

## **My Benefits Saga by Alex Wootton**

In last month's newsletter I gave you some hints and tips on appealing your ESA decision, and I hope they have helped you, as hopefully with us sharing our experiences we will all learn what to do and what not to do. There have been quite a few developments within the last month which is affecting all of my benefits.

In March I had to reapply for my DLA benefits and received their decision last week. I have still been granted the higher level for mobility, but my care rate has been down graded from the middle rate to the low rate. So my mum got in touch with Bury Carers who have been very helpful as they got in touch with the CAB on our behalf telling them what help we needed.

So on Thursday someone from the CAB came to my house (as they are able to do home visits), and she asked to look at all of my proof of benefits letters. After she looked at them she told me that because DLA have downgraded my Care Component to the low rate from the middle rate, that I will lose the "Extra money because you are severely disabled" component from my ESA benefit. She then told me to ring up the ESA benefits to make sure that they have been notified of this by the DLA, so they don't over pay me and I then end up having to pay them back. When I rang up the ESA benefits they told me that they had already been notified and had adjusted my benefits accordingly. I asked them if they would be sending me a letter notifying me of this change and they said no, but if I wanted a letter they would send me one. Needless to say I requested a conformation letter for my records. Also I found out why my ESA only runs from April 2012 till November 2012, as they think I may be better by then to go out to work and that I will have to reapply for ESA again before it runs out in November. The person from the CAB told me to copy what I'd put in the forms that I filled in, in February. This means however long ESA has been awarded to you whether it for 6, 12 or 24 months before this time comes to an end they should send you your reapplication forms. She also told me that I have been put in to the ESA Work Related Group because I'm still of working age and that I might be able to go back to work one day, and that the only people who get into the Support Group are people who will never work again.

Now back to my DLA care component down grade: The person from the CAB told me to ring up DLA and register a request for reconsideration where they will take another look at my claim (this must be done within a month of the date on your DLA benefits entitlement letter), and in the meantime someone else from the CAB will be coming out to my house to help me gather everything I need and help me process an appeal.

Lastly I also received a letter from Bury Council telling me that because my ESA has changed that my Council Tax Benefit will also be changing, so I rang them up asking why my Council Tax Benefit was ending and they said it was because I'm losing my ESA benefit. I told them that my ESA amount has changed, because I have been down graded with my DLA care component but that I'm still in receipt of ESA, so they are going to send out a form for me to fill in stating that I'm still in receipt of ESA.

### **Useful Contact Numbers for Benefits help & appeals**

Community Care Advocacy Service Tel: 0161 206 0283.  
Rochdale Law Service: Tel: 01706 657850 Mon – Wed 10am – 12 noon.  
Shelter: Tel: 03444 515 1640. Provide support at tribunals for people on low incomes.

Bury Coalition for Independent Living: Tel: 0161 253 5151  
Bury Carers: Tel: 0161 763 4867  
Bury CAB (Citizens Advice Bureau): Tel: 0161 761 5355  
Bolton CAB (Citizens Advice Bureau): Tel: 01204 900 200 (/213 House Bound)

## **Applied for ESA? Please complete our survey by Action for ME**

Action for M.E. is collecting data from people with M.E. who have applied for Employment and Support Allowance **in the last 12 months**. If this includes you, please complete our survey.

<http://www.actionforme.org.uk/get-informed/news/archived-news/our-news/2012/applied-for-esa-please-complete-our-survey> The deadline for surveys to be completed is **Friday 22 June**.

More than 200 people with M.E. participated in a similar survey in 2010. Results showed that the Work Capability Assessment (WCA), the face-to-face assessment for ESA, was not suitable for testing fluctuating conditions such as M.E. This was reiterated in Professor Malcolm Harrington's independent review of the WCA in November 2011, which recommended that "fluctuating conditions descriptors" should be used to assess people with long-term conditions in order to avoid a "snapshot" assessment.

Action for M.E. is trying to find out how the ESA assessment process has improved – or not – since then for people with M.E.

*For our postal members please find a photocopy of the survey in with this newsletter, for our email members please use the link above.*

## **Late Edition**

*This is a new feature, which rounds up some of the recent news covering CFS/ME. We'll try to give you a flavour of what's being written around the world.*

The Telegraph used a Freedom of information request to prove that fewer than one in three of primary care trusts in England are offering levels of care as recommended by the National Institute of Clinical Excellence. Out of 151 trusts, only 15 were providing a specific pathway for getting patients the right treatment. **Fewer than 1 in 3 health trusts offering adequate care for ME sufferers** – by Christopher Bird – the Telegraph – 8 May 2012

Newcastle and Northumbria Universities, along with Sheffield University, have been given £61,000 by the charity Action for M.E for three pilot projects. The Newcastle team will be looking at muscle dysfunction and ME, whilst Northumbria will be looking at sleep patterns and how they affect people with ME. **Universities awarded ME research grant** – ITV News - 8 May 2012

