The East Anglia ME Patient's Partnership (EAME) and the 25% Severe ME Group .

A survey of Severe ME patients in Norfolk and Suffolk, November 2007.

Greg & Linda Crowhurst

A statement from the 25% Severe ME Group :

"The 25% ME GROUP, a national organization supporting ME sufferers, feels that this survey conducted in Norfolk and Suffolk shows an ever increasing problem, especially if you take into account the bigger picture across the UK.

The recent publication of the NICE Guidelines also do not show the true picture of the problems being experienced by patients with ME. It also does not give adequate advice of how to support and treat such patients

Most importantly it does not highlight the desperate need for biomedical research and practical medical intervention that is so urgently needed."

Simon Lawrence, Chair.

Introduction

Myalgic Encephalomyelitis , is a serious biomedical disorder; only those in the final stages of terminal cancer or dying of AIDS can possibly know what it is like to experience the level of sickness that a severe ME patient has to endure for years, often decades on end ; yet the severely affected in Norfolk and Suffolk receive virtually no ME service whatsoever.

Any service for people with ME should :
(Crowhurst & Crowhurst 2007) [1]

- **Honour the fact that ME is a serious neurological disease** (WHO ICD 10. G93)
- **Respect the fact that ME is a multi-system disease affecting all systems of the**

---

[1] Crowhurst G, Crowhurst L (2007) The Five Core Components of Service Delivery, ME Training Co

body and each person's individual experience of this disease.

- **Validate the ME sufferer's experience by using appropriate criteria for assessment and adequate biomedical testing using up to date equipment and methods.**
- **Identify the full need and aim to treat/support the whole range of symptoms , with honest prognosis.**
- **Competently provide ongoing support**

The full range of current support is outlined in the table below :

GP (ME) Support	James Paget	None	Other
x	Pacing, some limited help		
		x	
		x	
		x	
			Occasional physiotherapy
x(pain management advice from Dr Mitchell)			
			Social services – homecare and OT help with wheelchair
x	questionnaire		
		x	
		x	
x	diagnosis		
		x	
	"marvellous ongoing : initial consultation at home ongoing support by email and phone."		
		x	
x very good GP	Told I was too ill to benefit from help at JP		
	Monthly visit from an OT		
	3 OT assessments		
		x	
		x	

		x	

People were asked **‘ What services , if any, are you receiving to help you with your ME ?’**

Out of 21 people , ten people say they are receiving “none”, when asked **‘ What services , if any, are you receiving to help you with your ME ?’**

receiving no service.

"I currently receive nothing." says this patient, after the PCT "*decided to withhold any further funding for* <u>*outpatient*</u> *treatment ." "None"* says this patient, in reply to the question : "what services , if any, are you receiving to help you with your ME ? "

"*None*" says another patient.

“None” says yet another.

One patient reports how the James Paget sends them a : *“Questionnaire every six months after initial visit. GP who only teats "a symptom" and not ME/CFS as a whole."*

However this patient : *Attended James Paget once last year – no follow up.*

Another severely ill patient recounts how they have been deemed “too ill” to receive a service : *I saw an ME Consultant in 2003 and was told I am too ill to benefit from any help. There is currently no service available in Norfolk that offers help to someone like me with severe ME with neurological symptoms.*

After years of not receiving any help, after their leg muscles had "*atrophied*" a severe ME patient states how : *in later years I saw Terry Mitchell at James Paget - he is superb Consultant. But even so, the damage has been done for me physically and no one has been able to help me recover further.*

Another patient is a :“*Current patient with NHS CFS Service (Since Sept 2004 diagnosis) 3 OT Assessments the last being May 2007”*

However they have experienced :*“General ignorance and prejudice of former GP and a Consultant Neurologist. “*

In addition, the severely affected in Norfolk and Suffolk encounter disbelief, an almost total lack of proper biomedical treatment and they even encounter abuse from some medical professionals and are left to deteriorate; left untreated ME can get worse.

(Peckerman et al 2003[2])

This patient reveals how she was : *Told to get out more and get up earlier and do my housework early because my husband who has been fighting lymphoma was far iller and suffering far more than my daughter (who has ME too) and myself. We tried and we were very ill and I have suffered severe pain in my feet, knees and joints. My daughter also. The cold way my doctor treated me , made me really cry when I came home and I was very stressed for a long time afterwards. She made my daughter and I feel a fraud even though we were not.*

This patient describes how they were referred to a : *Consultant specializing in Diabetes – he seemed to have no interest in CFS and offered no help beyond suggesting, following various blood tests, I might have CFS.*

One severely ill patient describes how they were forced to undergo : *" hospitalisation and enforced mobilization . I had to walk to the canteen to get food and drink which I only managed once a day. Lost 9lbs in 5 days. "*

Another patient states how *"It does not hep to take time and energy to see medical professionals who do not believe I have a neurological illness. "*

