Models) – research the physical aspects of the disease, its cause, management and treatment instead.

**40.** Put more money into researching causes of ME & fund alternative therapy treatments (acupuncture/homeopathy etc)

**41.** I feel its time children and grown ups with this terrible illness should be treated more fairly and listened to by their doctors.

My daughter, who is severely affected, has over last six years been through a really bad time and has been made so ill and we have had to fight for her to see a ME consultant paediatrician of our choice

**42.** Please put some money into supporting research into physical reasons for the illness and stop messing about with the psychiatric stuff.

ME is a physical illness and whilst counselling etc. is a helpful adjunct in any severe chronic illness, it is not going to make anyone better.

No one suggests nowadays that Multiple Sclerosis is 'all in the mind' as they did once. Medical science has moved on for MS sufferers. Help it to do so for ME sufferers.

**43.** PLEASE LISTEN TO THE SUFFERERS NOT THE SO CALLED EXPERTS!

**44.** Listen to the real experts on M.E - the patients - and do some proper biomedical research to try and find proper effective treatments. Take it seriously, please.....

**45.** Please make all doctors, especially company doctors, aware that ME is a neurological illness with different degrees of severity and with a different age-related prognosis. There is too much variance with this illness to have one general statistical prognosis, eg. 90% make a full recovery after 5 years.

**46.** I WAS TOLD I SHOULD BE BACK TO FULL OR SUBSTANTIAL GOOD HEALTH IN A FEW MONTHS OR A YEAR OR SO AS EVERYONE MAKES A FULL RECOVERY BY 5 YEARS AND IF I DIDN'T BELIEVE I WOULD GET WELL THEN I WOULDN'T

**47.** The key area to address is for all GPs, consultants and medical professionals to be educated away from the thinking of the CBT and psychological route and that this illness has been recognised by the World Health Organisation as a neurological and real physical disorder and is not all in the mind, and therefore GPs etc need re-educating. There is an urgent need for the Government to fund money to go towards proper biological scientific research.

**48.** Adopt the Canadian criteria for diagnosis and stop calling ME Chronic fatigue or Chronic Fatigue Syndrome. We have multiple symptoms that need validating. Using fatigue alone enables psychiatrists to bring in other sorts of illness /conditions and ignore the physical needs of the severely ill and disabled person with genuine ME. Don't let them do this to us any more. We need real physical research to find out the underlying causes and a possible cure, which would then lead to proper treatment, as opposed to inappropriate psychiatric management interventions that are dangerous to the person with real severe ME and will potentially make us even more ill.

**49.** Follow the lead of WHO and CMO and take M.E. seriously and DO something to help the thousands of us invisible sufferers whose lives have been devastated.

**50.** Please tackle the prejudice and bias that has held back an understanding of this illness for far too long. Please support biological research.

**51.** This illness makes life hard enough as it is. It is so much worse that, whilst there is the ability to investigate this illness, opportunity is being deliberately ignored. The choice the medical profession is making to treat a physical illness with psycho-nonsense is never going to cure anybody. I have been ignored for 20 years. Will you carry on for another 20?

**52.** Serious money for serious research please; proper funding for home services for severely affected

**53.** Why are 200,000 people all telling their health carers they feel desperately ill being told to practice CBT and do some exercises? 25% of them are like me housebound, isolated and often bed bound, to even speak to their relatives or give themselves a wash is a huge task every day. Why are we who suffer still being ignored by the medical governing bodies of this country and the Minister of Health? Why is CBT training and graduated exercise still being offered as the only direction, when quite patently, as is well documented it, appears to be potentially dangerous and abusive for those with severe ME? It's like asking a person with no legs to get up and walk or a person with cancer to just get their negative thinking processes sorted properly!

**54.** More physiological research. Especially post mortem studies. (I've forgotten the exact wording)

**55.** With reference to the Mar - Szmukler correspondence [http://www.meactionuk.org.uk/Mar\\_Szmukler\\_Correspondence.htm](http://www.meactionuk.org.uk/Mar_Szmukler_Correspondence.htm), it is clear that many psychiatrists & therefore GPs are misled by Prof. Simon Wessely & coerced by the Dean of Psychiatry to abuse their positions, & they have absolutely no concern for the consequential cruel denial of what is often a severely disabling illness, & terrible symptoms which often includes intractable pain, leaving patients in my experience with no treatment available from GPs.

I refer of course to the following: 18th August 2003 - 8th September 2003: An exchange of letters between the Countess of Mar and the Dean of the Institute of Psychiatry Dr George Szmukler relating to the wrongful classification of ME/CFS.

**56.** MAKE M.E. A PRIORITY PLEASE.

WE NEED A TEST FOR M.E.

WE NEED MUCH MORE RESEARCH INTO THE PHYSICAL ASPECTS.

WE NEED TO BE TAKEN SERIOUSLY.

WE NEED HELP.

WE DON'T NEED TO BE NEGLECTED AND FORGOTTEN THE WAY WE ARE NOW.

WE ARE SUFFERING NOW! WE ARE SERIOUSLY ILL NOW! WE NEED SOMETHING DONE NOW!

**57.** Please fund research to look at circulatory abnormalities.

**58.** There is a great need to train medical students in the history of unrecognised illnesses eg asthma, Multiple Sclerosis, autism, so that they can learn how to listen to patients and think outside the box.

There will always be illnesses which have not yet been recognised or understood.

Understanding this would greatly improve some of the relationships between doctors and patients, and patients' perception of their expertise. It is OK for doctors to say that they don't know something, and it is not OK to tell sick people that they are not ill.

**59.** LISTEN to the ME sufferers and focus research and treatments and care around what they are saying. At all costs put no more money into psychiatric research. IT IS A BLIND ALLEY.

**60.** Recognition that ME exists and suitable treatment. As a very severely effected sufferer I am unable to access any services or treatments. Since being discharged from hospital in June I have not been visited by any health professional at all and my GP is unable to get any help at all for me from physiotherapists or occupational therapists. I am only ever offered outpatient appointments which I cannot attend as I am bedridden.

**61.** Fund Research into PHYSICAL CAUSES of ME/CFS and find an effective treatment(s). Stop wasting money on research into psychological/psychiatric causes.

Provide DISABILITY LIVING ALLOWANCE and other benefits to help enable a bearable existence and to help me to help myself - particularly important for those too disabled to work, like myself.

EDUCATE the medical profession, care services, benefits offices, social services etc on ME/CFS

ENSURE that HELP AND CARE is available to the housebound and semi-housebound

Stop the 'all-talk-forms-correspondence-etc- and no -real-help-syndrome'. It costs money and wastes everyone's time and energy.

**62.** I am 33 years old, and because of my illness I have no education beyond my GCSEs, no job, no qualifications, no partner, no children, I live with my parents, and have a very limited social life.