Meanwhile in the United States they are expecting to start a study to comprehensively examine ME patients before and after exercise. This may seem unusual, but the team are looking to understand whether graded exercise therapy should be recommended as a treatment. The study will also help with the understanding of CFS/ME in general. **Mount Sinai ME/CFS Center Expects to Recruit Soon for Many-Faceted Exertion Physiology Study** - ProHealth.com - May 18, 2012

To mark ME awareness week, the Daily Mail ran a piece by a journalist who didn't know anything except what she'd read in the media. She then trotted out all the usual myths about people with ME, e.g. being workshy and lazy. However if you read on, the writer described how she investigated a bit further to find out more about the disease. She then lists 12 myths and sets the record straight. **All in the mind? Why critics are wrong to deny the existence of chronic fatigue** By Sonia Poulton – Daily Mail May 8, 2012

In this article, the writer describes his battle with CFS. He's a Canadian, and describes the difficulties he came across in getting his diagnosis. So much so he had to travel to the US to get fully tested, and then come out with a diagnosis of CFS. He briefly described the frustration felt by us all, and ended by saying he has to live his life within the limits of his disease. **Chronic Fatigue Syndrome unmasked** by Brendan K Edwards - The Suburban News - May 23rd, 2012

Adrienne Dellwo works for about.com writing about CFS/MA and fibromyalgia. She regularly provides insights and information on symptoms, research, living with the disease etc. In this article about gluten intolerance, she runs through everything from symptoms and getting a diagnosis to living with a new gluten-free diet. **Gluten Intolerance in Fibromyalgia & Chronic Fatigue Syndrome** By Adrienne Dellwo, About.com Guide May 23, 2012

Former journalist Claire Peacock is profiled in the Fulham Chronicle, about her new business offering Emotional Freedom Technique. Claire used to have CFS/ME, but used the technique herself to make a recovery. This then led her to open up a small business. **Clare offers an escape from a crippling turmoil** – Fulham Chronicle By Rupert Basham May 25 2012

Another local article profiles 2 sufferers in South Tyneside. Both of them describe how their lives were turned upside down by the disease, and how they are dealing with it now. One of them, Jessica, aged 15, is using physiotherapy as part of her regime, and is using a therapist who specialises in children's illnesses. **Shining a spotlight on mystery of ME** – Jarrow and Hebburn Gazette – May 10 2012

### **Facebook Page:**

We are now on Facebook this is a closed group so only the members of Bury/Bolton ME/CFS Support Group can join. To find us on Facebook put in the following: <http://www.facebook.com/groups/buryboltonmecfs/> or alternatively visit our website at [www.mesupportgroup.co.uk](http://www.mesupportgroup.co.uk) and click on the "Facebook" link.

# **All in the Mind? Why critics are wrong to deny the existence of chronic fatigue** by Sonia Poulton from the Daily

**Mail website 8<sup>th</sup> May 2012**

This week is Myalgic Encephalomyelitis Awareness Week or, as it's more accessibly referred to these days: M.E. That may not mean a great deal to you. Certainly, it didn't to me. Oh wait, yes it did. Based on no personal knowledge whatsoever - fortunately neither I or my loved ones have M.E. - my judgement was gleaned from how the world has portrayed the illness.

Like millions of others, I have seen M.E. through the eyes of the medical establishment, the Government and the Media. The picture has not been good.

Here is what I have previously understood about M.E. and those who have it. M.E. sufferers are workshy malingerers. They whine, constantly, about feeling tired. They are annoying sympathy seekers. Damn it. We're all tired. Especially those fools like me who work all hours God Sends (and even some he doesn't) to support the type of people who say they are too tired to work. Oh, and mostly, importantly, M.E. is 'all in the head' and can be overcome with a bit more determination and a little less of the 'poor me' attitude. That, generally, is what I thought about M.E.

Until, that is, a reader sent me a DVD of a British-made film about the illness titled 'Voices From The Shadows'. I receive dozens of clips and films each month, and I try and see as many as I humanly can, but there was something about 'Voices...' that stopped me in my tracks. One of the reasons the film had such an impact is because it challenged my deep-seated preconceptions about M.E.

Through 'Voices...' - and the subsequent research I have conducted - I have come to realise that what I thought I knew about the illness was a fallacy but, more importantly than that, was actually detrimental to those affected.

So, as a naturally curious individual (I'm not a journalist by mistake) I began to question why I had been furnished with one version of events - and inaccurate ones at that. The more I began to delve into the subject the more curious it all became. Like for example, why are records pertaining to ME locked away in our national archives in Kew for 75 years? The normal period would be 30 years. 75 years, the period generally used for documents of extreme public sensitivity and national security, is excessive. The reason given, that of data protection, is a nonsense as it is perfectly acceptable, and easy, to omit names on official documents. The excuse, supplied in Parliamentary questions by the Department of Work and Pensions, didn't wash with me.