This patient goes on to explain how : "*It is soul destroying* to have a World Health Organization recognized illness that neurologists *are not interested in even exploring or validating. The neurological symptoms can be extremely frightening and severe . I don't have the energy or the physical ability to cope with being insulted and demoralised on top of being dismissed, when I have extreme paralysis , spasms, all over body numbness, facial palsy - things not to be dismissed lightly and not to be left to get on with by yourself.*

A patient describes how :*When I visit hospital I need to lay down - as sitting up causes me severe pain . I spasm in my abdominal chest muscles and the same in my neck and lose the inability to support myself thereafter*

Yet another patient describes how : *The woman I saw had no compassion or understanding of ME and I felt like throwing myself under a bus when told I had no life, I should get out into the world and do more.*

1. Damaging influence of the UK Psychiatric Lobby :

ME, which can occur in both sporadic and epidemic forms, has been described in the medical literature for about 70 years.

---

[2] Peckerman et al (2003) Abnormal Impedence Cardiography Predicts Symptom Severity in Chronic Fatigue Syndrome, The American Journal of Medical Sciences 2003; 326 (2) : 55-60

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 is currently classified under ICD code G93.3.[3] It cannot be emphasised too strongly that this recognition emerged from meticulous clinical observation and examination (Hooper 2007) [4]

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 [5]

ME appeared in the standard textbook of Neurology as long ago as 1962 ([6]yet under the influence of a powerful UK school of psychiatrists, "the (UK) medical establishment has chosen to largely ignore the wealth of international biomedical expertise and the need for proper physical patient investigation and has effectively recommended abuse and neglect of patients in place of genuine science-based medicine. "[7] (Short 2007)

In what other neurological disease would psychiatric interventions, designed to convince the patient there is nothing wrong with them, be advocated as first-line / core treatments ? The psychiatric lobby's influence, the undermining of the serious physical nature of ME; the focus upon fatigue, has had a negative impact upon people's experience and treatment.

This patient describes how : *A Neurologist dismissed my neurological symptoms and made me ill by demanding I lift my legs when I was unable.*

Another patient recounts how they were offered : *Anxiety counselling . 7 week course made me extremely ill and was not helpful. Medication - antidepressants (worse).*

---

[3] 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* (The Montague/Hooper paper) [Online], Available: www.theoneclickgroup.co.uk/.../ME-CFS_docs/MONTAGUE%20HOOPER%20PAPER%20-%20AMENDED%20CORRECTED%20VERSION.pdf

[4] Hooper M (2007) Myalgic Encephalomyelitis (ME): a review with emphasis on key findings in biomedical research. jcp.b**m**j.co**m**/cgi/content/abstract/60/5/466

[5] Hyde, Byron M.D. 2005 *The Nightingale Foundation*, http://www.nightingale.ca/index.shtml

[6] *Diseases of The Nervous System. Lord Brain. Oxford University Press, Sixth Edition, 1962*),

[7] (Kevin Short 2007 Myalgic Encephalomyelitis (ME), the NICE and New Labour: ABUSE OF SCIENCE, ABUSE OF THE SICK AND DISABLED August 2007 www.pressbox.co.uk/detailed/Health/ABUSE_OF_SCIENCE_ABUSE_OF_THE_SICK_AND_DISABLED._Myalgic_Encephalomyel..

Betablockers (worse) Gabapentin (worse) (Adverse reaction to most medications).

This sufferer outlines how sensitive an ME patient can be to medication :

1. Antibiotics. Have had them twice. Always feel extremely ill afterwards. Seems to cause severe intolerances/allergies to start up, plus Candida/Thrush symptoms. They destroy god bacteria in the gut.
2. Antidepressants. Can have the same effects. Too sensitive/unwell to cope with them.

And this patient recounts a drug reaction they suffered : *I am very sensitive to certain medications and endure constant severe pain. A pain relief clinic prescribed Fluanxol, most other options having been tried. I had a terrible reaction to this , ended up in hospital for nearly a year, have diagnosis of temporal lobe dysryhthmia, am on heavy medication to control it (which has causes massive weight gain amongst other side affects).*

According to this patient : *Amitriptyline made me bed-bound and disorientated. Allergic reactions to antibiotics and some strong pain killers. Melatonin had an horrific impact on my already severe symptoms.*

Yet across the UK patients report how their severe reaction to medications are discounted purely on the grounds that since they have ME they must be exaggerating or making it up. "(Long 2007)[8] Dangerously, the recently published NICE guideline negate this patient experience.

The psychiatric lobby's constant and ongoing attempts to attribute a false psychogenic (psychiatric) attribution to ME have had and are continuing to have a profoundly damaging influence upon the lives of people with ME in Norfolk and Suffolk .