Yet I am incredibly self-motivated and positive, and spend almost all my available energy working towards getting better. I have a fantastic family, a few good friends (I became ill when I was 17, and most of my friends 'evaporated') and a good team of carers. The interesting thing is that none of them have ever offered to do a charity event on behalf of M.E. research. I can only guess, but I imagine that if I had cancer, M.S. or one of the other more 'acceptable' illnesses, people would have been running marathons and jumping out of aeroplanes at the drop of a hat!!! Understanding of my condition is improving all the time, but there seems to be no public awareness of the need for research. Perhaps part of the problem is that the more ill we are, the more invisible we become -- hidden away at home and unable to participate in life. The elements of my illness which are the biggest handicap, are also the biggest hurdle in terms of public perception. We are too ill to be out there and be seen to be bravely struggling on with life. It is an unfashionable and boringly chronic illness. Yet because it IS such a long-term condition, there is a wealth of experience out there, which could be used to inspire and

support scientific research. We have done the groundwork -- it's up to you to fund the research to enable us to take it to the next level.

**63.** Look to Australia for innovation in medicine. That is where the best English trained doctors go. That is where all the best new thinking comes from. In England the medical profession is dominated by male bigots and good medicine is suppressed.

**64.** STOP all funding into Psychiatry into CFS/M.E and spend it on biomedical research on M.E, of the sort that MERGE do.

Accept M.E is not Chronic Fatigue.

Accept M.E can be fatal.

Accept M.E ruins lives and is NOT a mental illness.

Accept M.E needs RESEARCH into the PHYSICAL causes, no more Psychiatric research which is pointless.

## **References**

25% Severe Group (2005) DWP Covering Letter

[www.25megroup.org/Campaigning/DWP/DWP%20Covering%20letter.doc](http://www.25megroup.org/Campaigning/DWP/DWP%20Covering%20letter.doc)

Abbot N (2004) Severely Overlooked by Science — An Overview of Research on Severely-ill People with ME, MERGE <http://www.meresearch.org.uk/melibrary/publications/severe.html>

Andersen MM et al. Illness and disability in Danish CFS patients at diagnosis and 5-year follow-up. *J Psychosomatic Research* 2004; 56: 217-229

Bassett J (2005) ME, the medical facts. Hummingbird

<http://www.ahummingbirdsguide.com/methemedicalfacts.htm>

Bassett J (2005) Ultra Comprehensive Symptom List. Hummingbird

<http://www.ahummingbirdsguide.com/themesymptomlist.htm>

Barnden,L., Kitchener,M., Casse,R., Burnet,R., Delfante,P., & Kwiatek,R. Regional cerebral bloodflow in chronic fatigue syndrome (CFS). Presentation 2001 (unpublished).

Bell, David S MD 1995, *The Doctor's Guide to Chronic Fatigue Syndrome*, Perseus Books, Massachusetts

Blackwood,S.K., et al (1998) Effects of exercise on cognitive and motor function in chronic fatigue syndrome and depression. *Journal of Neurology, Neurosurgery & Psychiatry*, **65**, 541-546.

Cairns, R. and Hotopf, M. (2005) Prognosis of chronic fatigue syndrome: a systematic review *Occupational Medicine* 2005 55 20-31

Carruthers B et al (2003) Myalgic encephalomyelitis/chronic fatigue syndrome: clinical working case definition, diagnostic and treatment protocols. *Journal of Chronic Fatigue Syndrome*. 11, 1, 7-115.

Cheney P & Lapp W.C. (2000) *The Diagnosis of Chronic Fatigue Syndrome: An Assertive Approach* <http://listserv.surfnet.nl/scripts/wa.exe?A2=ind0006D&L=me->

Costa,D.C., Tannock,C., & Brostoff,J. (1995) Brainstem perfusion is impaired in chronic fatigue syndrome. *QJM*, **88**, 767-773

Countess of Mar (2002) preface to **Unhelpful Counsel?** MERGE's response to the Chief Medical Officer's Working Group report on CFS/ME . April 2002

Crowhurst L (2004) The Experience of Severe ME.  
[www.onetree93.freemove.co.uk/experiencesevereme.html](http://www.onetree93.freemove.co.uk/experiencesevereme.html)

Greg & Linda Crowhurst (2005) Dangerously Diminishing : A response to the RCPCH Evidence Based Guidelines for the Management of CFS/ME , 25% Severe ME Group, Troon  
[www.25megroup.org/Information/ Medical/RCHCP%20response%202.wps.doc](http://www.25megroup.org/Information/Medical/RCHCP%20response%202.wps.doc)

Dr Darrel Ho-Yen (1994) BMJ 1994;309:1515

Dr Daniel L Peterson: Introduction to Research and Clinical Conference,  
Fort Lauderdale, Florida, October 1994; published in JCFS 1995:1:3-4:123-125

De Becker P, Roeykens J, Reynders M, McGregor N, De Meirleir K (2000). Exercise capacity in chronic fatigue syndrome. Arch Intern Med 2000, Nov 27;160(21):3270-3277.

de Lange et al (2005) Gray matter volume reduction in the chronic fatigue syndrome [www.cfids-cab.org/MESA/de\\_Lange.pdf](http://www.cfids-cab.org/MESA/de_Lange.pdf)

Dowsett, Elizabeth (2001) THE LATE EFFECTS OF ME Can they be distinguished from the Post-polio syndrome? <http://www.ott.zynet.co.uk/polio/lincolnshire/library/dowsett/lateeffectsm.html>

Englebienne P and De Meirleir K (2002) "Chronic Fatigue Syndrome: a biological approach". CRC Press 2002, pp 291

van de Sande M.(2003) ME/CFS Post-Exertional Malaise / Fatigue and Exercise  
<http://www.mefmaction.net/default.aspx?Page=selectedarticlesmedical>  
Quest #60, June/July, 2003

Fischler,B., D'Haenen,H., Cluydts,R., Michiels,V.,Demets,K., Bossuyt,A.,Kaufman,L., & DeMeirleir,K. (1996) Comparison of 99m Tc HMPAO SPECT scan between chronic fatigue syndrome, major depression and healthy controls: an exploratory study of clinical correlates of regional cerebral blood flow. Neuropsychobiology, **34**, 175-183.

Fukuda K et al (1994) The chronic fatigue syndrome: a comprehensive approach to its definition and study. Annals of Internal Medicine. 121, 12, 953-959.

Goldstein JA. (1993) Chronic Fatigue Syndrome: The Limbic Hypothesis. Haworth Medical Press, Binghamton, NY 1993;pg 42-43

Goldstein J. (1993) CFS and FMS: Dysregulation of the limbic system. Fibromyalgia Network Oct 1993;pp 10-11.

Goudsmit E (2002) Comments on the Report to the Chief Medical Officer from the Independent Working Group on CFS/ME.

