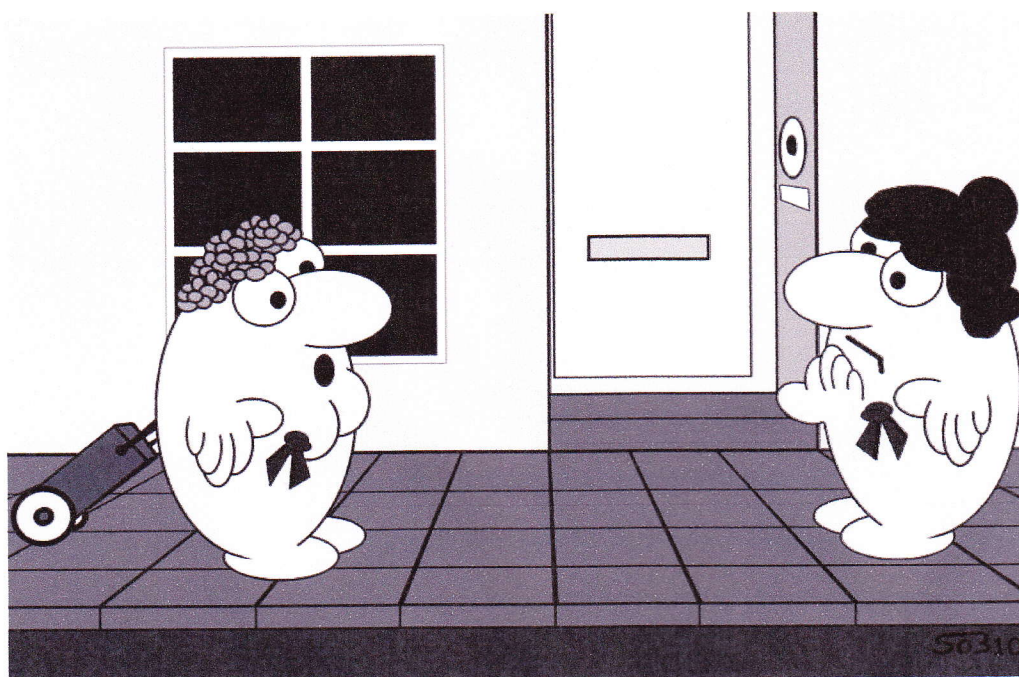


## Welcome to Our November 2011 Newsletter



**I MIGHT DO THINGS FAR SLOWER THAN YOU BUT ON THE OTHER HAND I GET TIRED  
FAR QUICKER!**

With thanks to Invest in ME ([www.investinme.org](http://www.investinme.org)) for their kind permission to reprint this cartoon from the calendar available to download from their website.

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# **Bury/Bolton ME/CFS Support Group & Sponsors**

**[www.mesupportgroup.co.uk](http://www.mesupportgroup.co.uk)**

The Bury/Bolton ME/CFS Support Group was founded in September 1990 and is managed by a committee of six members:

Pam Turner, Margaret Benn, Ann Richards, Maria Sale, Sheila Myerscough & Kim Finney.

## **Support Group Posts & Contact Information:**

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Minutes Secretary:	Margaret Benn	0161 761 2723
Bolton CVS Contact:	Ann Richards	01204 521769
Meetings Secretary:	Maria Sale	01204 575613
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Medical Sub-Group, Group Rep & Carers' Contact:	Yvonne Leech	0161 764 7822
Bury Socials:	Sheila Myerscough	0161 7970026 (after 12noon)
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**Supported by:**  
**Health for Bolton, via Bolton CVS**



## Dates For Your Diary

**Longsight Meetings:** Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). Entrance is £1, tea, coffee, water, biscuits, etc provided.

**Thursday 17<sup>th</sup> November – Dr Carolyn Chew-Graham,** The Head of the Manchester Research Team will be joining us so she can chat and mingle with us informally during our pre-Christmas social with “Bring & Share” buffet supper. Also I will be bringing my cards if anyone needs to buy a last minute Christmas card or Birthday card and hopefully I’ll have some 2012 Calendars as well. Don’t forget that all of the profit from the sale of my cards goes to our group.

