

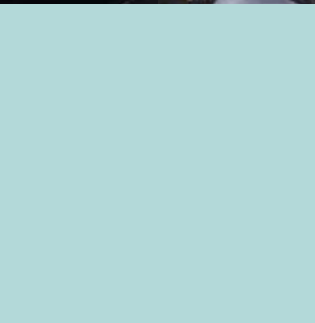


# 2010 Election manifesto for M.E.



action for **M·E**





# Summary of manifesto commitments

1. Put an end to inequalities in health provision faced by adults, young people and children with M.E.
2. Bring about a fundamental shift in attitude in welfare policy and practice towards chronic fluctuating illnesses.
3. See that robust scientific evidence of the biology of this disease is obtained and disseminated across all government departments.
4. Guarantee that all children, young people and adults with M.E. who are well enough have access to education and receive appropriate support to fulfil their potential.
5. Ensure that all young people and adults with M.E. who are well enough have access to employment and will receive appropriate support to fulfil their potential.
6. See that all adults, young people, and children with M.E. receive optimal respite care, support and information.
7. Make sure that all carers of adults, young people and children with M.E. receive optimal support and information.

The pictures in this manifesto pullout are from our *Faces of M.E.* campaign, which aims to show that people of all ages and backgrounds can be affected by the illness.

## All about M.E.

M.E. (Myalgic Encephalomyelitis/ Encephalopathy) is a chronic, fluctuating illness, also known as Chronic Fatigue Syndrome (CFS) and sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS). Common symptoms include persistent exhaustion, un-refreshing sleep, poor concentration and memory, headache, muscle pain and digestive problems.

Patient surveys indicate that 25% of people with the illness are so severely affected that they become housebound or bedbound, some for many years. M.E. can affect anyone, at any age and from any ethnic group.

### Key facts:

- The NHS recognises that M.E. can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions<sup>1</sup> yet understanding and service provision for M.E. lags seriously behind that of other illnesses.
- There are 100,000 people with M.S. in the U.K.<sup>2</sup> and 50,000 with systemic lupus erythematosus<sup>3</sup> but far more – 250,000 people – live with M.E.<sup>4</sup>: a significant number within the electorate.

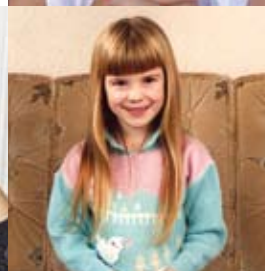
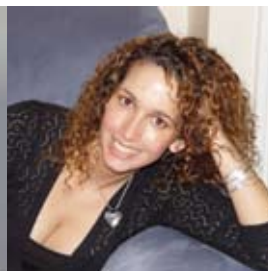
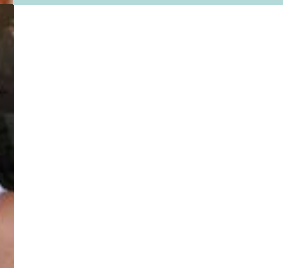
## Our vision

This election manifesto has been produced, following wide consultation with people with M.E., by Action for M.E. and the Association of Young People with M.E. (AYME) – in conjunction with the Princess Royal Trust for Carers (for the section on carers) – so that all major political parties can know and address the issues faced by people with M.E.

Action for M.E. ([www.afme.org.uk](http://www.afme.org.uk)) is the UK's leading charity dedicated to improving the lives of people with M.E. AYME ([www.ayme.org.uk](http://www.ayme.org.uk)) is the largest charity for children and young people with M.E.