Goudsmit E (2000) Chronic Fatigue Syndromes: A Different Approach  
By Ellen Goudsmit (2000) <http://www.ncf-net.org/library/goudsmit.html>

Harrison T (2002) Personal response to the Working Group on CFS/ME, BRAME

Hooper, M. & Montague S (2001). Concerns about the forthcoming UK Chief medical officer's report on Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) notably the intention to advise clinicians that only limited investigations are necessary  
[http://www.meactionuk.org.uk/Comments\\_on\\_advice\\_given\\_\(by\\_a\\_member\\_of\\_the\\_Key\\_Group\).htm](http://www.meactionuk.org.uk/Comments_on_advice_given_(by_a_member_of_the_Key_Group).htm)

- Hyde B (1998) Are Myalgic Encephalomyelitis and Chronic Fatigue Syndrome the same thing ?  
Nightingale Research Foundation, New South Wales, <http://www.nightingale.ca/1CAustralia2.html>
- Hyde B (2003) The Complexities of Diagnosis , Handbook of Chronic Fatigue Syndrome, John Wiley & Sons Inc, Hoboken, New Jersey
- Hyde, Byron M.D. (2005) The Nightingale Foundation, <http://www.nightingale.ca/index.shtml>
- Inbar O, Dlin R, Rotstein A, Whipp BJ. (2001) Physiological responses to incremental exercise in patients with chronic fatigue syndrome. Journal: Med Sci Sports Exerc 2001 Sep;33(9):1463-1470
- Jammes Y, Steinberg JG, Mambrini O, Bregeon F, Delliaux S (2005) Chronic fatigue syndrome: assessment of increased oxidative stress and altered muscle excitability in response to incremental exercise. J Intern Med 2005; 257(3): 299-310
- Johnson H (1996) OSLER'S WEB: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic (Crown Publishers, Inc., March 27, 1996)
- Kennedy A (2004) *Some serious problems in Doctors' attitudes towards ME/CFS sufferers uncovered.*  
Rapid Response to Raine et al ( 2004) General practitioners' perceptions of chronic fatigue syndrome and beliefs about its management, compared with irritable bowel syndrome: qualitative study BMJ 2004; 328: 1354-1357 <http://bmj.bmjournals.com/cgi/eletters/328/7452/1354>
- Kennedy G, Spence V et al (2004) Increased neutrophil apoptosis in chronic fatigue syndrome. Kennedy G, Spence V, Underwood C, Belch JJ; J Clin Pathol 2004;57(8):891-893
- Komaroff A.L. (2000) The Biology of the Chronic Fatigue Syndrome. Am J Med:108:99-105
- Marshall E, Williams M and Hooper M (2001) What is ME ? What is CFS ? Information for Clinicians and Lawyers [http://www.btinternet.com/~severeme.group/papers/whatisME\\_whatiscfs.htm](http://www.btinternet.com/~severeme.group/papers/whatisME_whatiscfs.htm)
- Marshall E and Williams M (2003) UNUM Provident, Dr Mike Sharpe and Cognitive Behavioural Therapy: information which the MRC might wish to consider [http://www.meactionuk.org.uk/UNUMProvident\\_Sharpe\\_and\\_CBT.htm](http://www.meactionuk.org.uk/UNUMProvident_Sharpe_and_CBT.htm)
- Marshall E Williams M (2005)[Evidence-based Psychiatry ?](http://www.meactionuk.org.uk/Evidence-based_Psychiatry.htm)  
[http://www.meactionuk.org.uk/Evidence-based\\_Psychiatry.htm](http://www.meactionuk.org.uk/Evidence-based_Psychiatry.htm)
- Mark L (2005) Symptoms, Information on Myalgic Encephalomyelitis <http://www.mesite.dk/Symptoms.htm>
- MERGE (2002) **Unhelpful Counsel?** MERGE's response to the Chief Medical Officer's Working Group report on CFS/ME . April 2002 [www.25megroup.org/Information/Medical/MERGE.htm](http://www.25megroup.org/Information/Medical/MERGE.htm)
- MERGE (2005) Oxidative Stress, Symptoms and Genes, MERGE Breakthrough Winter 2005-12-11
- ME Society of America: <http://www.cfids-cab.org/MESA/framework.html>
- Munson P (ed) (1995) Stricken: Voices from the hidden epidemic of Chronic Fatigue Syndrome, Haworth Press, New York.
- National CFIDS Foundation <http://www.ncf-net.org/memorial.htm>
- Okada T et al (2004) Mechanisms underlying fatigue: a voxel-based morphometric study of chronic fatigue syndrome BMC Neurology 2004, **4**:14 doi:10.1186/1471-2377-4-14
- Schwartz,R.B., Komaroff,A.L., Garada,B.M.,Gleit,M., Doolittle,T.H., Bates,D.W., Vasile,R.G., & Holman,B.L. (1994) SPECT imaging of the brain:comparison of findings in patients with chronic fatigue syndrome, AIDS dementia complex, and major unipolar depression. AJR Am.J Roentgenol., **162**, 943-951.

Sharpe M (1999) ME what do we know ? Real physical illness or all in the mind ?  
[http://www.meactionuk.org.uk/ME\\_-\\_What\\_do\\_we\\_Know\\_-\\_October\\_1999\\_-\\_310805.htm](http://www.meactionuk.org.uk/ME_-_What_do_we_Know_-_October_1999_-_310805.htm)

Shepherd C. (2001) Pacing and exercise in chronic fatigue syndrome. *Physiotherapy* 2001 Aug;87(8):395-396.

Spurgin M (2003) Maryann Spurgin , PhD reviews the 2003 ME/CFS Clinical Case Definition  
[http://www.cfids-cab.org/MESA/cccd-1\\_p.html](http://www.cfids-cab.org/MESA/cccd-1_p.html)

Streeten DH. Role of impaired lower-limb venous innervation in the pathogenesis of the chronic fatigue syndrome. *Am J Med Sci* 2001 Mar;321:163-167.

Sieverling C (1999) The three phases of CFS. Dr Paul Cheney's theory:  
<http://www.virtualhometown.com/dfwcfids/medical/phases.html>

Spence V (2005) Biomedical Research in ME/CFS: Issues and Challenges. Presentation to the Scottish Parliament on 2nd March 2005. <http://www.meresearch.org.uk/melibrary/publications/advances.html>

Tirelli,U., Chierichetti,F., Tavio,M., Simonelli,C., Bianchin,G., Zanco,P., & Ferlin,G. (1998) Brain positron emission tomography (PET) in chronic fatigue syndrome: preliminary data. *American Journal of Medicine*, **105**, 54S-58S.

Vercoulen et al (1998) Evaluating neuropsychological impairment in chronic fatigue syndrome. *Journal of Clinical & Experimental Neuropsychology*, **20**, 144-156.

Wall D (2000) Encounters with the invisible. In Munson P (Ed) *Stricken: Voices from the Hidden Epidemic of Chronic Fatigue Syndrome*. New York. The Haworth Press.

Walker MJ (1998) SKEWED: Psychiatric hegemony and the manufacture of mental illness in Multiple Chemical Sensitivity, Gulf War Syndrome, Myalgic Encephalomyelitis and Chronic Fatigue Syndrome. pp 156.

Williams M (2004) Critical Considerations  
[http://www.meactionuk.org.uk/CRITICAL\\_CONSIDERATIONS.htm](http://www.meactionuk.org.uk/CRITICAL_CONSIDERATIONS.htm)

Wright A.J. (2003) Chronic Fatigue Syndrome/ME and Fibromyalgia plus Associated Syndromes Evidence for their organic basis: A summary of the suggested underlying pathophysiologies and treatment approaches CFSResearch 2005 <http://www.cfsresearch.org/cfs/research/treatment/9.htm>

## **APPENDIX 1**

### **We asked the following question in a rapid response survey to our members**

**What impact if any does the prevailing bias towards psychiatric treatment of ME have upon your life as a sufferer?**

**These are the responses of 59 severely affected ME sufferers.**

1. It annoys me intensely. Psychiatric treatment would be totally inappropriate for me. I know perfectly well that my symptoms are physical and neurological (rather than psychological or psychosomatic) and consider this bias extremely unhelpful; I feel that more resources should be channeled into research to seek a clinical cure.