**DON’T FORGET THERE IS NO MEETING IN DECEMBER, OUR NEXT WILL BE:**

**Thursday 19<sup>th</sup> January – Book Swap.**

We thought in these tough times we'd help each other and raise a little money for the group, too. Bring along books you think others would like and hopefully pick up some books you haven't read. A donation of 50p for each book you choose would be gratefully accepted (may be able to arrange discount for bulk!) We will arrange to take any "orphan" books to a local market stall to raise even more, so please bring books that you think someone will want to read and that are in good condition.

**Radcliffe Socials:** We meet informally on the first Monday of each month, our next will be on **Monday 12<sup>th</sup> December at 4pm, at The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY.** It has plenty of parking, good accessibility, comfortable seating, is relatively quiet and serves very tempting chips that we just can't resist. For anyone who does fancy a snack, these start at just £1.50, with main courses from £3.50. For more information please phone 07919 234256 or email [dave@mesupportgroup.co.uk](mailto:dave@mesupportgroup.co.uk). **Don't worry about getting to the venue and not being able to find us – just phone 07919 234256 when you get there and we will find you!**

**Bury Socials:** These are continuing on the first Thursday of every month, the next will be **Thursday 1<sup>st</sup> December, 3pm at The Automatic, next to the Met theatre** (it is across the street from Yates, not the Met Café next to Yates), **Derby Hall, Market Street, Bury, BL9 0BW.** [http://themet.biz/location/find\\_the\\_met.pdf](http://themet.biz/location/find_the_met.pdf). If you need any more information, please phone Sheila on 0161 7970026 after 12noon.

**Yoga Classes:** Are **3:15pm-4:15pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX.** Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Contact Olivia on 07746 197511, or [olivia@oliviayoga.co.uk](mailto:olivia@oliviayoga.co.uk) for more information.

**Neuro Support Groups:** These groups, run by Greater Manchester Neurological Alliance, provide information, advice and support for people with any type of neurological condition and/or their carers. Call 0161 743 3701 or visit [www.gmneuro.org.uk](http://www.gmneuro.org.uk) for information about meeting times and locations.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANKYOU.

**Please Note that we have changed the date of our Radcliffe Social in December to avoid the children's choir that will be taking place on our usual Monday. The new date is Monday 12<sup>th</sup> December 2011 at 4pm. We will also be having a meal which you will have to pay for yourself.**

# **Bury/Bolton ME/CFS Support Group Meeting**

## **October 2011**

Our speaker for the October meeting was Sara Grimshaw nee Kirkman, who is the occupational therapist with our Bolton and Bury M.E. clinic. Sara, like the rest of the clinic team, is passionate about trying to help M.E. sufferers.

Sara explained the role of an occupational therapist and said that she assesses the activities of daily living, to ensure that people get the right aids to help them carry out their activities as comfortably and safely as possible. She is also able to do assessments in the workplace to help people who are trying to get back to work. Sara brought along many gadgets to show us and a list of helpful hints. The evening was both interesting and helpful. Anyone living in Bolton or Bury who needs an assessment can be referred to the clinic team by their G.P.

Below is the list that Sara went through with us all:

### **ACTIVITIES OF DAILY LIVING TIPS-CONSERVING ENERGY**

#### **COOKING**

- Organise areas to meet your needs.
- Ensure frequent items are accessible.
- Position items used together nearby, such as cups near the kettle.
- Use a perching stool during preparing and cooking meals.
- Store items at an accessible height or in small containers.
- Position equipment at elbow height.
- Use electric/lightweight tools e.g. electric tin opener, jar opener.
- Do not carry equipment/items, if possible slide and push on the work surface or use a kitchen trolley. If you do need to carry it use both hands and maintain a good posture.
- Gather all the items you need before you start your task.
- Use a wet cloth or anti-slip mat to stabilise items.
- If possible use a tabletop oven or grill to avoid bending.
- Fill your kettle with a plastic jug and fill to the amount you require. A kettle tipper or travel kettle may help.
- Use a chip pan basket when cooking vegetables, these can be lifted out of the pan and the hot water can cool before emptying.
- Prepare enough food for a second meal or in bulk to freeze for a bad day.
- Instead of three large meals, split meals every couple of hours and small amounts to conserve energy re digestion.

#### **HOUSEWORK**

- Do not try and get everything done at once on a good day, remember to PACE.
- Do not stoop over the kitchen sink; raise the height of the basin inside by placing a basin on top of another up turned basin.
- Use long handled brushes and dustpans.
- Kneel down when making the bed and cleaning the bathroom, avoid stooping. Protect your knees with a pillow or towel.
- When vacuuming work in short stretches, keep it close to your body. Alternate your arm used, where possible. Use a hand held/light weight vacuum and if finances allow have one on the ground and one on the first floor.
- Use a damp cloth for dusting.