This patient remarks : *In 1990 no-one in health profession seemed to know what to do to manage our illness. I believe that not resting properly following diagnosis has made me permanently ill and disabled (80%)*

This patient then goes onto describe how : *The worst experience I had was with a physiotherapist (NHS) sadly a very ignorant person who believed I had "illness behaviour" and refused to help.*

The danger is that if medical professionals do not understand this neurological multi-system disease , they will cause great distress and not be able to help the people

---

[8] Jean Long (2007) BMJ Rapid Responses to R Baker and E J Shaw
Diagnosis and management of chronic fatigue syndrome or myalgic encephalomyelitis (or encephalopathy): summary of NICE guidance
BMJ 2007; 335: 446-448 http://www.bmj.com/cgi/eletters/335/7617/446)

who need their service and the people they see will most likely go away disillusioned, dismayed and
feeling worse from the experience and untreated.

There are over 4,000 papers documenting the evidence of biomedical aberrations found in ME/CFS [9];. If the severely affected are to gain any hope of their illness being accepted ,understood and being given proper support and treatment, these papers must be made freely available to health professionals in Norfolk and Suffolk .

Medicine has a long history of giving a false psychogenic attribution to diseases, before their actual physical causes are known; this is currently the issue in ME, even though there is not a single shred of evidence that ME is a psychiatric, behavioural condition.

For example, Multiple Sclerosis , a neurological disease now known to be caused by demyelination and subsequent neuronal dysfunction was widely attributed to an "hysterical personality structure" .[10]

Parkinson's disease was once considered to develop as a result of an insecure childhood and poor adjustment to stress. Lupus too was considered an "hysterical" condition. Interstitial cystitis used to be described in a major medical textbook as being the discharge of unconscious hatred. Migraine, the result of a perfectionist personality. Psychogenic explanations have also been advanced for rheumatoid arthritis, asthma, peptic (gastric) ulcers and ulcerative colitis, all now known to have clearly identified physical etiologies.

According to Professor Pall (2007) psychogenic advocates typically ignore " crucial genetic, physiological and biochemical evidence inconsistent with their views, they substitute emotional terminology for sound argument. They often use flawed logic. They rarely make any clear testable predictions that may be used to distinguish their views from those of physiological explanations, a cardinal sin in science."[11]

In the survey no one wanted a biopsychosocial clinic, which shows how
strong is the view that the severely affected people of Norfolk and
Suffolk absolutely do not want a psychiatric bias in their ME
service.

---

[9] (www.cdc.gov/od/oc/media/transcripts/t061103.htm)

[10] Aring CD (1965) Observations of multiple sclerosis and conversion hysteria. Brain 1965 : 88 663-674

[11] Martin L Pall (2007) Explaining Unexplained Illnesses, Disease Paradigm for Chronic fatigue Syndrome , Multiple Chemical sensitivity, Fibromyalgia, Post-traumatic Stress Disorder, Gulf War Syndrowm an Others" Harrington Park Press, New York and London pp189/90.

2. Danger of Graded Exercise Therapy & Cognitive Behaviour Therapy :

CBT and GET are the two first line treatments advocated by the psychiatric lobby, despite their inappropriateness, especially for the severely affected .

It cannot be emphasized enough how wrong this treatment regime is - as one Norfolk/Suffolk patient found out , to their cost :

Graded Exercise Therapy worsened me dramatically and I have no doubt had been a large factor in my being severely affected after 20 years.

Cognitive Behavioural Therapy - this did not make me worse but I feel was completely inappropriate and didn't have any relevance to my day to day life.

Another patient describes how :

"the damage has been done for me physically and no one has been able to help me recover further. "

Yet another patient descries their experience :

"At one hospital I was given a cycle test on an exercise bike. When I finished I couldn't get off the bike and was in a lot of pain. After this my symptoms worsened. "

These results should not be surprising . Graded Exercise Therapy is probably the worse possible intervention in ME. As Ruth Nolan (2007) points out [12]: In submissions to NICE, The British Psychological Society said that "there is no evidence that GET (with or without CBT) actually increases activity levels", the Royal College of Physicians said "Clinical evidence and patient experience suggests strongly that some patients may be worsened with GET", while the Association for British Neurologists said that "the guideline needs to be thoroughly revised to reflect our current understanding of this condition rather than the supposition of the psychiatrists".[13]

This Norfolk/Suffolk patient recounts how : "I've had CBT and GET. Both of these made me extremely worse for a number of years and from which I am still recovering from and

---

[12] Nolan R (2007) **A serious lack of evidence for NICE guidelines** BMJ Rapid Responses to R Baker and E J Shaw Diagnosis and management of chronic fatigue syndrome or myalgic encephalomyelitis (or encephalopathy): summary of NICE guidance
BMJ 2007; 335: 446-448
http://www.bmj.com/cgi/eletters/335/7617/446)

[13] http://guidance.nice.org.uk/page.aspx?o=449805

which has still affected me."