2 .Graded exercise doesn't work.

3. When I am asked how my health is generally and I mention ME it is hard to get taken seriously from then on. This has been a horrible and serious problem and has cost me a fortune to see private doctors in the hope that paying them may silence their scepticism – it doesn't.

Have been made angry and frequently humiliated by articles in the media that continue to portray ME as mental disorder or personality disorder. Family and friends also read these articles and was told by own sister that I could maybe think myself better if I really wanted to.

If funding was directed at serious research instead of analysing the personality failings of such severely ill people I might be cured by now. I might have been able to participate more in the lives of my two sons who were 1 and 3 when I became ill and are now 13 and 15.

4. I never tell people I have ME – I either explain how things DON'T work in my body or just say I have a chronic neurological condition. Some of the doctors at my GP Surgery are quite rude and the current appointment system makes it very difficult for me to see the same doctor every time. SO I do not go to the Doctors unless I have a new symptom. For the same reason I do not apply for other help

5. Some people don't believe I'm physically ill. I have had very hurtful comments passed by ex-colleagues at school who say I wasn't up to the job & am using the M.E. as a way of avoiding work. I was a teacher for 27 years before I was forced to retire because of the M.E.

Even my husband has had doubts about the physical nature of my illness & we've been together for over 20 years.

Having said this, my GP has never doubted the physical nature of the illness, even though some of the other doctors at the practice have expressed their doubts.

6. I find all this talk about CBT and GET (and just this) demoralising as it in no ways deals with ME ..the facts as we know them, from all over the world, but it may help those with Chronic Fatigue.

I find it irresponsible on the part of the medical profession to offer any treatment for an illness that they choose to stay almost totally ignorant about? Until the cause effect duration management and benefits. Until we are sure ... we do nothing to make it worse?

7. Until recently, I had not come up against the bias by health professionals, only by the DSS and now DWP. The benefits system seems to work on the basis that sufferers have no physical illness & are psychiatric cases. As has recently happened in my own case. This decision is made by an Examining Medical Practitioner who spent less than an hour in my home. He concluded that as he could see no clinical signs then I must have a gross illness behaviour problem! The tribunal panel were hostile, nasty and confrontational and totally believed the EMP saying I was a wholly unreliable witness. I stated that I had concentration problems only to be told that there was "nothing wrong with you at the moment" by the doctor on the tribunal. As a result of the stress my health has deteriorated & I now have the added financial worries as a result of losing the benefit.

It is scandalous that the DWP treat genuine cases as if they were criminals. If there was no psychiatric bias then I feel that the benefit claims would be much easier.

8. What about spending the money on biophysical research instead of giving all to psychiatrists!

9. It makes me disappointed and annoyed to say the least, every time I see a Doctor or someone who is in health care or social services, I don't know how they will react to my illness or if they will believe me or take me seriously. This attitude filters into the press and the public and no one really knows how badly this illness affects people.

Also the lack of medical testing saves the government money which I feel is the main reason!

10. Please take M.E. seriously! Please realise it is not just "fatigue". The medical profession got it wrong previously with MS ("hysterical paralysis"), diabetes, Parkinson's disease. It's about time they acknowledged they have got it wrong with ME as well.

Giving GET and CBT to people with ME is like trying to prescribe treatment without first investigating the disease – madness! We need proper biomedical research to find out the cause(s) of this illness, and to investigate fully what it does to the body, before any treatment can be prescribed. GET and CBT have been found to be at best unhelpful to those with ME; at worst, harmful.

11. I strongly avoid the NHS attempts at ME treatment as they clearly have no idea what they are doing when it comes to ME and have caused me far more harm than help.

12. I've just had this discussion whilst I was in hospital. My neurologist told me that he felt that there is a psychiatric element to ME. He believed that an unknown psychological problem can manifest itself in the body producing bodily symptoms typical of ME. I asked him why anyone would choose to live like this; he said they don't. He sweetened this statement by saying that one had no control over this. He also said he believe ME to be a genuine illness so now I'm thoroughly confused and am finding it very difficult to get my head round this.

13. I now have a lot of knowledge about my condition and have taken a pro-active stance towards management. I let all doctors I see know I am going to be in charge of my health and if they need it, I will tell them why! Any treatment for "psychiatric" problems which are not there are likely to kill me!

All this is very difficult as I have severe memory problems and get tired very quickly.

14. Cognitive Behavioural Therapy is a psychological therapy, and is only useful for psychological problems.

15. It makes me furious! Would they say the same about MS?

16. It means that I am simply offered no treatment whatsoever. I am just left to get on with it.

17. Makes life very difficult especially when trying to be taken seriously and when you need others to take you seriously like during Benefit reviews when you find the Doctor to be unsympathetic.

18. I don't feel that because of the prevailing bias towards psychiatric treatment, sufficient effort is directed towards researching the cause/s of ME/CFS - this leaves me feeling hopeless and ignored

The use of the term "CFS" is unhelpful as it in no way reflects the severity of the condition and the devastating effect it has on my life – the emphasis on psychiatric treatment reinforces the false perception that this is a short-term, treatable condition.

ME/CFS is recognised and defined as a neurological condition – while some forms of psychiatric treatment may be helpful with some symptoms in some patients (e.g. anti-depressants), no amount of psychiatric treatment will treat the neurological and other physical damage which causes many of the symptoms

19. The prevailing bias towards psychiatric treatment makes me feel that I am not believed and that it is thought that my illness is 'all in my head'.

20. It has had a huge impact. After seeing a neurologist and having tests that came back normal I was referred to a neuro-psychiatrist. Whilst I found that the neuro-psychiatrist was of the view that ME was a physical illness, the problem came when other people realised that I was seeing a psychiatrist. My GP, OT and others then assumed that my illness was psychiatric and I noticed a huge difference in the way that they treated me.

21. Private testing has shown up lots of things. Detailed below. The NHS has found NOTHING. Private testing (NHS tests negative) has shown several intestinal protozoan parasites including Entamoeba histolytica, blastocystis plus giardia was suspected – my intestinal function improved after treatment. Private testing has also found Lyme borreliosis and I am improving while being treated (paying for treatments myself) - I had been bitten by a tick before my illness started.

I have also been found to be deficient in zinc and magnesium. I have an abnormally low superoxide dismutase enzyme level – so I am not mopping up some toxins and free radicals properly. Recent testing of my ATP profile has shown that I have a very poor conversion of ADP to ATP, this is most likely blocked by chemicals and will explain why I get exercise induced fatigue/malaise. I have a genetic mutation of my manganese – superoxide dismutase too – probably caused by toxins. My liver glutathion-S-transferase is also raised. Recent new tests available to show DNA-adducts (DNA bound

to toxins forming precarcinogenic lesions) have shown I have lindane and nickel DNA adducts – these may possibly be causing my ADP to ATP conversion blockage. My cell walls are leaking DNA – they shouldn't.

People don't believe I am ill – it is very stressful.

22. No direct impact, because my GP doesn't subscribe to that view. Taking the wider view though, it is very depressing, as it significantly reduces the funds available, and the focus on, research into the physical causes and potential treatments.

23. The bias towards psychiatric methods of treatment has left me with no support, treatment or understanding of my condition. I have had to face the problems & consequences of my symptoms alone and have to deal with them the best I can. As a result I have to live my life in a way some people are unable to grasp, understand or believe. This has resulted in feeling of isolation, alienation and stigmatisation.