### LAUNDRY

- Where possible, kneel down in front of the washer, remembering to protect your knees or use a perching stool. Avoid bending and over stretching.
- Divide wash loads into smaller loads as when wet the weight increases.
- Place washing on a kitchen trolley to transport to drying area. If practical use a perching stool to hang washing out.
- Remove clothes from dryer before completely dry and place on a hanger to minimise ironing.
- Use a perching stool whilst ironing.

### SHOPPING

- Do not try and do it all yourself, get family and friends to help with heavier items.
- Ask for shopping to be packed by the till operator.
- Consider home delivery service or internet shopping.
- Try and avoid going out to many shops, PACE yourself and plan in your rest periods.
- Remember the time spent during a shopping trip includes:
  - Planning time
  - Travel/driving time
  - Queues
  - Meeting people you may know
  - Other incidents
  - Petrol
  - Money from the bank
  - Packing in the shop and the car
  - Unpacking at home

### PERSONAL CARE

- Consider using a long handled sponge to avoid bending.
- Use a perching stool when strip washing.
- Use bath/shower equipment to avoid dizziness and conserve energy.
- Use a towelling bath robe to dry yourself rather than rubbing yourself down.
- You can buy hairdryer stands/long handled brushes to assist with hair.

### BED/CHAIR/TOILET TRANSFERS

- In the bathroom do not hold on to sinks or radiators they can be pulled off the wall, consider some equipment to aid sitting and standing.
- Remember nose over toes, bring yourself forward and push up from the piece of furniture.
- When getting out of bed turn onto your side, push your feet off the side of the bed and push up with your arms – let gravity help you.

**Equipment Hire:** We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846.

**Newsletter Articles:** Please carry on sending us anything you would like to share with the rest of the group; whether it is a whole page, or just a few lines, it all counts! It could be recipes, tips, experiences, book reviews, etc. Please send your contributions to: alex@mesupportgroup.co.uk, or if you are unable to email, post to Alex Wootton 49 Lepp Crescent, Brandlesholme, Bury, BL8 1HX

## **Should You Take The Flu Jab?** By Andrew Levy

As winter approaches you might be faced with a decision on whether or not to take the flu jab. Fortunately advice has been given by Action for ME's Principal Medical Adviser Doctor Alistair Miller.

He immediately refers to Amanda McGough, Specialist Nurse for Tees CFS/ME team, who said, "I would recommend that anyone with CFS/ME considering vaccination ensures that they are in the best health before having it. I advise our patients to ensure that they have a quiet few days after the vaccination as a small number of patients have had a reaction in previous years. These reactions can be mild and only last for a few days. It is advisable to stock up on simple analgesia, pre-jab, in case it is needed. I would also recommend that if anyone has a reaction, it might be worth letting their GP know as data is usually gathered on reactions and fed back centrally for monitoring."

Having a flu jab could be seen as taking a risk. However whilst no one has died from CFS/ME, flu kills thousands of people each year. If you fall into a high risk group (e.g. asthma, pregnancy, chronic chest and heart disease, etc.) then you should seriously consider taking the jab. It's the same advice if you go out and about, and are in contact with lots of people. On the other hand, if you're housebound you're far less likely to get the flu.

It makes sense not to be vaccinated if your CFS/ME originally came from a previous vaccination. Doctor Miller also points out that any vaccination could result in a patient contracting CFS/ME. As CFS/ME could happen after getting the flu, he also makes a link with a person's immune system, although evidence and research are thin on the ground.

The bottom line is that it's your decision, all based on knowing the risks involved. However, if you decide to be vaccinated then you should do it as soon as possible before the "flu season" starts.

## **Update on September's Article: Researching CFS/ME can be Bad for Your Health**

Thanks to the ME Association for letting us reproduce the transcript from Friday 29<sup>th</sup> July's The Today Programme from BBC Radio 4 with Dr Charles Shepherd.

You can find this article in the ME Association's Autumn Magazine, ME Essential, Issue No: 119 Russell Fleming a member of the MEA provided the following Transcript.