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# Manifesto commitments

## 1: Health

**Put an end to inequalities in health provision faced by adults, young people and children with M.E.**

### Key facts:

- On 6 May 2009, Lord Darzi told the House of Lords: "It is the responsibility of Strategic Health Authorities to ensure that services are available – and sufficiently funded and staffed with appropriately trained staff – to meet the health and social care needs of those of their local population diagnosed with CFS/M.E."
- On 2 December 2009 the All Party Parliamentary Group on M.E. presented its Inquiry report on NHS services for M.E. to the Minister of State for Health Services. The report described evidence of gross discrepancies in the quality of care provided by Primary Care Trusts for patients with M.E. and found the variations in availability and access to services unacceptable.
- Only 2% of respondents to Action for M.E. and AYME's most recent health survey felt their GP was well informed about M.E.<sup>5</sup>
- NICE published its guideline on the diagnosis and management of CFS/M.E. in 2007. Concerns have been raised that recommended treatments such as graded exercise therapy (GET) have harmed many patients.<sup>6</sup>

### Our expectations:

- M.E. will be included in all pre- and post-registration training of healthcare professionals.
- Increased funding to primary care trusts, ring-fenced to enable access to specialist services for all patients, including domiciliary visits for the severely affected.
- The review of the National Institute for Health and Clinical Excellence (NICE) guidance on chronic fatigue syndrome/ myalgic encephalomyelitis will be properly informed by patient reported outcomes and the widest possible medical consultation.
- Every GP will be enabled to make a timely diagnosis and refer to an appropriate specialist, provide treatment and management advice tailored to the specific symptoms the person has, and a long-term condition care plan.
- The role of alternative therapies that patients have reported as helpful in alleviating the symptoms of M.E. will be incorporated into the NHS.
- Care of patients with ME will be included in the Quality and Outcomes Framework for General Practice.

## 2: Welfare

**Bring about a fundamental shift in attitude in welfare policy and practice towards chronic fluctuating illnesses.**

### Key facts:

- Because M.E. is a chronic fluctuating illness, patients who are too ill to work (and their carers) are exceptionally vulnerable within the welfare benefits system. Their health suffers and too many experience a relapse in the struggle to access, claim and retain the benefits they need<sup>7</sup>.
- Our surveys consistently show that Department for Work and Pensions (DWP) and Jobcentre Plus staff – including doctors and assessors in subcontracted medical services – do not understand the fluctuating complexities of M.E.
- The problem is illustrated by the high number of awards made at the appeal stage after rejection of the first claim<sup>8</sup>.

### Our expectations:

- Sufficient safeguards will be put in place to protect people who are genuinely unable to work from being pressurised into unsuitable work or work-related activity prematurely, when a return to such activity could be detrimental to their health.
- Introduction of up-to-date and accurate M.E. training within local authority Social Services departments, the Department for Work and Pensions (DWP), Jobcentre Plus and subcontracted medical services.
- A full review of the guidance on M.E. for new and existing assessors and other staff in the Department for Work and Pensions.



### 3: Research

**See that robust scientific evidence of the biology of this disease is obtained and disseminated across all government departments.**

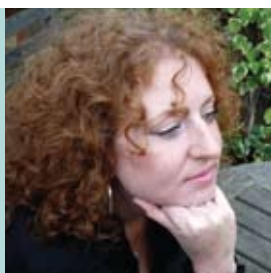
#### Key facts:

- In 2006 the Gibson Inquiry into the progress of scientific research on M.E. found that the issues outlined in 2002, in a Report to the Chief Medical Officer, had not been addressed. It said: "Although some interesting biomedical research has been done in the UK precedence has been given to psychological research and definitions. The UK should take this opportunity to lead the way in encouraging biomedical research into the potential causes of CFS/M.E. Further research is the single most important area in this field."
- In 2008 the MRC set up a new Research Expert Group under the leadership of Professor Steven Holgate, Southampton University, to review current research, identify research opportunities and encourage new research to understand the causes of CFS/ME.



#### Our expectations:

- Substantial resources will be committed to identify the cause of this marginalised condition once and for all.
- The Medical Research Council will update its highlight notice on M.E., in response to the findings of the Gibson Inquiry which said that more funding should be allocated to "research into potential causes, which might lead to better diagnostic tests... Investigating potential sub-groups must be a strong priority."
- Identify whether advice can be given to those with significant infections in order to prevent them from developing M.E. This should include the possibility of establishing testing and treatment for Xenotropic Murine Leukemia Retrovirus (XMRV), herpes and enteroviruses and other infections which may be found in people with M.E.
- Clinical trials of medications which have been found to be helpful to some people with M.E.
- M.E. will be designated as a reportable health condition to enable the robust collection of data on the number of children, adults and young people with M.E. in the UK, the degrees of severity experienced by different groups, demographic data, and any family history of the condition.



