

Do you know someone who has M.E.?

M.E. (Myalgic Encephalomyelitis/Encephalopathy) is a serious disabling chronic neurological illness.^{1a}

M.E. Uncut

Creating a better understanding of M.E. in Somerset



“Very few GPs fully understand the illness.”²

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

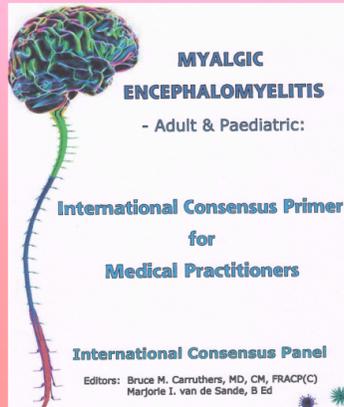
During ‘Somerset M.E. Awareness Year’ (May 2014-Apr 2015) **M.E. Uncut** will provide:

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

M.E. symptoms^{1b} destroy quality of life

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

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

Common neurological symptoms^{1c}

Reduced stamina.^{1d}
Usually very tired (or irritable³) after an activity.^{1e}

Always present

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

Very pale skin.^{4a}
Cold, painful, tingling hands, wrists, feet & lower legs.^{1g}

Other symptoms may be present

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

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

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

Diagnosis, Remission & Relapse

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

Long-term effect^{5d}

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

All Somerset GP practices are likely to have several patients who have M.E.⁹

Management

The UK government¹⁰ and the Department of Works & Pensions¹¹ accept that M.E. is a physical illness.
The World Health Organisation classifies M.E. as a neurological condition.¹²
Neurological conditions occur due to illness or injury damaging the brain, spinal column or nerves.¹³

References:^{1a-11} 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); ²Dr Clare Gerada, see <http://www.investinme.org/IIME%20Conference%202013/IIMEC8%20Conference%20Report.htm>; ³In very young children irritability may be more noticeable than fatigue see <http://www.iacfsme.org/portals/0/pdf/pediatriccasedefinitionshort.pdf>; ^{4a,4b} *Dr Nigel Speight—ME Handout Myalgic Encephalomyelitis (ME) in Childhood* available at <http://voicesfromtheshadowsfilm.co.uk/nigel-speight-me-handout/>; ^{5a-5e} *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; ⁶<http://www.meassociation.org.uk/wp-content/uploads/2010/09/2010-survey-report-lo-res10.pdf>; ⁷<http://www.nhs.uk/conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx>; ⁸ *Risk factors for severe ME/CFS* by Pheby D. & Saffron L. see http://biomedonline.com/Articles/vol1_4_50-74.pdf; ⁹based 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 *Nice Clinical Guideline 53* page 4 (<http://www.nice.org.uk/nicemedia/live/11824/6193/36193.pdf>) and <http://fingertips.phe.org.uk/profile/general-practice/data>; ¹⁰ http://www.erythos.com/gibsonenquiry/Docs/ME_Inquiry_Report.pdf; ¹¹ *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/>; ¹²<http://www.mereseearch.org.uk/what-is-me/>; ¹³<http://www.neural.org.uk/living-with-a-neurological-condition/what-is-a-neurological-condition/>; ^A 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

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.

This poster (and other M.E. awareness posters) can be downloaded from our website. Please ensure permission has been granted to display the poster. © Blue Moon Care Ltd (May 2014)