**Sarah Montague:** "Scientists researching chronic fatigue syndrome or ME have received death threats and been subject to a campaign of intimidation. It's being carried out by campaigners who object to any research that suggest the disease could be a mental illness. Thirty years after the disease was first recognised, it's still not know what causes it. The scientists have told us about the abuse because it is stopping people working in their field and affecting the hunt for a cure. Tom Feilden has been talking to some of those scientists affected."

**Dr Esther Crawley:** "So we run a large service for children with chronic fatigue syndrome. We see over 250 children and their families a year..."

**Tom Feilden:** "Consultant Paediatrician Dr Esther Crawley who runs one of the UK's biggest clinics specialising in chronic fatigue syndrome or ME, at the Centre for Children and Adolescent Health in Bristol..."

**EC:** "...it is a huge problem. Not only is it very common but for each child the estimates are that they miss about a year of school. So a very large problem and probably mostly undiagnosed."

**TF:** "As well as offering clinical treatments for patients, Dr Crawley's also involved in research into the causes of CFS, and its socio-economic impact. She's a well respected academic working in a field crying out for further analysis, and whose results are regularly published in peer-reviewed scientific literature. But it was when Dr Crawley got involved in a study to assess the efficacy of a particular treatment, an alternative therapy known as the Lightning Process, that the trouble started:

**Actor's Voice:** "To those of you who are responsible for preventing us sick ME sufferers getting the help we need, wasting 5 million pounds on flawed bullshit, you will pay."

**Actor's Voice:** "how are you evil bastards going to explain away another concrete piece of evidence that shows clear abnormalities..."

*[Voice continues in background with more voices joining in...]*

**TF:** "Dr Crawley found herself the victim of a vicious email hate campaign, vilified on the internet websites, and the subject of a series of formal complaints, alleging both personal and professional misconduct..."

**Actor's Voice:** "...time is running out for all of you so you better start denouncing your flawed inhuman bullshit, and pray to god for forgiveness."

**EC:** "It felt to me that what happened was that they were trying a variety of strategies to get the study stopped and then as they were failing, they were increasing the erm. heat as it were..."

**TF:** "it's worth mentioning, none of the complaints against Esther Crawley to the University, the Ethics Committees overseeing her research, or the GMC, have ever been upheld, but also that she's not alone..."

**Professor Simon Wessely:** "Direct intimidation in the sense of letters, emails, occasional phone-calls and threats, and but more often indirect intimidation through my employer, the General Medical Council..." [*Continues in background*]

**TF:** "At the eye of this storm is King's College London's Professor Simon Wessely, who, over 20 years he has been involved in the field, has been compared to the Nazi scientist Joseph Mengele and has received a series of death threats..."

**SW:** "All of it intended to denigrate and you know try and try and make you into a kind of leper, so that no one would have anything to do with this 'terrible Person'."

**TF:** "Given the vitriolic nature of the attack it's hard to discern a rational motive behind them, but it seems clear to Dr Wessely that it's the association of Chronic Fatigue Syndrome with mental illness that provokes such anger..."

**SW:** "I think sadly some of the motivation here comes from people who really do believe that any connection with psychiatry and the world of psychiatry is tantamount to saying, 'There is nothing wrong with you, go away, you're not really ill.' Now, that's profoundly misguided. It fails to understand the whole nature of so many disorders, and instead they fall victim to the label and, and believe that the mere involvement of psychiatry denigrates them and denigrates the condition..."

*Recorded Broadcast American Music:*

"ABC news now, Good to know..."

**Dr Donnica Moor:** "What we do know is there is a biologic basis for Chronic Fatigue Syndrome..." [*Continues in the background*]

**TF:** "Sadly, the series of follow-up studies published in the BMJ, the Lancet and the Public Library of Science, failed to replicate that finding, unleashing another torrent of abuse, this time aimed at virologists like Imperial College's Professor Myra McClure..."

**Professor Myra McClure:** "It really was quite staggeringly shocking, and these were all from patients who seemed to think that I had some vested interest in not finding this virus, and that I I couldn't understand and still cant to this day, what the logic of this is. I mean any virologist wants to fins a new virus."

**TF:** "But it's not an area you're going to be doing any more research in?"

**MM:** "Absolutely not No."

**TF:** "And that according to The Wellcome Trust's Dr Mark Walport, may be the single most important consequence of this campaign of abuse and intimidation."