### 4: Education

**Guarantee that all children, young people and adults with M.E. who are well enough have access to education and receive appropriate support to fulfil their potential.**

#### Key facts:

- M.E. has been reliably diagnosed in children as young as two<sup>9</sup>.
- The prevalence may be up to 4.6% in children, much higher than has been generally recognised.
- M.E. was found to be the most significant cause of long term school absence among 885 individual sickness records received in six local education authorities (51%), followed by: cancer and leukaemia (23%), general medical or surgical conditions (13%), musculo-skeletal problems (12%), psychiatric disturbance and virus infections (5% each).<sup>10</sup>

#### Our expectations:

- Schools will have a statutory, rather than the current voluntary, responsibility to support the health and well-being of children with medical needs.
- All schools will produce and implement medical condition policies, covering M.E. as part of their duty to promote pupil well-being.
- Ofsted inspections will include support for key health conditions including M.E. specifically.
- The numbers of children affected by M.E. experiencing long term school absence will be investigated.

## 5. Employment

**To ensure that all young people and adults with M.E. who are well enough have access to employment and will receive appropriate support to fulfil their potential.**

### Key facts:

- M.E. patients need to “pace” very strictly all physical and mental activity, or their reservoir of energy is rapidly exhausted and they can relapse.<sup>11</sup>
- People with chronic fluctuating conditions want to work but may be subject to set-backs and may be limited in what they can do.

### Our expectations:

- Measures will be introduced to encourage employers to retain and take on staff who have long term conditions which limit the way they can work, eg. highly flexible hours and the option to work from home.
- Investment in technology to support home working for those people with long term fluctuating conditions who are able to use it.
- DWP (Department for Work & Pensions) will monitor employers regarding number of people with long term conditions and disabilities they employ and how many employees are retained after developing a disability.



## 6. Social Care

**See that all adults, young people, and children with M.E. receive optimal respite care, support and information.**

### Key facts:

- In a 2008 Action for M.E. survey of 1162 people with M.E., 114 respondents described themselves as bedbound and 776 as generally housebound, with a further 1195 mobile only over short distances, yet only 115 people received care from social services – a surprisingly low level of support for a disabling long-term condition.<sup>12</sup>
- Current social care proposals will have a significant impact on people with long-term conditions, in the short term and as they get older. The current economic climate threatens the provision of welfare support to those who need it most.

### Our expectations:

- Social care staff will ensure there is a designated key worker to co-ordinate the care of those most severely affected adults, children and young people. They will ensure that families are aware of the physical aids they are entitled to, to make daily living safe and manageable.
- All people with M.E. will be provided with a “disability survival kit” in order to help with benefits applications forms and accessing other kinds of support such as ‘Blue badges,’ aids and adaptations. This will be made available both in paper format, and online, and must be reviewed regularly to ensure it is kept up to date.

## 7. Carers

**Make sure that all carers of adults, young people and children with M.E. receive optimal support and information.**

### Key facts:

- Carers save the Department of Health £87 billion per year due to the free care and support they provide.<sup>13</sup>
- The NHS could not cope if carers did not provide care, so how Primary Care Trusts (PCTs) support this most valuable resource should be a prime concern.
- In 2008 Action for M.E. survey<sup>14</sup>, 86% of respondents relied on carers within the family. 312 relied on someone aged 66 or over. Older carers will increasingly have their own health and support needs.

### Our expectations:

- Carers will be moved from Tier 3 of NHS Vital Signs to Tier 2. So that the support that PCTs give to carers would inform the performance scores for PCTs.
- Every school will have a young carers policy and named lead member of staff (not necessarily a teacher).
- A move towards greater transparency in how the local authority carers grant is used, along with an improved indicator that measures the support available to carers in that local area, rather than the number being assessed.
- Every local area will have a local carers support service that provides information, advice and access to services.

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