Minutes of the meeting of the Cross Party Group on ME in the Scottish Parliament

Held on

Wednesday 4th April 2001 in Committee Room 1

Attendance - John McAllion, MSP, Alex Fergusson, MSP, Christine Grahame, MSP, Mike Watson, MSP, Holly Sutherland (PA to Linda Fabiani,MSP), Alison Calvert (Researcher for Alex Fergusson), Helen McDade (MERGE), David Dall (West Lothian MESH), Iain Lee (sufferer), Madeline MacLaverty (Parent), Linda Macgregor (MEEK), Margaret Williams (MEEK), Ann Campbell (ME Association), Andrew Gardner (ME Self-Help Dunfermline), Robert Sclater (ME Self-Help Dunfermline), Rhona Barton (Association of Young people with ME), Kathy Barton (Carer), Ewan Dale (Glasgow West ME support), Simon Lawrence (25% ME Group), Nick Stroud (Edinburgh MESH), Allan Stroud (sufferer), Euan MacPherson (sufferer), Dr. John Breward (sufferer), Robin Cole (carer), Merryn Fergusson (parent), Linda Dunn (ME Association), Niccola Simpson (ME Association), Catherine Lewis (North East Fife ME Support), Michele Savage (Cross Party Group on Autism), Dr. Betty Dowsett (speaker), Dr. Abihijit Chaudhuri (speaker)
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Apologies- MSPs - Rhoda Grant, Lord James Douglas-Hamilton, Fiona Hyslop, Lyndsay Mcintosh, Iain Smith, Kate MacLean, Elaine Thomson, Donald Gorrie, Des McNulty, Johann Lamont, Mike Russell, Nicola Sturgeon, Kenneth Gibson, Sandra White, Marilyn Livingstone, George Lyon, Bruce Crawford, George Reid, Dorothy-Grace Elder, Roseanna Cunningham, Margaret Smith, Bristow Muldoon, Margaret Ewing, John Scott, Andy Kerr **ME representatives -** Catherine Lewis, Dr. David Mason Brown, Dr. Vance Spence

Introduction- John McAllion welcomed everyone and stated that he was delighted to say that the Cross Party Group had now been officially recognised by the Standards Committee. He informed the group that a **Parliamentary Motion** was being put down by himself and Alex Fergusson. The wording being -

That the Parliament, in view of 2001 being the Year of the Severely Affected with ME and in view of ME Awareness Week in May 2001, acknowledges the suffering of an estimated fifteen thousand patients with myalgic encphalomyelitis (ME) and/or Chronic Fatigue Syndrome (CFS) including an estimated two and a half thousand children, and asks the Scottish Executive to commission urgently a strategic needs review assessment into ME and CFS and to set up a specialist ME and CFS clinic for diagnosis and treatment of sufferers.

that a **Petition** to the Parliament was being circulated. The wording being as follows -

We, the undersigned, call on the Scottish Parliament to urge the Scottish Executive to:
- carry out a Strategic Needs Review Assessment on ME and CFS in Scotland
- establish the size of the ME and CFS patient population
- establish the proportion who are severely affected, their Benefits entitlement and the uptake of these
- establish a clinical centre of excellence for the treatment of, and clinical research into ME and CFS
- ensure that GPs are informed of the new centre and liase with it

and that Alex Fergusson had had a **Parliamentary Question** asked on the 8th of February - "to ask the Scottish Executive what plans it has to increase awareness and treatment of conditions such as chronic fatigue syndrome and myalgic encephalomyelitis - or ME - particularly among young people".