**Dr Mark Walport:** "Well it would be a tragedy if the outcome of all of this was that good scientists thought that it was just too difficult to research this condition. We clearly don't understand exactly what's going on, and if we are going to find out it needs good scientist's to work on it. But why would any scientist work on it if they know that all they are going to receive is a torrent of abuse?"

**Dr Charles Shepherd:** "Good morning Sarah."

**SM:** "Can you understand? Can you try to explain to us the mindset of the people who are carrying out this abuse?"

**CS:** "Well, first of all let's be clear Sarah, this sort of personal intimidation that you've been describing. Is I believe, completely unacceptable, and it's also counter-productive because it doesn't stop the type of research that you've been talking about going on, and it puts good researchers off and I mean there's no doubt about that. But I think you've got to put this into the context of the fact that we have around about 250.000 people with this illness. A very tiny, tiny minority of those people are involved in this sort of behaviour, but what people do have a justifiable complaint about is the fact that there has been very little or almost nil government funding research into the biomedical aspects of this illness.

And really all this stems from the fact that the way that the medical profession has re-named and re-defined what we used to know as ME, which is Myalgic Encephalomyelitis, which is a symptom complex of muscles symptoms, brain symptoms, infective symptoms, to Chronic Fatigue Syndrome, which is a much wider group of clinical presentations – and we have a whole spectrum of patients there who have an illness ranging from a psychiatric illness at one end to a psychiatric cause of their chronic fatigue at the other.

And it's rather like putting everyone who's got a chronic headache – from migraine to brain tumours – under a chronic headache syndrome and saying they all have the same cause, they all have the same treatment and at the moment we have the thing called the NICE Guideline recommending only the psychological side of treatments – Graded Exercise, CBT – for people to whom these treatments in some cases of Graded Exercise Therapy, makes them worse. So that's the context of the anger."

**SM:** "Are you saying the government's wasting money in the research that's being done at the moment?"

**CS:** "Well, I think the main complaint about the governments funding to the psychological-based research is that's where all the government pot of money has gone. It hasn't gone to the biomedical – this has had to be done by the charities, and most of this money has gone into CBT and Graded Exercise and we spent a vast amount of money a few years ago, two to three million pounds on something called the PACE trial, and I think there were again justifiable complaints about that because we felt it wasn't going to tell us anything that we didn't already know, and there are things that we do want to know about this illness."

**SM:** "OK, well one of the things that came up in Tom Feilden's report there is that there was a suggestion in the United States some years ago that there was a viral basis for this but it has not been replicated. There isn't a candidate virus that could be causing this, is there?"

**CS:** "Erm, well I think you misinterpreted what's going on with the virology of this illness which is quite complex. What is agreed is that a wide variety of infections can trigger this illness – glandular fever, parvovirus, hepatitis virus, Q fever infection – where the debate is whether these viruses then persist in the body, and there is conflicting evidence there."

And, if these viruses do persist, should we then be looking at the use of anti-viral medication, which is one of the things the Medical Research Council's Experts Group on research priorities wants to look at, or should we all abandon all this? And those of us who want biomedical research want the answers to these different aspects of the illness. We want to know more about the virology, we want to whether virological treatments may be effective."

**SM:** "But don't scientists want to know that? That's what seems illogical about this... why would someone be working on something that was ineffective? Why would there be a conspiracy to avoid working on something that might produce results?"

**CS:** "Well, I think the point is the anger stems from the fact that this illness encompasses a variety of ologies if you like. It involves muscle pathology. It involves brain, immunological abnormalities and yes there may be a psychological input to the illness in some people – but the anger, the frustration is that all this effort, all this government funding is, or has been, just going to the psychological side."

**SM:** "You, you had ME didn't you?"

**CS:** "Um I got involved, like a number of doctors with this illness and really only changed my mind after contracting it myself following chicken pox which I caught from one of my patients."

But I came out of medical school, and I am afraid that this is where a lot of the prejudice among the medical profession comes from, back in the early 1970s – being told at the Middlesex Hospital that this was hysterical nonsense, 'Go away forget about it. Its an illness that doesn't exist.' And that's what I believed before I actually contracted it myself."

**SM:** "Could, are they not likely to be connected?"

**CS:** "Sorry, what, what connected?"

**SM:** "I'm talking about the sort of the virus and the psychological. I mean there's sort of such an objection to it having a psychological basis, but one wonders if there isn't a connection."