Another patient says how : *Have had CBT before I moved here and the exertion, traveling and questioning was exhausting and made me worse.*

Another patient describes how : *the GP I was seeing was obsessed with I must be depressed. depression doesn't put you in a wheelchair ??*

And a patient remarks how : *I have been ill/disabled for many years with no remission and have a lot of experiences /mishaps concerning my treatment by the NHS.*

Another comments that *"Hydrotherapy, using a form of GET, made me more and more ill and I developed spasms."*

"Common sense helps with pacing and graded exercise etc. CBT and GET I don't think are helpful, as often any course is very draining and I cannot concentrate anyway" remarks this patient.

From the survey, 90% of Norfolk and Suffolk severe ME patients reject GET , though one person wondered if GAT might be helpful and thought that a biomedical clinic should offer appropriate emotional /psychological support and access to OldChurch /Queen's when deemed necessary.. 72% of ME patients however reject CBT and even one who said they want it offered said " *it should not be offered as sole treatment.*"

And another saying that they thought it could be offered if the person feels it would be helpful but goes on to say that, " I personally didn't(find it helpful)But an ME trained therapist - perhaps."

Only 4% ie one person actually wanted a psychiatrist and that was because they thought that ME can lead to depression - especially due to lack of help, info and support. This is not a person who wants a psychiatrist because they think ME is a psychiatric illness- 92% rejected a psychiatrist absolutely and one other person wondered if they might rule out secondary psychiatric disorder. This indicates how little the true ME sufferer wants psychiatry in the treatment of severe ME.

Though 61% of respondents felt counselling should be offered, this was not an overwhelming demand. 39% did not want counselling. One person said no to counselling being offered as they were "*concerned about confidentiality issues in a hospital setting*."

Another makes an important point :Yes, counselling should be offered, "BUT only if the patient wants this and only by those who really understand the condition."

Someone else said only "maybe " counselling should be on offer indicating a level of ambiguity to psychological intervention as well as psychiatric, for ME. 70% of respondents thought that pacing should be offered. It is important to be aware that the

Gibson Parliamentary Inquiry (2006) recognised CBT, GET, Pacing as potential symptomatic treatments and not cures, GET in particular was recognised as potentially dangerous (4.6) and evidence from the 25% Group was used to show this.

In actual fact for pacing to be effective one needs 80% functional ability, which eliminates the severely affected from the starting position. Dr Darrel Ho-Yen (1994)[14] states that " Patients with (ME/CFS) should be advised not to increase their activities gradually until they feel 80% of normal. "

In the 1980's Loveless [15], found that ME/ICD-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

The unboundaried , catch-all, psychiatric construct "CFS ", with its constantly shifting goal-posts represents much too high a starting point, especially for the severely affected :

In previous surveys of the severely affected , the 25% Group found :

25 % Group Survey Results into CBT & GET	
2004[16]	**2005 (Gibson Inquiry)[17]**
Cognitive behavioural therapy (93% unhelpful) and psychotherapy (90% unhelpful)	**4% found CBT helpful** **96% said CBT had a negative impact on them**

---

[14] Dr Darrel Ho-Yen (1994) BMJ 1994:309:1515

[15] Munson P (ed) (1995) Stricken : Voices from the hidden epidemic of Chronic Fatigue Syndrome, Haworth Press, New York.

[16] www.25megroup.org/Group%20Leaflets/Group%20reports/March%202004%20Severe%20ME%20Analysis%20Report.doc

[17] Crowhurst G (2005) 25% Group Submission to the Gibson Inquiry www.25megroup.org

Worsening of condition with graded exercise therapy (tried by 39% of members, and 82% made worse by it)	**5% found GET helpful** **95% said GET had a negative impact on them**

As Marjorie Van de Sande (2003) [18] points out , exercise programmes are often prescribed with little thought to the impact they might have upon the ME patient :

Response to Exercise	Healthy People	ME/CFS Patients
Sense of well-being	Invigorating, anti-depressant effect	Malaise, fatigue, worsening of symptoms*
Resting heart rate	Normal	Elevated
Heart rate at maximum workload	Elevated	Reduced heart rate
Maximum oxygen uptake	Elevated	Approximately ½ of sedentary controls
Age-predicted target heart rate	Can achieve it	Can NOT achieve it
Heart functioning	Increased	Sub-optimal
Cerebral blood flow	Increased	Decreased
Body temperature	Increased	Decreased
Respiration	Increased	Decreased
Cognitive processing	Normal, more alert	Impaired
Oxygen delivery to the muscles	Increased	Reduced
Gait Kinematics	Normal	Abnormalities
Recovery period	Short	Days or weeks*

These results clearly highlight the dangers of exercise for people with ME.

3. The need for a biomedical service

100% of people in the survey said they do not want a biopsychosocial clinic, they want a biomedical clinic.