Since contracting ME over 10 years ago I have experienced misunderstanding, neglect, rudeness, ridicule, ignorance and what can only be described as downright cruelty from almost every area of society (medical profession and some ME charities & their officials included).

My ability to work (therefore unable to contribute towards a pension), socialise or contribute to society has been severely curtailed. Some relationships with friends and family have been tested to the limits with some connections being irretrievably damaged. Like many sufferers who are in similar position I have been denied the chance to have and raise a family of my own.

No doubt members of the psychiatric lobby might consider some of the above descriptions reveal underlying psychiatric issues. They seem to be either unwilling or unable to understand that these realities & sentiments come as a result of having to live with the consequences of their interventions, approach, attitudes, and ignorance towards ME, and the inability to admit that it is not a psychiatric condition.

24. This has a huge impact. The suggestion that this illness has a psychological basis, fuels many of the misconceptions about this illness. I am very ill, and I have had to suffer comments from people that are extremely upsetting ie, 'I need to be dragged outside for my own good'. Or 'fresh air is the answer' or 'A change of environment is needed'. I left my home 7yrs ago to live in a warmer country for a few months. I taught English part time. It made no difference to my condition.

I have been turned away by a neurologist, who did no tests, his comments were 'you need to get out more'. I am severely affected and 80-70% bedbound, 90% housebound. I am desperate to be free of dreadful pain and illness, and go out and live my life. I cannot find the words to express how frustrating it is when the suggestion is, that I am in bed ill out of choice. I am not clinically depressed nor have I ever been. I have no mental illness that is evident, so what psychiatric basis exactly is it? I was a nurse before I became ill. I lived a full socially active life.

I have been told by an ex-friend that I might be attention seeking, at that if they don't give me attention when I am ill, then that is best for me! I have even been told by a GP that if I meet someone and fall 'in love', I might find all my symptoms disappear. The notion that this illness has a psychiatric basis fuels these ridiculous and hurtful remarks, and is pervasive in most dealings with health care professionals and the general public. It undermines the seriousness of this illness.

The World Health Organisation classifies M.E as a serious neurological condition, that is as debilitating as Motor Neurone Disease and MS. It classifies "fatigue" in another category, possibly with some underlying psychiatric cause, ie depression. These distinctions have to be made. M.E/CFS and "chronic fatigue" are in my view (as with the WHO) two different conditions. Yet they are umbrella terms, that seem to include all conditions of fatigue. Fatigue is not my core symptom, but one symptom. Some psychiatric measures, including CBT, may help some, but I strongly feel that in such cases you are most likely dealing with a depressive disorder.

I cannot understand why, when the government went to war with Iraq, that they used the World Health Organisation to support the invasion. The WHO commented that there is an 'appalling human rights

violation in Iraq'. Yet the government ignores the categorization of M.E and CFS, put forward by this organisation. Is it up to the government what they use from the WHO, and what they ignore?

25. Well in my case it was the only way to start any treatment and therefore I had no choice but I think that when you have ME it's hard enough to get people to believe you; then when you have to go down the psychiatric route it makes you feel angry because it seems as though others think that the illness is all in your mind and that's the message that having to go through psychiatric treatment sends out to others around you, oh it's all in her mind -- she's seeing a psychiatrist.

It also means that there is no importance given to ME because the first thing is they do as treatment is give you psychiatric treatment. I bet they don't do that for MS or other neurological illness. It also means that your GP doesn't take you seriously and so you don't get any treatment until the psychiatrist signs you off as being sane, hence the delay in getting the help that you need and more frustration and humiliation for you --the patient -- because no one believes that you are ill.

26. THEIR ATTITUDE HAS been an absolute bane on my health and well-being. I have had problems with doctors, benefits, and my permanent Health Insurance, thanks to the psychiatrists attitude towards ME and appalling treatments suggested. The book SKEWED is full of the true facts and what has really gone on in the school of Simon Wessley. And has caused me 8 years of anxiety and stress brought about by their ignorance, leaking into the insurance companies, benefits and GPs waiting rooms. I am about to start legal proceedings concerning my PH Insurance because of the psychiatrists link with these organization. A battle that has gone on for 5 years now, when I have enough to cope with having a serious severe illness. I am appalled to learn that ME has been used just to make more money by these psychiatrists etc. Psychiatrists should be taken off ANY list or bearing as far as ME is concerned. They should not have this hold on physical illness simply because in the name of human rights and peoples health and well-being.

27. It makes life very difficult – everyone assumes that if I say I'm feeling rotten then there must have been a life event which has caused the worsening (of course sometimes they're right).

28. It's now nearly 4 years since the publication of this report. In reality though it seems to have made little if any real difference though to people with ME. There has still been no public funding of biomedical research into this illness. Contrast this with the millions that have been handed over to a "select" group of psychiatrists to perpetuate their own flawed theories in the PACE & FINE trials as they continue to play their statistical games with other peoples lives.

In theory, the establishment of a network of "CFS/ME Clinics" is a step forward. But it is apparent that most of them are being run by those who do not really believe that ME is a physical illness. As a result it's unlikely that sufficient resources will be made available for thorough and comprehensive diagnostic testing, including SPECT and PET brain imaging and that everybody will continue to be diagnosed under an "umbrella of CFS". All that is being offered is illness management (in the main being taught by those with very little if any experience of ME) – it looks like being an opportunity wasted.

The support I receive from my GP is the same now as it was before the CMO's report. She is supportive, prepared to listen, but effectively powerless. GPs receive no information or training – which may paradoxically be a good thing - as she is able to read literature on biomedical research from MERGE, excellent diagnostic guidelines such as the Canadian Criteria, without being prejudiced by fatigue orientated material from the Department of Health. She also knows that not all patients "with ME/CFS" are the same. So why no compulsion to sub-group accordingly in the new "clinics" ?

I have been ill in different phases for 15 years. I have worked it out for myself that you can only "exercise" within very narrow limits. It is simply not the case that you can exercise your way out of this illness. If it were that simple most people with ME who were previously very fit and active would have been long since recovered.

29. A huge one. As a sufferer we have be labelled with an illness which covers a multitude of conditions, and to drop the umbrella term.

To allow those who have a biomedical background to be introduced to include microbiologists etc

To bring awareness to those in the know that it is a physical illness and not to accept the prescribing of SSRIs does more harm than good and only mask the problems

To allow a full investigations to the role that the pharmaceutical companies have on our treatment and to how they govern and influence the GMC

30. It's an added stress to live with – I feel that I have to constantly explain myself. I think most people understand and believe I've got a real physical illness (especially these days as I'm having big problems with my digestion and I've lost a lot of weight and look rather "ill".) but there's still this idea that there may be a psychiatric component to it. I feel that if I had another more recognised neurological illness like MS I wouldn't have to continually explain things. I think attitudes have improved though, and I find myself sometimes being overly paranoid that people don't understand, when in fact they do!

31. Find it annoying.

32. I have been, and still am, appalled at the manner in which M.E. (or chronic fatigue syndrome as NHS clinicians, irrespective of their area of specialism, seem to want to call it) is perceived in the UK. For many years, at the onset of my symptoms, like many sufferers, I kept returning to my GP informing him/her that I was not well. This went on from 1996-2003, at which point I "finally" got to see someone with special knowledge of the illness who confirmed my long term suspicions of M.E. (but this was only after a very arduous and stressful battle with the local health authority which compounded my already poor health).