The Chairman then introduced the first speaker, Dr. Abhijit Chaudhuri, Senior Clinical Lecturer in neurology at Glasgow University.
The **text of Dr. Chaudhuri's slides** follows -

Myalgic encephalomyelitis (ME) & Chronic Fatigue Syndrome(CFS):
an overview and current research
Abhijit Chaudhuri
Senior Clinical Lecturer in Neurology
University of Glasgow
Consultant Neurologist
Institute of Neurological Sciences
South Glasgow University Hospitals NHS Trust

Fatigue as a symptom
* Common
* Multifactorial
* Subtypes: peripheral and central
* Difficult to measure
* May be acute or chronic
* Chronic fatigue is a symptom of known diseases
* Otherwise unexplained chronic fatigue of new onset is characteristic of ME/CFS

History of ME/CFS
* Documented over centuries since the outbreak of the "English Sweats"
* Called neurasthenia in the 19th century
* Many epidemic outbreaks after viral infections ("atypical poliomyelitis")
* Name of Myalgic encephalomyelitis (ME) used on clinical grounds during the Royal Free outbreak
* Post-viral fatigue syndrome (PVFS) in 1970s and 1980s: similarity with post-polio fatigue syndrome

"Chronic fatigue syndrome" (CFS)
* Name introduced in 1988 by CDC, Atlanta
* May not be the ideal name
* Very broad diagnostic criteria (e.g. Oxford)
* Concerns about selection of patients
* Differences on epidemiological data
* Modification of CDC criteria in December 1994 (current international criteria)
* ?More changes
* ME/CFS is categorised as a neurological disease by the WHO

ME/CFS in UK
* Unknown prevalence (?0.2% -2% of population)
* Economic cost: £1-4bn
* Medical cynicism
* Multiple referrals, inappropriate investigations and often forced interventions
* Special problems in children

* Low rate of spontaneous recovery
* Job losses and social exclusion
* Long term disability
* Benefit issues

ME/CFS care in Scotland
* Substantial number even on conservative estimate (0.2% of 5 million = 10,000)
* No dedicated centre
* No designated specialist paediatrician
* Newly diagnosed cases may not have a choice of Consultant opinion at any stage
* No coordinated physical and occupational rehabilitative programme
* No educational guidelines for ME/CFS children
* Disability of chronic ME/CFS sufferers may be ignored

Nature of symptoms in ME/CFS
* Neurological
* Very similar to fatigue in known diseases like multiple sclerosis, post-polio fatigue, Parkinsonian disorders, head injury or stroke
* Characterised by physical and mental fatigue
* Persistent or relapsing
* Not substantially improved by rest or sleep
* New onset (i.e. not life long): often after a combination of viral infection and stress
* Not due to depression, hysteria or somatisation in correctly diagnosed cases

Fatigue in ME/CFS
* Fluctuates in severity ("good days" and "bad days")
* Worsened by stress and exertion
* Impairment in short-term memory, attention span and concentration ("forgetful")
* Naming errors frequent
* Interferes with occupation and personal life styles (educational problem in children)
* Not improved on antidepressants or graded exercise

Neurologist and ME/CFS
* Similarity with other neurological diseases
* Predisposing neurological illness
* Altered neurohormone functions
* Autonomic symptoms
* Memory impairment
* Long term disability
* The diagnosis of ME/CFS is entirely clinical and there is no diagnostic test for this condition

Research in ME/CFS
* Changes in muscle function (skeletal and cardiac)
* Changes in brain function:
- stress hormone response: differentiating from depression
- cerebral blood flow
- functional neuroimaging
- effects of stress and infection on brain neurohormones
- cognitive impairment

Managing patients with chronic fatigue/ME symptoms

* Exclusion of other possibilities by a good clinical examination and simple investigations
* Consultant referral to confirm diagnosis
* Institute early rehabilitation programme
* Educational advice for children
* Maintain follow up with liaison nurse service
* Research studies
* Intervention trials
* Patients with ME/CFS should not be treated any differently from patients with fatigue due to other neurological diseases

Greater Glasgow scene on CFS/ME
* No organised service
* No paediatric clinic
* Two interested physicians: but may be short term
* South Glasgow University Hospitals NHS Trust does not provide support for the dedicated CFS/ME clinic
* Currently talks in progress with the local Health Board for developing a "care package" for CFS/ME patients, with proposals for
- Consultant-led service for first-time diagnosis
- GP-led service supported by Consultants and Therapists for long term care of patients already diagnosed
- Liaison nurse maintains contact with patients, physician and therapists
- Offer for a pilot trial