---

[18] Van de Sande M (2003) ME/CFS Post-Exertional Malaise / Fatigue and Exercise http://www.mefmaction.net/Patients/Articles/Symptoms/PostExertionalMalaise/tabid/238/Default.aspx

In the current survey people were asked: **What do you think an ME service should offer?**

Patients are clearly asking for : *Acceptance that the person has a real illness, that they are not choosing to be ill and that if a full recovery doesn't occur quickly, that doesn't upset anyone more than the patient.*

This patient points out how :*We need a biomedical service which honours the World Health Organization definition that ME is a neurological disease. Any other sort of service, like a psychiatric -styled biopsychosocial service means the root cause of my illness is being denied not looked for.*

Simply just being left without any biomedical investigation is very worrying for sufferers.

As this patient states : *My symptoms are downplayed and invalidated. My safety is at risk because I have no one to turn to give proper advice or medical help, even with severe symptoms. Without a biomedical service my life continues to be physically diminished. I am desperately physically ill, neglected and concerned for the future."*

The survey results outlined in part 2 give more detailed information regarding what the severely affected of Norfolk and Suffolk want from a Biomedical service.

The Canadian consensus document , which has already been accepted by Dr Mitchell and Great Yarmouth and Waveney PCT would underpin the way forward

Following publication of the Canadian Consensus Document[19] and a summary entitled, ‘A Clinical Case Definition and Guidelines for Medical Practitioners’ , “it is no longer possible for any UK clinician to assert that there are no valid clinical tests for physicians to use when investigating ME patients” states Professor Malcolm (Hooper 2007).

The EAME/25% Group Survey clearly shows that patients are asking for these clinical tests.

---

[19] www.cfids-cab.org/MESA/ccpc.html

PART TWO

2. 1 The EAME / 25% Group Patient Survey and the Great Yarmouth and Waveney 2005 Service Model :

The current survey, for the severely affected house and bed bound people with ME in Norfolk and Suffolk clearly asks for a biomedical clinic and 85% of patients wantb a biomedical clinician to lead the service for them. The Service Agreement of 2005 simply does not meet the needs of severe ME sufferers as it proposed to provide a therapist or nurse led service .

“It is proposed to develop the service over time as a Therapist or Nurse-led Service. It is unlikely that it will be possible to recruit someone with all the necessary skills and experience and therefore it is envisaged that it will be necessary to develop this role gradually.” (2005 Service Model)

100?% of Norfolk/suffolk Severe ME patients want neurological tests

100%of Norfolk and Suffolk Severe ME patients want blood tests
(beyond the normal tests)

However this respondent qualifies the need for appropriate blood tests: *“ Blood tests? Yes if they were appropriate and the correct ones to test for conditions associated with ME: we’ve all had the usual battery of tests from G.P’s which are a waste of time”*

and another qualifies the need with the following comment: *“Blood tests that will show up the dysfunction and not just the normal standard tests.”*

100% of Norfolk and Suffolk severe ME patients want Medical confirmation of the full range of their symptoms and disability.

100% of Norfolk and Suffolk severe ME patients want ongoing support
for secondary infections and diseases.

100% of N and s severe ME patients want Symptom management.

None of the above can be done without a full time Biomedical Clinician in place. A therapy led service could not offer what these people are asking for : a biomedical clinic.

The current service plan of 2005 is extraordinarily inadequate, because it emphasises “assessment, rehabilitation and symptom management” ; without first investigating “causes, pathogenesis or means of confirming the diagnosis” as recommended in the Gibson Inquiry[20].

“The service should be established as a tertiary service to provide specialist

---

[20] www.erythos.com/gibsonenquiry/Report.html

advice/opinion to patients and GPs about assessment, rehabilitation and symptom management. The objective should be to help patients devise a strategy to manage their own condition, within their lifestyle, in partnership with their own GP. The responsibility for long-term maintenance would rest with the patient's own PCT. "(Great Yarmouth and Waveney 2005 Service Plan)

This effectively leaves the severely affected ME patients in Norfolk and Suffolk at great risk with no appropriate cover; the complexity of the condition is far beyond the remit of any Nurse or Occupational Therapist.