During 1996-2003, I was subjected to derision and dismissal, with repeated accusations of "anxiety and depression" to which I replied, "its no wonder I'm depressed, I keep coming to you so called medical professionals, putting my trust in you, to be told "there is nothing wrong with you". It is not your quality of life (I said) which is being affected, including the loss of employment and social status, as well as loss of friends, family, and living an isolated existence, largely now housebound. If you were going to a doctor and you knew your own body and you were unwell but the so called medical professionals kept telling you everything was normal, wouldn't you be depressed?"

Even now, after engaging in another battle with the local health authority because I was confronted with a doctor (previously) who would not even discuss a report with me which had been produced and provided by the ME specialist I saw, I feel the new doctor, at times, is merely paying lip service to the fact I got put on his list via the local health authority, rather than by his choice. This, lately, has caused him to develop an "attitude" with me and I keep biting my tongue when confronted with such an attitude. Not only is it appalling behaviour but I believe he is trying to see how far he can push me and then he can feel justified in saying to the local PCT he wants me to be removed from his surgery list. Granted, he has, since I became one of his patients, supported me in terms of provision of a medical report for the Benefits Agency and some other local stuff, for which I have been grateful, given the very poor level of health care I previously enjoyed, but just lately there have been a couple of incidents e.g. he took some blood for some pathology testing and the report which was sent to me was clearly not my report. Like any intelligent person recognising that I had been sent someone else's report, I challenged its validity, and my current doctor did not like that. Also, I asked him if some of the medication I was buying over the counter was obtainable on the NHS? He agreed to provide some of it, but not all and I cannot seem to find, from any source, whether I can get the rest on the NHS or not as he is not prepared to supply it, and he got uppity about that.

I have also, during 1996-2003 been subjected to some very invasive surgical procedures, involving general anaesthetic, which had (an M.E. specialist) been available on the NHS in my area, would, I am sure, have recognised some of the symptoms with which I suffer, and the surgical exploration therefore would not have been necessary.

Because of the ongoing accusations of clinical depression (instead of M.E) when I was going to see doctors, I ultimately said "I want a psychological assessment" conducted. I was fed up with the way, over many years, I was being treated. This I got and it clearly stated that no worrying or underlying psychological factors were inherent – I was experiencing real pain!

33. I have been fortunate that my GP understands my condition – we have learnt about it together over the past twenty years! The consultant psychiatrist I saw for CBT (at my request) was sympathetic but recognised that my problems were physical and not psychological and therefore not within his province.

34. Makes life very difficult esp. when trying to be taken seriously and when you need others to take you seriously like during Benefit reviews when you find the doctor to be unsympathetic.

35. It means a constant struggle against the bias, particularly within the medical profession when dealing with doctors other than my GP.

It also has a great impact when applying for benefits. I am currently on DLA and SDA, and about to undergo my next review. This is something I always dread – it is exhausting in itself, and constantly having to stress and repeat that ME is not “all in the mind” and battle against this bias makes the whole process 10 times worse.

Past media coverage hasn't helped – it colours people's view of ME. The fact that I am on antidepressants is a result of my being ill for 17 years – anyone who has been ill for that long would not exactly be happy, but with any other illness that would be an accepted factor. The depression did not occur before the ME. If I see a new doctor, eg the surgeon I saw in hospital recently, they see Fluoxetine on my medications list and automatically start looking round for mental problems, instead of the acute physical pain in the side I had presented with (possible appendicitis or kidney problems, nothing to do with ME).

36. In a practical way, it has made no difference to my life as a sufferer (since I haven't been offered treatment anyway) although it will prevent any clinical treatment of my M.E becoming available for decades rather than in the near future since no clinical advances are being made.

37. It ruins lives. If you do not respond to CBT and Graded Activity you are given up on. The medical profession, and lay persons, think that ME is just pain and fatigue and we are all depressed, even in the face of evidence to the contrary. The only treatments offered aim to correct these symptoms, and any other symptoms are classed as psychosomatic. Because of this serious, debilitating and potentially life threatening symptoms are left untreated causing unnecessary suffering.

The psychiatric bias towards ME seems to be pervasive amongst the medical profession. For example, despite an extensive psychiatric evaluation which resulted in a report stating: “she is severely physically disabled”, “has no mood or behavioural problems” and “is coping remarkably well given very difficult circumstances” I was still offered CBT and counselling, and my symptoms of severe nerve pain, nausea, difficulties with speaking, sight, swallowing and eating, seizure like brain activity, intermittent paralysis, contractures in hands and feet etc. were left un-investigated and untreated. A hospital psychiatrist put in my notes that she suspected anorexia as I was very underweight - my inability to chew solid food due to muscle weakness and oesophageal spasms were classed as anxiety related. If they had been classed as the physical problems they were, I would have been put on a high protein liquid diet (or even been tube fed which would have been a Godsend) and given muscle relaxants to stop the spasms – both of which would have been invaluable. Once I was back home, my GP prescribed the muscle relaxants I needed (at my request) and I easily gained weight on store bought high protein shakes. Yet the anorexia notes are still in my hospital file and place a stigma on me which colours any future dealings with hospital medical staff, despite me proving that anorexia was not the issue – a physical difficulty was, and despite an earlier psychiatric report which stated I had no behavioural problems. No matter what evidence to the contrary, the psychiatric label prevails.

If you do not respond to Graded Activity, the Benefits Agency seem to think you are either malingering or depressed and benefits are refused. The Agency, and in particular their Medical Examiners, seem oblivious to the problems and symptoms of severe ME and all seem under the impression that everyone with ME recovers in under 5 years. If you are still ill after that it either isn't ME or you are mentally or behaviourally ill in some way. Also, because there is no diagnostic ‘test’, clinical findings are largely normal, severe ME is vastly under-researched and there is such a psychiatric bias, the Benefits Agency seems unwilling to accept that people with ME have care or mobility problems and an illness which is often chronic, severe and does not respond to behavioural treatments.

38. It makes me not want to use NHS for treatment as feel physical symptoms will be attributed to psychological causes. Also do not feel graded exercise / CBT relevant unless given by person with adequate knowledge of severe ME & do not want my condition to worsen

39. I was initially under great pressure to accept CBT, but after reading various reports, extracts and articles my GP agreed it would be unhelpful and probably detrimental to me.

He talked to the CBT officer i.e. and got them off my back.

40. The treatment offered causes depression! A physical illness is easily accepted by family and friends but not so with something that is talked about as being psychological. We need help and medication to deal with our physical problems such as pain and mobility NOT more drugs for the brain!

Generally ME sufferers do not look 'ill' and other fit people do not appreciate how you feel and the limitations that you have for physical activities.

41...terribly bad - makes my situation twice as hard - now I have to deal with the illness and the negativity of the medical profession and media. I have been ignored by the medical profession on the whole, and at other times ridiculed and verbally abused. This has all caused me untold stress and suffering.