**CS:** "Well, as I say I think we are dealing with a spectrum, a wide spectrum of clinical conditions under this Chronic Fatigue Syndrome umbrella. We have people that we originally called ME with their muscle, brain, infective-type symptoms. We have people with chronic fatigue, which doesn't come on following an infection, which seems to appear for a variety of causes, and we are mixing them all up, and this is the problem."

We need to sub-group all of these different people that come under this umbrella and in actual fact because we do now have a Medical Research Council Expert Group on this, this is one of the priorities which we have identified – I am a member of this group – to look at now from the research point of view so we can actually sub-group people with different types of fatigue and give them the right type of treatment. But until we find the causes of these different types of sub-groups and the role of infection and immunological disturbance, muscle abnormalities, etc, within the different sub-groups, we can't find effective forms of treatment. And this is not what had been happening; this is why people are frustrated."

**SM:** "We also I suppose, you would accept, we have a tragedy that we have scientists leaving the field."

CS: "I don't want to see scientists leaving this field. I want a debate with scientists, and it's the way I feel we should do it – it's the way I do it – scientific debate. Criticism is healthy, but it should be conducted through the medical journal. It should be conducted through constructive criticism.

As I said at the start of this interview, intimidation, personal abuse and whatever has no role to play whatsoever in this."

SM: "Dr Charles Shepherd, thank you very much."

## **ME is Just Fatigue, Right? WRONG** by Tymes Trust

# **Research showing ME is a physical disease**

Dundee University Studies co-funded by  
The Young ME Sufferers Trust and ME Research UK

### **BBC World Service Interview**

*Scientists in Scotland have found new evidence that ME, or Chronic Fatigue Syndrome could be caused by a virus. They studied children affected and found abnormalities in their blood which they say points to an infection. It's reckoned that millions of people, mainly in the developed world, have ME; many of them are children. Jill Belch [pictured], who's Professor of Vascular Medicine at Dundee University, led the research:*

'There are two important things that we've found, and the first is that there's an abnormal level of an inflammatory chemical in the blood, and this is matched by abnormal white blood cell behaviour, and that's important because finding an abnormality is half way to finding a treatment. But the second thing that I think makes these findings important is that it is a physical abnormality, and there has been some question in some people's minds as to

whether this disease might actually be a disease of the mind, and I think finding a physical abnormality reassures us that this is a genuine physical illness.'

*Indeed, some doctors have been reluctant to diagnose ME, in the belief that it is a disease of the mind. Jane Colby was a Head Teacher until she was struck down by ME; she's now Executive Director of The Young ME Sufferers Trust here in the UK. First, her reaction to these new findings.*

'I welcome it, and frankly it's exactly what I would have expected. because the important thing is, it's not just evidence of infection in children with ME, but persistent infection. So they're fighting something, and they're fighting it on an ongoing basis, which means there's an explanation for why they are so ill for so long.'



### **Biochemical and Vascular Aspects of Pediatric Chronic Fatigue Syndrome**

- We showed for the first time, to our knowledge, that oxidative stress [...] and increased WBC apoptosis occur in children with ME
- The data are also consistent with a reactivating or persistent viral infection

*Arch Pediatr Adolesc Med*  
2010;164(9):817-823

*Can the symptoms be different from person to person? Can they be very severe in one case and mild in another?*

'Well, like any other illness, yes you're going to get severe cases. The important thing to do is not to let a milder case turn into a severe case, and if you manage it wrongly that's what it will do.'

### **Physical and Functional Impact of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis in Childhood**

#### **Key findings with educational implications**

- Only 1 child out of 25 was able to attend school full-time (4%)
- 12 children were attending school part-time (48%)
- 8 children received home tuition (32%)

These results are in accord with similar findings for adults, indicating that physical symptoms can be at least as disabling as those of multiple sclerosis and other chronic conditions.

**The quality of life of children with CFS/ME was significantly impaired compared with their healthy counterparts and that of children affected by other chronic illnesses (type 1 diabetes mellitus and asthma).**

*Pediatrics 2010; 125:e1324-e1330*



The Young ME Sufferers Trust  
Registered Charity 1080985  
Founder Patron : Lord Clement-Jones CBE

[www.tymestrust.org](http://www.tymestrust.org)

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PO Box 4347, Stock, CM4 9TE



The Queen's Award  
for Voluntary Service  
The MBE for volunteer groups

# Press Report on Tymes Trust's Visit to Carlisle

by Tymes Trust

## Press Report on Trust's visit to Carlisle

Former Head Teacher Jane Colby, Executive Director of the The Young ME Sufferers Trust (Tymes Trust), talked to Carlisle ME/CFS support group about her recent presentation to the All Party Parliamentary Group on ME. The Trust has helped thousands of families over the years and in 2010 received the Queen's Award for Voluntary Service: the MBE for volunteer groups.