According to our survey (n=21) ,the severely affected in Norfolk and Suffolk experience a wide range of severe physical symptoms :

LIST OF SYMPTOMS	Number of sufferers experiencing this symptom	Percentage of total
Tender lymph nodes	11	52
Sore throat	16	76
Flu-like symptoms	16	76
General malaise	21	100
Post-exertional fatigue	21	100
Development of new allergies	11	52
Hypersensitivity to medications and/or chemicals	14	66
Loss of thermostatic stability	20	95
Heat/Cold intolerance	16	76
Anorexia or weight gain	12	57
Food Sensitivity	14	66
Hypoglycaemia	10	48
Worsening of symptoms with stress and slow recovery	16	76
Emotional Lability	14	66
Postural hypotension (low blood pressure)	12	57
Vertigo	11	52
Head ache/head pain	18	85
Visual disturbance	17	80
Light-headedness	14	66
Extreme pallor	16	76
Intestinal dysfunction	13	62
Bladder dysfunction	18	85
Respiratory irregularities	13	62
Difficulty with information processing	12	57
Perceptual/sensory disturbances	17	80
Photophobia	13	62
Hypersensitivity to noise	13	62
Pain	15	71
Transient Paralysis	14	66
Pins & Needles	13	62

Numbness	**18**	**85**
Nausea & Vomiting	**17**	**80**
Muscle dysfunction	**12**	**57**
Unrefreshing sleep	**10**	**48**
Speech Difficulties	**10**	**48**
Swallowing difficulties	**11**	**52**
Spasms	**7**	**33**

(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)

The maximum number of symptoms included in the survey was 37 though there are in fact at least 64 recorded symptoms in ME.

Each symptom is of extreme concern because it implies an underlying pathology of severe physical dysfunction in the body. Yet the main three symptoms that tend to be focussed upon are mainly ' undefined fatigue' , pain and sleep disorder.

Fatigue as such is not even necessarily a symptom of neurological ICD G 9.3 ME and for many people pain is not controlled in ME and sleep is not possible to balance in many severely affected .Considering how many symptoms there are likely to be experienced by a person with true ICD G9.3 ME it is a concern that the rest are not given more priority, proper, detailed investigation and support.

' My pain has never been alleviated by NHS drugs. My sleep pattern is delayed in general by at least 5 hours from the norm and I sleep extremely lightly through the night before entering into a deep sleep from which it is it is impossible for me to wake myself up from and in which I become severely paralysed. I have had no ongoing alleviation of any of my symptoms in 14 years nor proper investigations into my symptoms..' says co-author Linda Crowhurst a severe ME sufferer.

We asked participants in the survey to identify the 5 symptoms that they experienced as most severe. Incredibly there was a range of 23 out of a possible 37 that people identified as individually most severe.

This is of concern. How many symptoms are people experiencing with no hope of relief? Each of these is a serious symptom in itself!

The symptoms experienced most severely , as reported by patients are (in descending order) :

Post exertional fatigue
Unrefreshing sleep
General malaise
Pain

Head ache/head pain
Respiratory irregularities
Difficulty with information processing
Intestinal dysfunction
Hypersensitivity to noise
Swallowing difficulties
Hypersensitivity to medications
Anorexia/weight gain
Food sensitivity
Hypoglycaemia
Light-headedness
Bladder dysfunction
Perceptual / sensory disturbances
Photophobia
Transient Paralysis
Pins & Needles
Numbness
Nausea /Vomiting
Muscle dysfunction

We only asked for the 5 most severe symptoms ; people may have a higher number than 5 that they suffer most extremely. It is significant that the person who has all 37 symptoms actually was unable to distinguish 5 and ticked 10 that were experienced equally severely.

This is a shocking number of severe symptoms for anyone to endure.

Out of a possible 37 symptoms, the range acknowledged as most severe was 23 and even though we can say that some , such as post exertional fatigue were identified more often, it does not mean that the others are less significant.

It is of concern that :

- 85% have head ache/pain
- swallowing difficulties were experienced by over half (52%) the people surveyed
- 62% have noise sensitivity
- 67% have difficulty processing information
- 48% have unrefreshing sleep
- 66% of people have transient paralysis
- 85% have numbness
- 62 % of people have photophobia
- 80% have perceptual /sensory disturbances
- 76% have heat/cold intolerances
- 48% have speech difficulties
- 33% have spasms.

None of these severe symptoms could be treated or 'managed' by an OT or a nurse in a therapy led service. They require highly specialist advice and treatment from a biomedical clinician.

The smallest number of symptoms experienced per sufferer is 12 and the maximum number of symptoms experienced is 37, the average number of symptoms experienced is 25.

Their impact upon a person's life is extreme and we must be mindful that all of these severe symptoms are taken account of , when offering a service to people.

How many "well" people experiencing body numbness, severe muscle shaking, and transient paralysis would not want to know exactly what is going in their body and how it can be helped ? It is not good enough to leave such severe suffering without appropriate support and recognition.

We have to develop proper services that can support people with this severity of illness and not leave them completely isolated, dismissed and deteriorating, often for decades on end.

It is not appropriate for severely ill people to have the only available service focusing upon a vague fatigue state and how to pace your energy. This is nowhere near good enough for such a serious illness and for those people who are so severely affected.

It is to the NHS's shame that these people have little to no service or support.