42. My life was made hell by this bias held by company doctor and the advice she gave my employers

43. Generally it makes me feel extremely frustrated, annoyed, deeply hurt and upset with the inappropriate attitudes with the majority of the medical profession, taking the view as labelling ME as psychological and all in the mind. Some of these new clinics that have been set up, the treatments to be offered are mainly psychologically biased and that the clinics appear to be making no distinction between the effects of neurological ME and Chronic Fatigue (& as a result, medical staff involved in delivery of treatment may be misinformed or poorly advised).

I have experienced extensive problems with the NHS from 2002 until the end of 2004 as I developed an underlying medical condition which was unrelated to ME in which it was not investigated properly until I put a complaint in with my local MP, as I had frequent trips to A&E and 5 hospital admissions and every time I arrived at A&E or admitted into hospital when they took my medical history and discovered that I had ME they were reluctant to investigate into my new symptoms and on my medical notes they documented that I was psychosomatic and anxious and they kept sending me home and telling me to live with it. By my final admission into hospital my MP had forwarded my complaint to the PCT and proper investigations commenced in which it was discovered that I had a large amount of Gallstones in my Gallbladder, but despite the results of the ultrasound they were still saying that the new symptoms that I was suffering with were unrelated to the Gallstones and that it was my ME and irritable bowel syndrome. My MP carried on fighting for my case and in December 2004 the hospital finally surgically removed my Gallbladder which resolved the problem. In January 2005 I obtained a copy of my histology report on my Gallbladder which revealed that my Gallbladder was in a very bad way and chronically inflamed and compacted with Gallstones.

44. It means that I live in fear of professional involvement because I want to be treated for my physical illness and am afraid that a) they will not believe I am really ill b) they will not understand the symptoms I suffer or accept they are real c) they will give me inappropriate treatment d) they will say I am lying about my disability. (I have experience of all these things in the past from various professionals). It results in a no treatment, no win situation for me and definitely no trust of professionals.

There is no hope of a cure because there is no government funded physical research.

There is an inappropriate diagnostic criteria of fatigue because the medical establishment have adopted The Oxford criteria which main symptom is fatigue. The Canadian definition is the one which best fits the symptoms of people with genuine ME which is a neurological illness and as such is a more honest way of defining the illness for diagnosis, to make sure that the people diagnosed with ME really do have it. Calling it Chronic fatigue only adds to the watering down of the seriousness of this illness and

opens 'the goal posts' to allow in other undefined fatigue conditions which would not fit the Canadian criteria and would not be called ME.

Until it is honoured as a neurological illness by the medical profession it will not get the adequate funding and respect it deserves and peoples lives will continue to be wasted with the endless suffering of this chronic illness.

There is only stress when it comes to applying for benefits because I am invariably treated as someone who should not be on them and they always want more information than has been provided. The process takes months because of the underlying attitude towards ME.

I am not given the respect as someone who is physically chronically disabled and extremely ill, with no cure or treatment available and a 2% chance of recovery at best. I keep having to reapply every few year which is exhausting, upsetting and always make me more ill. It simply is not good enough. ME needs to be given the full acknowledgment that it deserves of a severe and serious physical illness. And people need to be treated properly with the same respect that someone would get if they have cancer, MS or AIDS for example.

45. Claiming DLA is problematic if the condition is considered to be psychological – only physical conditions count. When renewing Mobility allowance etc. I've had visiting Drs write that 'I would make good progress taking anti-depressants' despite their recording elsewhere on the form that I have tried numerous a-ds and get no benefits, only bad side-effects.

Some people hold to the view that if I really made an effort then I could do things. They, of course, do not witness the after-effects of physical or mental effort and they have no concept of an illness that can be chronic and disabling yet leave the sufferer looking fairly normal. More general acceptance of ME as a physical illness and less exposure of some 'rent-a-quote' psychiatrists would be so helpful.

Money currently squandered on psychiatric areas could be so much better used by addressing and researching the physical problems and possible treatments; giving the chance of something really useful and beneficial to me and other sufferers. If psychiatric interventions were really so useful then there would be no need of other stuff – we'd all be 'cured'. As this is patently not the case then more effort (MUCH more effort) must be directed at physical causes. And this might give us some hope for the future, where currently there is no hope for severely affected sufferers such as myself.

46. DEVASTATING.

47. This illness makes life hard enough as it is. It is so much worse that, whilst there is the ability to investigate this illness, that opportunity is being deliberately ignored. The choice the medical profession is making to treat a physical illness with psycho-nonsense is never going to cure anybody. I have been ignored for 20 years. Will you carry on for another 20?

48. Focuses attention away from serious research and diminishes general attitude to severity of condition for some

49. The prevailing bias towards psychiatric treatment of ME has had a tremendous impact upon my life as a severe sufferer so much so as to have caused feelings of despair at times. Although I have been lucky enough to have my immediate family members believe me when I tell them I am feeling physically ill there have been a lot of times when I have balked at telling others that the illness I suffer from is ME because of the stigma it carries of simply being a malingerers disease. I am a highly intelligent person I worked in one of the country's most prestigious institutions Manchester University as a library assistant for ten years. I am fifty-six years old. I worked abroad for two years and have brought up three children. I am an expert on my own body. When I was younger I was unfortunate to suffer from two diagnosed episodes of Clinical Depression, the physical feelings I have now are very different from the heavy black cloud I would feel then as I came to first consciousness on awaking every morning blotting out even the joy of colour in my life. I do not feel that way now I feel very poorly. One incident stands out particularly when I was feeling deathly and my husband took me to the local hospital A&E department, where a young intern asked me had I heard of the diagnosis 'hypocondriasis' after he'd noticed in my notes that I'd been prescribed Amitriptyline. Even though I informed him that my Consultant Dermatologist had recommended this for pain relief of my genital

skin disease. He told me 'To go home and be at one with my body!' I complained to the governing board of the hospital and later received an apology. However the utter despair I felt on that occasion was terrible and had I been a person of more fragile nature with no back-up help at all it would have been enough to turn a person to suicide. It subsequently turned out that as usual my body was producing an allergic reaction to an antibiotic the GP had administered, every time I have to take a drug of any kind I suffer an exaggerated response of side effects. Positive physical symptoms. How can psychiatric help or graduated exercise possibly make allergic reactions improve? Am I supposed to wait for a gap in vomiting to drag myself up and step up and down on the bottom stair? Would that be expected of a cancer sufferer?

50. For over twenty years I was diagnosed as having various psychiatric disorders, borderline personality disorder, hysteria and many more. This is in my notes and I am treated with contempt by most hospital doctors, nurses, GP's etc. I was treated with many different psychiatric drugs and the extreme emphasis on 'pull your self together' and get up and do things and to be seen to be doing things has had a significant, overall detrimental effect on my ME. I pushed and pushed myself and was pushed to do more than my body was able to do with the result that I gradually got worse and worse. For many years I hid my symptoms and am still afraid to go to the doctor with any symptom at all because I know I will not be believed or taken seriously. Nor will I be treated unless it is a very obvious symptom and easy to diagnose and treat. Nearly all my symptoms are 'psychological' according to most doctors. Also occupational therapists, physiotherapists, Social Workers etc.

51. The worst possible, I feel that no doctor has taken the illness seriously despite it costing 'huge' amounts to the DSS, Social Work Dept & NHS.

However despite all this, my level & sustained nature of disability has resulted in an indefinite award of Disability Living allowance. After many years of hassle, whatever my illness – since there is not agreement between doctors, is at least now recognised!