Why, I thought, were they making such an exception? It got me thinking about what information the files actually do contain. And, seeing as the topic of M.E. is still beset with misunderstanding, we could all benefit from some enlightenment on the subject. So, to this end - and seeing as it is M.E. Awareness Week - here is my personal guide to shattering the myths and blatantly-pedalled untruths about M.E.

## **Myth No. 1: ME is a mental illness**

Not so. It is a neurological one. It is not a case of 'mind over matter' despite many GP's and health professionals still thinking it is. Psychiatrists have bagged it as 'their thing' and the General Medical Council has been somewhat remiss in supporting it as a physical condition.

I spoke with one ME sufferer, who asked to remain anonymous for fear of upsetting the medical professionals who are currently treating her. She said a new GP at her practice had suggested she take up meditation to help her combat her decades-old condition. Thankfully there are some doctors, few and far between admittedly, who really understand the physical nature of M.E.

Dr. Speight, a medical advisor for a number of M.E. charities does. Commenting on the wide-ranging debilitation of the illness, he has said:

'The condition itself covers a wide spectrum of severity but even the mildest cases deserve diagnosis and recognition because if they are given the wrong advice or don't handle themselves correctly they can become worse.

'At the more severe end of the spectrum there's a minority of patients who are truly in a pitiable state...some of them in hospitals, some of them at home...and this end of the spectrum is really one of the most powerful proofs to me of what a real condition this is and how it cannot be explained away by psychiatric reasons.' Sadly, there are still many health professionals who buy into the notion that M.E. is a psychological disorder and should be treated as a form of insanity.

## **All in the Mind? Cont...**

In Denmark, only last week, The Danish Board of Health sought to remove a 23-year old woman, Karina, from her family home on the grounds of mental illness despite the fact that what she really has is M.E. Karina, bed-bound, light and sound sensitive and too weak to walk is considered to be insane, rather than physically sick, and her family has been repeatedly told by Danish doctors that the diagnosis of M.E. is not recognised.

### **Myth 2: ME is just extreme tiredness, right?**

Wrong. Despite falling under the Chronic Fatigue Syndrome category - as does Fibromyalgia which has its own Awareness Day next week - it is entirely wrong to assume that M.E. is merely about lack of energy. This confusion arose over the past 20-odd years and is due to the condition being re-classified as a Fatigue Syndrome. The result of this has been to trivialise the illness which has served as fodder for ill-informed public commentators who have used M.E. and Fibromyalgia to talk about 'scroungers' in the benefits system who are 'too lazy' to get out of bed. For those who know about the illness, this type of commentary is viewed as dangerous rhetoric that deserves to be classified as a form of hate crime.

### **Myth No. 3: M.E. is just like a bad flu**

Oh, if only. M.E. is a complex, chronic, multi-system illness that affect the body in similar ways to Multiple Sclerosis. In addition, inflammation of the neurological system can lead to heart disease, extreme muscle pain and other debilitating and life-threatening conditions.

As one doctor put it, comparing M.E. to an illness like flu is like comparing Emphysema to a chest infection. It seriously undermines the truth extent of M.E.

### **Myth No. 4: M.E. sufferers should just 'pull themselves together'**

Many sufferers have found themselves abandoned by health professionals, struck off of registers and even rejected by their own families when they have failed to respond to 'tough love'. Too many people assume that M.E. can be overcome with the right mental attitude. This consequently leaves M.E. sufferers even more vulnerable to issues like depression as they are further isolated. M.E. is not a case of the mind being able to heal itself with determination. M.E. breaks the body down and that also includes the brain.

### **Myth No. 5: Only adults have M.E.**

Children have M.E. and their childhoods are destroyed as a consequence.

Margaret Rumney of Allendale, Northumberland, watched as her 11-year-old daughter, Emma, was reduced to a shell of her former self when she was struck down with M.E. nine years ago.

"Since then it has been a continual rollercoaster of emotions and has been one fight after the other," says Margaret. "It is very hard for my daughter being ill, she is virtually housebound, often reliant on a wheelchair, and to have to cope with disbelief and ridicule on top of this makes this illness even harder to bear.

"Our experience of my daughter's school was an awful one. When my daughter was receiving home tuition organised officially by the Education Welfare Officer we were threatened by one professional that if my daughter didn't return to school that it would be classed as a psychological issue and social services would get involved."

Threats and intimidation of this nature at the hands of the authorities are a constant feature of those in the M.E. community, and particularly those caring for children with the illness. Naturally, this pressure merely adds to the overall anxiety that sufferers are already experiencing. Education is key. Bullying is not.