It is not just the wide range and severity of symptoms that are of concern ; it is the large number of symptoms that the severe ME sufferer experiences at any one time . The majority of the severe ME sufferers in this survey have greater than 25 symptoms each :

As Byron Hyde (2006) points out ME is : "a discipline that requires physicians who are totally dedicated full time to the understanding of these patients, as are the specialists in any area of medicine. [21] This should be our aim.

A "Balanced" Service ?

According to Mr Stonard's Briefing Paper to MP's , the 2005 Service Model is 'balanced'

---

[21] Byron Hyde 's Little Red Book (2006) www.investinme.org/InfoCentre%20library.htm

because it includes both the **biomedical and bio-psychosocial** approaches.

The severely affected in this survey, the house and bed bound of Norfolk and Suffolk are not asking for a balanced biomedical and psychosocial clinic. They are unanimously asking for a biomedical clinic.

EAME (Aug 2007), pointed out to Mr Stonard how :

“Led by the increasingly discredited and outmoded "Wessely" school of psychiatrists, the "bio-psychosocial" model , persists on the basis of a handful of mostly inconclusive RCT's, in "treating" ME as a behavioural disorder; the aim is to change "wrong" thoughts and perceptions through a behavioural and exercise regime that has been proven harmful, indeed fatal to some patients. It is very expensive and there are also no proven long-term benefits.

The biomedical model, on the other hand, in line with the World Health Organisation classification, (ICD 10 - G93.3) and Department of Health recognition (National Service Framework), proceeds on the basis that ME is a neurological disease.

There is simply no ‘balance" to be struck ; psychiatric treatment of a physical, neurological disease is an impossible tenet.

Mr Stonard claims that the PCT agreed the 2005 service model for CFS/ME “ in conjunction with clinicians and local patients.” EAME has no record of this.

The opinion of the severely affected in this survey is unanimous ; it rejects the Biopsychsocial model completely.

The confusion concerning a balanced service model is surely linked to the confusion in treating people with chronic fatigue as people with ME : the two conditions are completely different and urgently require separating in order to honour and respect the needs of people with severe ICDC 9.33 ME in Norfolk and Suffolk.

This is a unique opportunity to lead the field in developing an appropriate biomedical service especially to meet the very real physical needs of the severely affected, highlighted in the survey results below :

What the severely want from an ME Service in Norfolk and Suffolk :

72%	Reject CBT
90%	Reject GET
95%	Want Physical Tests

76%	Want Pacing
90%	Want ongoing support for their symptoms
85%	Want a Biomedical Consultant
04%	Want a Psychiatrist
90%	Want advice on aids and equipment
95%	Want the opportunity to participate in physical research
61%	Want Counselling
95%	Want home visits/assessment by a consultant
90%	Want an appropriate Information Pack
85%	Want a prescribing service
90%	Want monitoring of their symptoms and medication
95%	Want Consultant-level monitoring of ongoing research into ME and appropriate feedback to patients.
95%	Want a short waiting time
95%	Want a silent waiting area
80%	Want wheelchair and mobility advice

In addition one person asks for the *"provision of audiological, optical and dental care in their own home.*"

Another stresses that home visits are most important. This backs the 95% of people who asked for home visits from a (bomedical) consultant - again - not possible to be provided in a therapist -led service.

Another stresses the need to lie down when attending a clinic .

Shockingly another person says that they have never been physically examined in 17 years and exclaims *Yes!Yes! by the need for physical tests.*

A further person stresses that they" *definitely want the opportunity to be referred to a* *neurologist, maybe for brain scans, to find possible causes for brain fog-like symptoms.*" This again highlights how poorly these people with serious cognitive and brain dysfunction are being served.

They are not getting worrying neurological symptoms thoroughly investigated and this must surely be unacceptable.

We need to stress however that a neurologist who understands the physical nature of ME is essential in pursuing these symptoms further.

Another asks for "honest acknowledgment that you are severely disabled and unlikely to recover and therefore unemployable in terms of benefit need .

This raises a further issue concerning the 2005 service agreement.

It is important to note that people who are severely ill for longer than 4 years have a 2% chance of recovery if that. As this is a statistically insignificant number the chances are indeed unlikely.A biomedical service then must be provided at all costs to help these very ill people with this very real physical illness that leads to severe and chronic disability.

Given this, it is quite extraordinary that the 2006 ME Service Referral Guidelines states:

EXCLUSION CRITERIA FOR REFERRALS
"History of failed rehabilitation specific to ME/CFS unless there are special reasons to reconsider the role of rehabilitation (Great Yarmouth and Waveney CFS Referral Guideline Oct 2006)"

This effectively excludes all severe ME sufferers, as they do not need rehabilitation, they need treatment and support.

Who would ask someone with a coronary difficulty to push themselves beyond their ability ? Who would expect someone paralysed to get out of bed ? Who would tell someone with terminal cancer, with severe pain, to think themselves out of their condition ? Who would expect someone with Cerebral Palsy to think themselves well ? Elements all of these conditions make up the awful multi-system illness that is ME.