Glasgow research on ME/CFS
* Functional neuroimaging (Magnetic Resonance Spectroscopy) in central fatigue (in collaboration with Professor Hadley and Dr. Barrie Condon in Neuroradiology, Institute of Neurological Sciences)
* Changes in gene expression and anti-viral pathway after infection (in collaboration with Dr. John Gow in Neurovirology, University of Glasgow)
* Effect on skeletal muscle physiology (in collaboration with Professor Ward, IBLS, GU)
* Changes in muscle microcirculation in fatigue (in collaboration with Dr. Walter Watson, Nuclear Medicine)

What we need for our ME/CFS patients...(a short wish list!)
* Early diagnosis with Consultant input
* Early rehabilitation (physical and occupational), retraining and reeducation of sufferers
* Liaison nurse service to ensure proper delivery of health care to those who need the most
* Funding for research
* Education for GPs

"When a patient calls on you, he is under no obligation to have a simple disease just to please you" (JM Charcot, 1887)

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John McAllion then introduced Dr. Betty Dowsett, Honorary Microbiology Consultant from Basildon and Thurrock Hospitals, saying that the Cross Party Group were grateful to Dr. Dowsett for breaking her holiday in Scotland to address them. Dr. Dowsett talked about her vast experience with ME patients over several decades - the only British

clinician to have been studying ME longer being Dr. John Richardson, who had provided some of Dr. Dowsett's data. A summary of Dr. Dowsett's talk is below -

THE LATE EFFECTS OF ME - **can they be distinguished from the Post-Polio Syndrome (PPS)?**

Dr. Dowsett showed an age distribution graph of Dr. John Richardson's patients, followed up for decades. This showed that most ME patients contract the illness in the 3rd and 4th decade, with a smaller peak at puberty. The incidence at below ten years was low and, until recently, this had also been the case for those above 50 years old. However, epidemiology surveys made between 1988 and 1998, in Essex clinics, showed patients over fifty who were presenting with new illness had risen from 6% to 18%.

Dr. Dowsett presented evidence suggesting that these older patients had actually suffered from mild undiagnosed non-paralytic polio (polio is caused by specific enteroviruses) or other enteroviruses in earlier life and were now suffering the delayed effects from damaged nerve tissue. She pointed out that the vaccine for poliovirus only included three polio enteroviruses whilst there were numerous other enteroviruses capable of causing damage to nervous tissue. She showed data where an outbreak of summer flu had been studied showing the different viruses from within this group, including polio viruses, that were involved in different cases.

Dr. Dowsett suggested that ME was a syndrome initiated by one or more of a related group of enteroviruses, often causing "summer flu". Most people infected will show no, or few, symptoms. Some 5-10% will have a more serious illness, with symptoms indicating central nervous system involvement, possibly progressing to viral meningitis and encephalitis. Some will recover, but are then susceptible to further effects in later years. ME is a life-long disability where relapse is always possible.

Dr. Dowsett showed, on Dr. Richardson's distribution graph, that 10 % of his ME cases had developed a multi-system syndrome involving permanent damage to skeletal or cardiac muscle and to other "end organs" such as the liver, pancreas, endocrine glands and lymphoid tissues, signifying the further development of a lengthy chronic, mainly neurological condition with evidence of metabolic dysfunction in the brain stem. Yet, stabilisation, albeit at a low level, can still be achieved by appropriate management and support. The death rate of 10% occurs almost entirely from end-organ damage within this group (mainly from cardiac or pancreatic failure). It has to be said that suicide in younger patients and in earlier stages of the disability is related to the current climate of disbelief, rejection of welfare support and loss of educational and employment prospects. It is an additional and potentially avoidable factor.

WHAT IS THE POST-POLIO SYNDROME?