On the whole I also have the support of my social worker who advised me to seek a solicitor when faced with unfair decisions by her bosses.

My previous social worker also cared enough to give me a large care package as required for years, which is unfortunately now a disaster of its own requiring legal assistance & there is no sign of abatement.

I have had to seek treatment outwith the NHS as it seems GPs do feel handicapped unless a consultant gives their approval & says some drug (which could be prescribed on the NHS) is okay to prescribe.

Thus it costs me thousands for health care which I take from my benefits, which the social work dept are trying to remove to the sum of £70.26 per week- even taking income support which is supposed to be guaranteed & top up my income to what the government says I need to live on!

I am in despair!

And leads me sometimes to ask the following: I don't even know why I am still alive! I don't even know why I am still sane!

If this much stress was put on to somebody else I could understand why they might take drastic action. However I know in truth that I am in the right, so I will just battle on as there is so much I would like to do with my life & with others!

I think my friend/ partner suffers more despair than I.

52. My GPs practice seems to have the opinion that ME is nothing, and that it is related to depression, and that if you are in bed, then you have "given in". When I have tried to explain to my GP how ill I feel, or try to explain different symptoms, I feel I am not believed or that I am exaggerating. My GP even said, "I didn't think it was that bad!", in such a way that I gave up trying to explain.

A family member asked me about my illness, and when I tried to explain what I was feeling, and how difficult it made my life, she dismissed every thing I said, and ended the conversation by saying that I

“should be locked up. And that I was not fit to be out, and I should be locked in the Psychiatric unit immediately”

Most people have no understanding of what ME is, most think “its just tiredness”, and many still refer to “Yuppie Flu”.

Because my GP is not treating me, people then assume that there is nothing wrong with me and I must be making it up.

When I was refused DLA, I went to appeal and was treated very badly by the panel, who assumed I was exaggerating all my symptoms. They also assumed because I was not on any medication or treatment, that there was nothing wrong with me. I felt humiliated, and I felt that no one was listening to me. I felt I had been judged before I even stepped into the room, and that any answer I gave only served to reinforce their preconceived ideas about ME.

My GP offered GET as “The Cure” for ME (if only), and said that it had been proved to cure people, she also said that if the patient dropped out of the exercise treatment because they felt it was making them worse, then they only had themselves to blame, and if they only persevered they would get better.

According to her, any one unable to get out of bed, had given in, and only had themselves to blame. Oh and yes she did tell me to pull myself together, and I really should try harder!

53. I have had many bad experiences and don't trust doctors.

54. Family members (parents, sister-in-law) seem to have the underlying attitude that I could do more if I tried harder, and are not willing to listen to descriptions of the way the illness affects me.

Most people of my acquaintance do not understand that how I look or act is not how well I am i.e. after seeing them I will have to rest.

I think that if doctors were treating this as the serious illness it is, the general public might listen more.

55. Feel it diverts funding away from the correct/appropriate forms of treatment e.g anthroposophical, homeopathic etc.

ME patients not given proper consideration when the diverse range of symptoms are classed as being "all in the mind". As a consequence my own condition deteriorated to my requiring 24hr care with a rota of three nurses and my husband to care for me.

56. It ensures that:

- \* professionals and others do not understand what ME/CFS is
- \* people do not take ME/CFS seriously and they do not offer appropriate treatment, help and support.
- \* my private health Insurance claim will not be paid
- \* Disability Living Allowance will not be paid
- \* my income is insufficient to pay for help of any kind.

57. Obviously it implies to some degree that I could get well if I wanted to. Although I have carers three or four times a day, it's still hard for them to SEE my illness -- there are no obvious physical signs such as deformity or amputation. I sometimes wonder whether they think my illness is all in my mind.

58. It has made me suicidal, and basically ruined my life.

I have read in my medical records, 10 years of lies. I am unable to remove these due to lack of funds. I have tried. I am told a Doctor is allowed to write anything about a patient, be it lies or not. Incredible.

When I realise that I have been UN NECESSARILY WHEEL CHAIR BOUND for 10 years, due to arrogance, and denial by the medical profession by REFUSING to give me medical tests and MEDICATION, it makes me very angry. Even more so, as there is no apology, no acceptance of what

they have done to me and my family's life, by making me such a burden on them as I am cared for 24/7.

I have personally had myself and my family slandered in my medical records, I have had such ridiculous statements as that I 'Skipped School to avoid sport' and that my grandmother was a drunk, all lies to discredit me. I have been shut in an AIDS ward for 7 weeks and the staff have been told to 'Limit Patient contact' and "Write down everything he says" despite being mentally sound, and never sectioned. This was in an Immunological ward. Astonishing that this should happen in the NHS after so much is known about M.E

What is DANGEROUS, is the medical professions OBSESSION with psychiatry led me to loose 5 stone in weight through stress, and end up in a resuscitation unit at 4 a.m in March 2004 due to the disease POTS (Postural Orthostatic Tachycardia Syndrome), that I never knew I had.

I never knew I had this, as the NHS REFUSED to give me a Tilt-Table-Test because I was an M.E patient, my symptoms must be mental illness. I went to casualty, 23 times, yes, 23 times before this event happened to me. EVERY time I was ignored, abused verbally, or sedated with VALIUM which I got addicted to. No, I am not joking. I got diagnosed by FLUKE, that a consultant was on duty the night it happened to me. In fact the next day, I had to fight being discharged despite being in a cardiac ward with chest pain, all because I am viewed as a mentally ill 'Fatigue' patient who is taking up a valuable bed from a 90yr old.

This is what the bias does to people, it is DANGEROUS as people can have REAL heart, breathing problems and simply be discharged time after time, over years, as is my experience.

This is especially worrying as I am not mentally ill, never have been, and I am educated, and lastly I am an adult. Being able to stand up for myself is irrelevant, if all doors are shut to medical tests and REFERRAL to private consultants.

I will never forgive these people as they refuse to apologise to me, in ANY form whatsoever and go about their merry ways offering me 'exercise' and NOTHING else.

59. I no longer see medical professionals because it is so hard to tell who is biased and who is not until it is too late.

The absolute worst are so called ME specialists as they do not admit that they think ME/CFS is a behavioural disease and they put on a charm offensive. They are such liars and cheats I keep away from all of them. On the rare occasions I am well enough to get out of the house for an hour or so I do not want to waste the trip on doctors.

Simon Lawrence, Chairman of the 25% ME Group's Concluding Comment: *"It is very clear from the above submission that ME sufferers are calling for biomedical research to be undertaken: also to redirect resources into this field (that are presently being wasted on psychological research programmes) in order to make a real difference to the lives of sufferers. The present models of management and treatment within the UK for ME sufferers are flawed as they do not seek to truly answer the question WHY these people are so sick and HOW they are going to be made better?"*

*Urgent research funds should be made available from central government in order to implement biomedical research but also to support research organizations like MERGE (in Dundee) and the CFS Research Foundation (in Berkshire). The level of suffering cannot be allowed to continue and this 'sticking plaster' of present approaches to treatment of ME sufferers should be stopped because of the harm being caused.*

*We hope and pray that the Parliamentary Inquiry will seriously consider, not only the technical submissions made, but also the very real human element and suffering caused by this disease."*