2.4 Conclusion

"I hope the ME service will differentiate between 'true ME' and Post viral fatigue and chronic fatigue syndromes.I believe this is crucial both for helping patients and crucial for research.The works of Melvyn Ramsay(The clinical identityof ME) illustrate the nature of ME and how

different are other fatigue syndromes'

Respondent to 25%/EAME survey 2007

The people that this Report is about should not have to carry on suffering such serious symptoms without relief and without an appropriate service

People with ME need to be separated, absolutely , from people with a Chronic Fatigue ; that is the great challenge of our time. This is an outstanding opportunity for Norfolk and Suffolk to lead the way.

Severe ME sufferers do not want :

- A behavioural "therapy"-led service
- To be "lumped in" with other undefined chronic fatigue illnesses and states.
- A psychosocial model of care.
- To be offered psychosocial CBT/GET 'treatments', as these have been shown to be dangerous for severely affected patients and cause setback and worsened prognosis for milder cases of ME.
- To be patronised by ill-informed medical professionals who do not believe that they have a physical disease.
- To be downgraded and treated as if their very real and severe neurological symptoms, such as paralysis, spasms, parasthesia and pain are insignificant or psychiatric in origin.
- To be offered psychiatric - originated management techniques, charading as treatment for this physical illness.
- To be described as "tired".
- A fudging or a pretending to meet the needs of people with ME, but actually working to a psychiatric paradigm that is rooted in vested interest and based upon pseudo-science and flawed patient selection criteria.
- Any service based upon the Fukuda or Oxford criteria.

As this Survey has shown , severely affected ME sufferers in Norfolk and Suffolk want the ME Service to **:**

Honour the fact that ME is a serious neurological disease (WHO ICD 10. G93) .

- Acknowledge that 'Myalgic Encephalomyelitis' is a World Health Organisation (WHO: ICD 10 - G93.3) defined neurological disease and is not the same condition as 'idiopathic chronic fatigue' described separately by the WHO at ICD -10-f.48.

- Use an appropriate biomedical definition that takes account of the above and accords with international research evidence, expertise and proper WHO illness category demarcation.

- Actively educate other clinicians, paramedical staff and social and child-education services regarding the true physical nature and impact of this disease.

- Use the primary WHO-listed name "Myalgic Encephalomyelitis" , as opposed to "CFS, Chronic Fatigue or Encephalopathy" (Hooper 2007)

Respect the fact that ME is a multi-system disease affecting all systems of the body :

- Acknowledge that biopsychosocial CBT/GET treatments are deemed inappropriate at best and conta-indicated at worst by leading international specialists and consensus diagnostic and treatment protocols [22] [23]

- Be particularly aware of the severity of severe ME symptoms and the high level of post exertional malaise and post- exertional fatigue experience and accommodate it; so that patients can be seen and given proper ongoing support.

Validate the ME sufferer's experience through adequate biomedical testing :

- Provide a biomedical clinician who can recognise the symptoms of real ME, their impact. and make appropriate recommendations, based on current physical research and state-of the-art practice.

- Offer appropriate biomedical tests and scans that prove that the severe ME sufferer has a physical illness and illuminates what is going wrong in their body.

- Provide appropriate state-of the-art biomedical assessment that will provide a medically-informed and scientifically objective report about the illness and disability.

---

[22] *'Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: 'a clinical case definition for medical practitioners*' by Carruthers & Van-de-Sande
www.mefmaction.net/documents/me_overview.pdf

[23] *'Chronic Fatigue Syndrome - assessment and treatment of patients with ME/CFS: clinical guidelines for psychiatrists*' by Dr Eeanor Stein
sacfs.asn.au/download/guidelines_psychiatrists.pdf

- Give patients the opportunity to choose to participate in physical research so that people who have Severe ME can be reflected in any research evidence compiled , in the hope of promoting better patient outcomes and disease prevention.

<u>Treat the symptoms as much as possible :</u>

- Explore, prioritise and validate the neurological symptoms of ME..
- Provide home visits from a biomedical clinician for those not well enough to travel.
- Have the ability and funding to prescribe drug and nutritional interventions for illness management (e.g. pain relief and sleep promotion) and, where possible, for better prognosis (e.g. appropriate antiviral treatments).
- Acknowledge that all other treatments/ therapies should be agreed with the input and agreement of the ME specialists as principle advisors- due to their understanding of possible adverse reactions, complications etc. This particularly applies if there are also mental health/ conditions/ complications.

<u>Competently provide support :</u>

- Acknowledge the genuine severe disability so that support can be given to sufferers to claim benefits and grants etc, to enable true entitlement.
- Offer advice based on awareness to ensure safe practice and safe treatments regarding how to deal with other medical conditions and illnesses that might arise.
- Provide access by phone for specific symptom management / backup.