**There are in Jane's view 3 misperceptions that affect patient care:**

1. That ME is a mental health disorder
2. That treatments recommended by the National Institute for Clinical Evidence (NICE), can always be expected to 'cure' or substantially improve the condition
3. That the illness is neither long lasting (chronic) or severe.

Tragic consequences of such mistaken views include parents unjustly suspected of harming or neglecting their children, the denial of suitable education, and incarceration of children in psychiatric wards when treatments fail to work as expected.

The Trust, Jane explained, is a practical charity that addresses such injustices in its case work, campaigning and research. The Trust has co-funded an exciting study at Dundee University which showed that ME is a physical illness. Researchers found an abnormal level of inflammatory chemicals in children's blood and an abnormal rate of white blood cells dying. Professor Jill Belch said this was consistent with a reactivating or persistent viral infection. The children's quality of life was significantly worse than children suffering with other illnesses (type 1 diabetes mellitus and asthma).

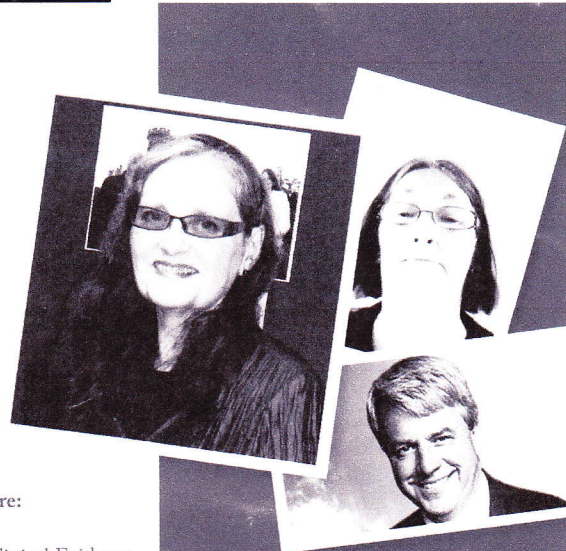
The study also found that only one child out of 25 was able to attend school full time. This confirms the Trust's experience that access to education is badly impaired. Children have a legal right to suitable education. This does not mean having to attend school – schools must provide other means of education if the child is too ill to attend. Virtual education or home tutors are suitable alternatives.

- In the last two years alone, the Trust has assisted more than 70 families subject to child protection investigation, whose children have ME.
- All 100% of these investigations were found to be without foundation. No figures are kept on such cases by government; it is not known how many more there may be.

Jane also explained that the Trust works with American virologist Dr John Chia, who is about to announce a new breakthrough. The Trust has funded tissue samples from some of its young members to be analysed for enteroviruses and all were positive. Enteroviruses are related to poliomyelitis. They infect the gut and can persist years after the original infection. There is a specific protocol that must be used for the test.

The Trust hopes that its work will help lead to a diagnostic test and that curative pharmaceutical treatments will be developed. In the meantime, Jane says: 'Doctors need to make sure that a mild case doesn't turn into a severe one through inappropriate treatment. We regularly work with our members' GPs to help and advise.'

by Linda Daniels and Jane Colby



## GP project praised by uk government

Building links with your GP

Earlier in 2011, our Founder Patron, Lord Clement-Jones, received a letter from Health Secretary Andrew Lansley about our GP Project. This project is our newest member service. Mr Lansley writes: 'I was encouraged to learn of The Young ME Sufferers Trust's work in building links with the GPs of those children suffering from CFS/ME. The lack of certainty surrounding CFS/ME poses very real problems for healthcare professionals...'

The Trust has always believed that an understanding GP is invaluable in helping the family cope with ME. If you would like to discuss how our personalised GP Project could help you, call the Trust's Advice Line Team on 0845 003 9002.

Register for Jane's monthly email News Alerts by letting us have your email address. (If the Alerts don't come into your Inbox, check your spam/junk mail box.)

You can follow Jane on Twitter @JaneCColby or read her latest tweets at [www.tymestrust.org](http://www.tymestrust.org) A facility that's personal, informative - and fun.