### **Myth No. 6 - You can 'catch' M.E.**

A hotly contested issue. Data suggests it's possible but the true cause is still subject to much debate among the more knowing professionals. What appears clear, however, is that ME seems to follow on from various viral infections, including meningitis. More research is needed.

### **Myth No. 7: Real M.E. sufferers are few and far between**

There are currently 250,000 recognised cases of ME in the UK. That's 1 in 250 so that's hardly an insignificant number, is it?

### **Myth No. 8: Only severe cases of M.E. are worth acknowledging**

Terrible misconception. M.E. ruins people's lives even if the patient is not entirely bedbound. The media tend to concentrate on the worst case scenarios but this does not help the full situation as it leaves others, who are still able to move at times, with the stigmatisation of 'not being ill enough'.

Claire Taylor-Jones, a mother of one from Rhyl in North Wales, has been unable to pursue her ambition of becoming a solicitor after she was diagnosed with M.E. In common with other sufferers, Claire has good days and bad days but she is not consistently well enough to pursue her goals and she is left in a type of limbo land. Her plans are on hold.



## All in the Mind? Cont...

### **Myth No. 9: Children with M.E. have neglectful parents**

There's the notion that children with M.E. are actually victims of mothers who have Munchausens by Proxy – the illness where parents act as if the child is sick to further their own need for attention. This is a particularly dangerous belief system as it leaves the true M.E. sufferer without sufficient support and diagnosis and the carer is treated as the problem.

### **Myth No. 10: Physical exercise will benefit M.E. sufferers**

Absolutely not true. Worse, still, enforced 'graded exercise' can escalate the condition to dangerous and irreparable levels for the patient. During the research of this subject, I have watched footage of hospital physiotherapists literally bullying M.E. patients to stand and walk. It is pitiful to witness. The physios say things like 'Come on, you can do it. You just have to put your mind to it' and, at worst, 'You're not trying hard enough.'

Julie-Anne Pickles, who has had M.E. for the past seven years, has experienced a serious deterioration in her condition as a consequence of wrong diagnosis and ineffective medical response. She is now 90 per cent bedbound and has been diagnosed with depression, diabetes and Angina. She told me:

"Cardiology phoned me with an appointment the other day and they told me to wear trainers because they want me running on a treadmill while on an ECG! I said: 'You do know I have M.E.?' They said they did but not to worry as I won't be running for more than five minutes! Running? I crawled on my hands and knees to the loo this morning!"

This idea among some of the medical professional that enforced exercise will help the condition of a M.E. belongs to a darker time in our history. A period when we thought that autistic children were a result of being born to cold and detached women or 'refrigerator mums' as they were heinously and immorally labelled.

### **Myth No. 11 - M.E. is not life-threatening**

It is, although the true mortality rate of M.E. is mired in great confusion. Recently, Labour MP George Howarth asked Paul Burstow, Minister of State for Care Services, to supply details of deaths to arise from M.E. Mr. Burstow replied that 'this information is not available and is not collected centrally'.

As with so many issues regarding our sick and disabled, the Coalition had this wrong, too. According to figures obtained from the Office of National Statistics, there have been five deaths listed as the cause of M.E. in recent years. For campaigners this is nothing less than a fudge of the true scale. Figures are easy to massage with M.E. because it triggers so many other illnesses, such as heart disease. Given that many health professional still deny that M.E. is a physical condition, they are unable to list it as a cause of death even if it is.

### **Myth No. 12: M.E. is an excuse not to work**

Despite recognition from the World Health Organisation in 1969 that M.E. is a neurological disorder, many Governments - including our present Coalition - have chosen to ignore this.

Consequently, M.E. sufferers are subject to a battery of controversial fit-to-work assessments. The anxiety and physical exertion this requires generally worsens the condition.

When the M.E. sufferer is unable to work, because of their illness, they are removed from disability benefit and are plunged into poverty.

So, for M.E. Awareness Week, let us be clear. M.E. is comparable to AIDS and cancer and all the other vicious and uncompromising diseases that savage the body and, in some extreme cases, kill it completely.

The fact that it is still so widely misunderstood is a modern day travesty that must be addressed without further delay. Or is it convenient that we still view M.E. as being 'all in the mind'?

I believe that we, as a nation, deserve to know the truth. Not only for those still battling the disease, but for those poor souls who have already been lost to it.

\* For further details on Voices from the Shadows: <http://voicesfromtheshadowsfilm.co.uk/shop-dvds/>

I would like to thank Sonia Poulton and the Daily Mail for giving me their permission to reproduce this article so all of our members have had a chance to read it for themselves. As it is one of the most favourable and well explained articles I have seen on ME for quite a while. Alex