

# Do you know someone who has M.E.?

M.E. (Myalgic Encephalomyelitis/Encephalopathy) is a serious disabling chronic neurological illness.<sup>1a</sup>

## M.E. Uncut

Creating a better understanding of M.E. in Somerset



**“Very few GPs fully understand the illness.”<sup>2</sup>**

[<sup>2</sup>Dr Clare Gerada, chair of the Royal College of General Practitioners 2010-2013]

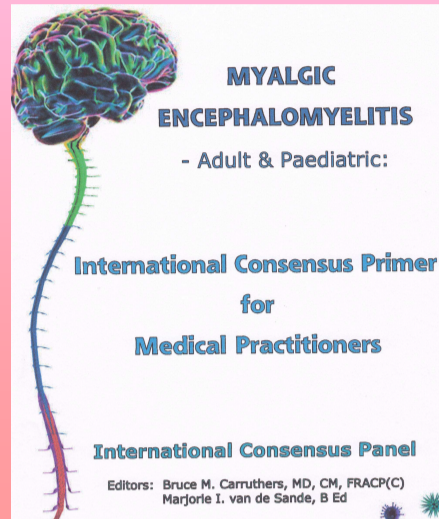
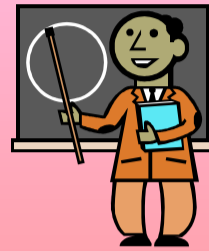
During ‘Somerset M.E. Awareness Year’ (May 2014-Apr 2015) **M.E. Uncut** will provide:

**free packs and seminars** enabling medical/social care/educational professionals to safely manage M.E.

**free professional conferences** providing the latest International Research on M.E. plus CPD points.

**Information Packs** will go to:

Adult & Children’s Social Workers,  
Libraries, Nurseries, Schools & Colleges.  
Neurologists & Paediatricians,  
GP Practices,  
Occupational Therapy  
& Physiotherapy Departments.



The **Medical Information Pack** includes the *International Consensus Primer* making it easier, and quicker, for professionals to identify and diagnose M.E. The **Primer** is the updated version of the *ME/CFS Overview of the Canadian Consensus Document*.

For more information on **M.E. Uncut** please go to: [www.bluemooncare.co.uk](http://www.bluemooncare.co.uk)

## M.E. symptoms<sup>1b</sup> destroy quality of life

Quality, quantity (and pattern) of sleep is affected.

Blurred vision. Muscle pain.<sup>A</sup>  
‘Brain fog’. Headache.  
Sensitive to light/noise.  
Talking/word-finding difficulties.  
Standing & walking difficulties.

**Common neurological symptoms<sup>1c</sup>**

Reduced stamina.<sup>1d</sup>  
Usually very tired (or irritable<sup>3</sup>) after an activity.<sup>1e</sup>

**Always present**

Nausea, Dizziness.  
Sensitive to food/chemicals/smells.  
Sweating, too hot, too cold.  
Stomach pain. Swollen glands.  
Keeps on being ill with viruses.<sup>1f</sup>

Very pale skin.<sup>4a</sup>  
Cold, painful, tingling hands, wrists, feet & lower legs.<sup>1g</sup>

**Other symptoms may be present**

**Children/adults with severe M.E. may be housebound/bedbound for years.<sup>1h</sup>**  
They [and their often exhausted carer family/friends] *“are isolated, ignored and invisible”<sup>5a</sup>*

M.E. affects all ages. Usually adults become ill at age 30-50 years & young people at 12+ years<sup>1j</sup> even 2-year-olds can have M.E.<sup>4b</sup>

**Diagnosis** may take years.<sup>6</sup>  
Have periods of “remission & relapse”<sup>5b</sup>  
**Relapse** if do too much physically/mentally.<sup>4c</sup> Fatigue after activity can be delayed by up to 4 days.<sup>1i</sup>  
**Remissions** can last months/years (children are more likely than adults to have them<sup>1k</sup>).

