

Supporting your constituent with M.E.

The All Party Parliamentary Group (APPG) on M.E. has produced this information resource to support MPs in assisting their constituents with Myalgic Encephalomyelitis (M.E.).

To contact the Joint Secretariat for the APPG, provided by Action for M.E. and the ME Association, please email policy@actionforme.org.uk or call the Action for M.E. Communications and Policy Team on 0117 937 6622.

What is M.E.?

Myalgic Encephalomyelitis (M.E.) is a disabling, neurological condition that affects an estimated 250,000 men, women and children in the UK, and around 17 million people worldwide.

The National Institute for Health and Care Excellence (NICE) states that the physical symptoms of M.E. can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions.

The NICE guideline for M.E. outlines three levels of severity – mild, moderate and severe – as follows.

- People with mild M.E. are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week.
- People with moderate M.E. have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for one or two hours. Their sleep at night is generally poor quality and disturbed.
- People with severe M.E. are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house, or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise.

Some criteria include a fourth level of very severe, ie. severe symptoms on a continual basis; bedridden, unable to live independently and require full time support and supervision with all aspects of personal care.



**Produced by the All Party Parliamentary Group on M.E.
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Key facts about M.E.

People with M.E. experience severe, persistent, activity-induced fatigue associated with post-exertional malaise (the body's inability to recover after expending even small amounts of energy; sometimes also called 'payback') and chronic pain.

Everyone who experiences M.E. has a different pattern of illness, and symptoms and severity can fluctuate and change over time. Common symptoms include:

- chronic pain
- sleep disturbance
- cognitive difficulties
- digestive problems
- sensitivity to light and sound
- inflammation
- autonomic dysfunction
- cardiac and circulation problems
- endocrine dysregulation.

Within the NHS M.E. is commonly called Chronic Fatigue Syndrome (CFS or CFS/M.E.). Sometimes it is known as Myalgic Encephalopathy or diagnosed in the early stages as Post Viral Fatigue Syndrome (PVFS). In February 2015, the Institute of Medicine in the United States recommended changing the name to Systemic Exertion Intolerance Disease, or SEID. This has not been universally adopted.

The causes of M.E. are still being investigated and mainstream research investment is urgently needed. Emerging evidence indicates that there are likely to be a number of factors involved and that there may be a number of different types or sub-groups of the illness. Potential biomarkers – a characteristic by which a particular biological process or disease can be identified – are still being investigated.

There is currently no specific test that can detect M.E. but a positive clinical diagnosis can be made based on a well-characterised constellation of symptoms. The earlier M.E. is recognised, the sooner symptom management and support can begin.

M.E. is defined as a disability under the Equality Act 2010 which refers to the “effect that an impairment has on that person’s ability to carry out normal day-to-day activities.”

M.E. can devastate the lives of children and young people. It is the main cause of long-term school absence (*Dowsett and Colby, 1997*), impacting on a minimum 25,000 children in the UK.

The economic impact of M.E. on the UK has been estimated at £6.4 billion each year (*Bibby and Kershaw, 2006*), with annual lost earnings of £102 million (*Collin et al, 2011*).



The impact of M.E.

Sam, who was diagnosed with M.E. in 2002 after being ill for five years, says:

“M.E. feels like having glandular fever, taking your glandular fever on an all-night drinking binge, then taking your glandular fever and your hangover and doing a 30km forced march over the Brecon Beacons. The way you would feel at the end of that is how it feels to have M.E. every day. It is like being on a carousel: you have ups and downs but you can never get off.”

Around 25% of people with M.E. are severely affected by the condition at some stage. They are left house or bed bound, unable to properly care for themselves or wash properly, sometimes for many years at a time.

People with M.E. can vary enormously in their experience of the illness, and also how long their symptoms last. Some make good progress, while others can remain ill for a number of years.

Some people find that they don't go back completely to the way they felt before they became ill, but they do improve sufficiently to lead happy and fulfilling lives. This is similar to many other chronic illnesses.

Even in its mildest form, M.E. can have a significant impact on an individual's life, and not just on their health. Many face isolation as friends and family struggle to understand the true impact of M.E. A lack of understanding and awareness about M.E. means patients can experience disbelief, and discrimination, from friends, family, health and social care professionals, policy-makers, welfare benefit providers and employers.

People with M.E. report finding claiming the welfare benefits they are entitled to very stressful, with frequent stories of lost or delayed applications, and assessors making uninformed assumptions about claimants' capabilities. The process itself is unsuitable for people with fluctuating conditions such as M.E.

Recovery rates for M.E. are not clear. Research (*Adamowicz et al, 2014*) has estimated recovery as ranging between 0 and 66%, but nearly every one of the 22 studies reviewed in this research had a different definition of recovery.

More information and signposting

M.E. charities in the UK can offer information, advice, support and signposting for people affected by M.E., and those professionals that support them.

The charity members of the All Party Parliamentary Group on M.E. are listed on the following pages. Each has highlighted up to three key resources from those that they produce; please contact each charity to find out more.





The 25% M.E. Group is a unique nationwide community based voluntary group. It has two paid members of staff and a number of volunteers - most of whom have M.E. We provide a range of services to people affected by severe M.E. including an advocacy service, a listening ear service which provides emotional and practical support to the membership. We seek to alleviate the isolation which this illness can cause by encouraging communication between members and participation within the group as well as assistance with articles and information for the newsletter.