Poliomyelitis is an acute enteroviral infection with a wide range of clinical manifestations and multi-organ involvement. 95% of people who contract the infection remain symptom free or suffer only a trivial non-specific respiratory or gastrointestinal illness as in ME. Some 5% of those contracting the minor illness develop muscle weakness or paralysis before more serious or fatal complications supervene. The diagnostic distinction between "paralytic" and "non paralytic polio" was entirely arbitrary in the days of the big epidemics. In fact, the category of "non-paralytic polio" contained many patients with mild or temporary paralysis and with encephalitis, which occurs in patients reaching the later stages of this illness. Modem studies indicate that overt paralysis in these patients depends entirely on the percentage of spinal nerve cells destroyed. For damage to be visible as weakness or paralysis at least 50%-60% of the nerves controlling muscular action must be damaged or destroyed. Thus, patients with less damage who may only have had a minor illness, and some who were asymptomatic can still present many years later with a classic Post-polio syndrome.

Recent publication of this information (originally derived from studies made in 1955) has resulted in a re-definition of the post-polio syndrome and will certainly include many patients currently seen in ME clinics. It is likely that many patients diagnosed as having ME are suffering from an illness clinically identical to "non-paralytic" polio. The late

effects of ME and the Post-Polio Syndrome are clinically identical and similar in respect of neuroanatomical, neuroendocrine, neuropsychological electroencephalographic and other techniques, including brain imaging and molecular biology, as indicated by a remarkable series of research papers published by Bruno and colleagues over the past 20 years.

COMMENT -

a. Dr. Dowsett said that there has been little government interest or support for patients suffering from the late effects of ME or from the post-polio syndrome. The Chief Medical Officer's Working Party on ME (set up in 1999 and funded privately by the Linbury Trust) has made it clear that its remit is only with management, and that all discussion about the cause, epidemiology and social benefit requirements of these patients is ruled out. It seems that it will be difficult to advise on rational management in the absence of such vital information.

b. The potential size and cost of the problem. This is impossible to assess in the UK because no official epidemiological surveys have been made. However, increasing numbers of patient support groups and individual research workers have been making their own calculations. In the case of ME, prevalence appears to range from 300/100,000 to 500/100,000 in occupations at high risk of infection, but no information is yet available about the number likely to suffer late effects (except that it may have trebled in the last 10 years).

   The number likely to be affected by the post-polio syndrome has been calculated as between 200-270/100,000 currently, but no account has been taken of survivors from non-paralytic polio which could easily double that figure. Possible costing for ME support has been based on 3x the cost of maintenance for multiple sclerosis on the supposition that ME is 3 times as common. The only costs that we can be sure of are those derived from the failure of appropriate management, and of inappropriate assessments which waste vast sums of money and medical time while allowing patients to deteriorate unnecessarily.

c. Some Immediate Steps that Could Be Taken These patients could be referred to NHS rehabilitation clinics and welfare facilities as for any other chronic neurological disease, but physiotherapy must include exercise suitable for patients with some damaged muscle fibres which have been overused while others are normal and liable to deconditioning. Separate "ME" and "Post-polio Clinics" are more expensive and often inaccessible. We should be educating doctors and paramedics now about the very common and seriously disabling effects of neglect. Rapid diagnostic tests for enteroviruses, anti-enteroviral drugs and possible vaccines are already in preparation here, or in use (in the USA) to deal with the tremendous burden of circulating enteroviral infections, (for example, leading to febrile respiratory infections, viral meningitis and myocarditis let alone unnecessary admissions to hospital and inappropriate prescription of antibiotics in children). These methods could well be employed for the benefit of young people in the UK and to prevent the rising tide of ME in schools - the commonest cause of long term absence and subsequent educational deficit!

d. Research workers must be encouraged and appropriately funded to work in this field. However they should first be directed to papers published before 1988, the time at which all specialised experience about poliomyelitis and associated infections seem to have vanished mysteriously!