**Diagnosis, Remission & Relapse**

A ‘partial recovery’ is common. A ‘full recovery’ after M.E. is present for more than 5 years is rare<sup>5c</sup> (but such a recovery usually means you are still unable to do as much as you did before you became ill.<sup>1l</sup>)

**Long-term effect<sup>5d</sup>**

**Pacing** (activity followed by resting/sleeping in armchair/bed) is vital. **Mild/Moderate M.E. patients** need days off to rest.<sup>7</sup> **M.E. may be Severe** at start or early mismanagement can cause Severe M.E.<sup>8</sup>. *“Early recognition with positive diagnosis is key to improving outcomes.”<sup>5e</sup>*

All Somerset GP practices are likely to have several patients who have M.E.<sup>9</sup>

**Management**

**The UK government<sup>10</sup> and the Department of Works & Pensions<sup>11</sup> accept that M.E. is a physical illness.**  
The World Health Organisation classifies M.E. as a neurological condition.<sup>12</sup>  
Neurological conditions occur due to illness or injury damaging the brain, spinal column or nerves.<sup>13</sup>

**References:**<sup>1a-1l</sup> for symptoms and what different terms mean (e.g. CFS, ME/CFS, CFS/ME) see [http://www.investinme.org/Documents/Guidelines/Myalgic Encephalomyelitis International Consensus Primer -2012-11-26.pdf](http://www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20International%20Consensus%20Primer%20-2012-11-26.pdf) (also see [http://www.nightingale.ca/documents/Nightingale\\_ME\\_Definition\\_en.pdf](http://www.nightingale.ca/documents/Nightingale_ME_Definition_en.pdf)); <sup>2</sup>Dr Clare Gerada, see <http://www.investinme.org/IIME%20Conference%202013/IIMEC8%20Conference%20Report.htm>; <sup>3</sup>In very young children irritability may be more noticeable than fatigue see <http://www.iacfsme.org/portals/0/pdf/pediatriccasedefinitionshort.pdf>; <sup>4a,4b</sup>Dr Nigel Speight—ME Handout Myalgic Encephalomyelitis (ME) in Childhood’ available at <http://voicesfromtheshadowsfilm.co.uk/nigel-speight-me-handout/>; <sup>5a-5e</sup>‘A report of the CFS/ME Working Group’ (to the Chief Medical Officer) [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4064945.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4064945.pdf); <sup>6</sup><http://www.meassociation.org.uk/wp-content/uploads/2010/09/2010-survey-report-lo-res10.pdf>; <sup>7</sup><http://www.nhs.uk/conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx>; <sup>8</sup>‘Risk factors for severe ME/CFS’ by Pheby D. & Saffron L. see [http://biomedonline.com/Articles/vol1\\_4\\_50-74.pdf](http://biomedonline.com/Articles/vol1_4_50-74.pdf); <sup>9</sup>based on data at <http://www.meassociation.org.uk/about/what-is-mecfs/> and [http://www.investinme.org/Article 651 — ICC for ME— Bruce Carruthers.htm](http://www.investinme.org/Article%20651%20-%20ICC%20for%20ME%20-%20Bruce%20Carruthers.htm) and <http://www.nice.org.uk/nicemedia/live/11824/6193/36193.pdf> and <http://fingertips.phe.org.uk/profile/general-practice/data>; <sup>10</sup>[http://www.erythos.com/gibsonenquiry/Docs/ME\\_Inquiry\\_Report.pdf](http://www.erythos.com/gibsonenquiry/Docs/ME_Inquiry_Report.pdf); <sup>11</sup>‘The DWP accepts the World Health Organisation classification of M.E.’ see <http://www.meassociation.org.uk/2011/11/cfsme-not-a-mental-health-disorder-minister-for-welfare-reform-tells-countess-of-mar-21-november-2011/>; <sup>12</sup><http://www.mereseach.org.uk/what-is-me/>; <sup>13</sup><http://www.neural.org.uk/living-with-a-neurological-condition/what-is-a-neurological-condition/>; <sup>A</sup> often linked to the presence of **Fibromyalgia** which is a condition that can often be seen alongside M.E. see [http://sacfs.asn.au/download/consensus\\_overview\\_fms.pdf](http://sacfs.asn.au/download/consensus_overview_fms.pdf)

Poster sponsored by **Blue Moon Care Ltd** (a CQC registered micro-care agency created, and run, by carers and clients). All references mentioned above are on our website.

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