Key resources include:

- *Pink leaflet*, a comprehensive but brief leaflet about the charity
- *Home care briefing* (August 2015) for commissioners and providers of social care
- *Home care key messages* (April 2016) for home care workers and carers

The 25% M.E. Group
21 Church Street, Troon KA10 6HT
Tel: 01292 318611
Email: enquiry@25megroup.org
www.25megroup.org



Action for M.E. takes action to end the ignorance, injustice and neglect experienced by people with M.E. We are passionate about collaborating with others to improve access to appropriate healthcare, social services and welfare benefits, and we drive and invest in much-needed research. Through our Online M.E. Centre, publications, social media and Welfare Advice and Support Service, we provide key information to help those with M.E. and their families make informed choices about their care.

Key resources include:

- *Newly diagnosed with M.E.* booklet, endorsed by the National Institute for Health and Care Excellence
- *Nothing about M.E. without me* self-advocacy toolkit for people affected by M.E.
- an online services directory listing local M.E. support groups and specialist health services, searchable by postcode.

Action for M.E.
42 Temple Street, Kenysham BS31 1EH
General enquiries: 0117 927 9551 and
admin@actionforme.org.uk
Welfare Advice and Support Service:
0800 138 6544 and
welfare@actionforme.org.uk
www.actionforme.org.uk
www.facebook.com/actionforme
www.twitter.com/actionforme



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The Association for Young People with M.E. (AYME) is the leading UK charity that cares for, connects with and campaigns on behalf of all children and young people affected by M.E./CFS. The charity ensures its members and their families are equipped with the information required to access the health, education and social care support they need. The children are at the centre of the charity and are involved in running all of the contact services.

AYME supports paediatric research facilitating user representatives and ensuring members' voices are heard at every level. The charity works closely with NHS Specialist services, and the Departments of Education and Health on behalf of its members.

Services offered by AYME include:

- information and support line, open Mon-Fri 10am -2pm.
Tel: 0330 2211223
- secure and moderated online forums for members and parents/carers
- specialist literature providing information on M.E./CFS and ways of coping

AYME, Tickford House, Silver Street,
Newport Pagnell MK160EX
www.ayme.org.uk
www.facebook.com/AYME.UK
www.twitter.com/AYME_UK



BRAME (Blue Ribbon for the Awareness of Myalgic Encephalomyelitis) works to create greater awareness and understanding that ME and CFS are very real, complex, and debilitating neurological illnesses, and the consequences of living with ME or CFS for the sufferer, carer, and whole family unit.

BRAME works with CCGs, Government (actively being involved in DoH and DWP reforms), and related organisations. The BRAME campaign became international, and BRAME's 1998 event in Parliament resulted in the APPG on M.E. reformation, and the setting up of the CMO Report Group – our Chairperson was patient representative on this, and the NICE guideline.

Resources include:

- information and symptoms of ME leaflet
- BRAME guide to diagnosing, managing and caring for people who are severely/very severely affected by ME
- Support and understanding for those affected by ME or CFS

BRAME, 30 Winmer Avenue,
Winterton-on-Sea, Norfolk NR29 4BA
Tel: 07401 630164
Email: info@brame.org
www.brame.org





Invest in ME (charity no. 1114035) transitioning to Invest in ME Research (Charity no. 1153730) facilitates/funds biomedical research into ME, provides educational material, raises awareness, organises educational events, international CPD-accredited conferences and research colloquiums and supports individuals with ME in need. A sister organisation 'Let's Do it for ME' was formed by three bed/housebound patients in 2011 to support the charity in its strategy for research. Invest in ME are a founder member of the European ME Alliance (EMEA) and initiated the formation of European ME Research Group (EMERG) in 2015.

Key resources include:

- educational DVDs from annual international conferences/colloquiums
- diagnostic guideline booklets (the Canadian Consensus Criteria and the International Consensus Criteria)
- brochures that outline the charity's 'Centre of Excellence for ME in Norwich Research Park' project

Invest in ME (Research)
 PO Box 561, Eastleigh SO50 0GQ
 General enquiries 02380 643736 or 07759 349743; info@investinme.org
 www.investinme.org and
 www.investinme.eu
 www.facebook.com/linME
 www.twitter.com/Invest_in_ME
 www.ldifme.org



The ME Association, Britain's oldest M.E. charity, is currently recruiting more members than ever. We provide information and support, education and training, a helpline that's open every day of the year and consistent critical analysis of major policy initiatives that affect people with M.E./CFS.

Key resources include:

- *ME/CFS/PVFS: an exploration of the key clinical issue*, clinical and research guidance, backed up by resources to help GPs make an early and accurate diagnosis.
- *No decisions about me without me*, our 2015 report on CBT, GET and pacing that shows which approach works best for people with the illness.
- The MEA Ramsay Research Fund which funds key biomedical research into ME/CFS.

The ME Association
 7 Apollo Office Court, Radclive Road,
 Gawcott MK18 4DF
 General enquiries: 01280 818 968
 and admin@meassociation.org.uk
 ME Connect helpline (open daily
 10am-noon, 2-4pm and 7-9pm):
 0844 576 5326
 and meconnect@meassociation.org.uk
 www.meassociation.org.uk



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ME Research UK commissions and funds biomedical investigations into the causes, consequences and treatment of M.E.. Since 2000, the charity has funded more specific research projects than any other organisation in the world outside of North America (£1.3 million for 41 distinct scientific studies in universities in the UK and overseas).

ME Research UK also has a mission to “energise M.E. Research” by raising awareness, providing high quality information, and informing the policy agenda. Our biannual *Breakthrough* magazine contains information on scientific research across the world, and is sent free to patients and their families, clinics, academics and research groups.

ME Research UK
The Gateway, North Methven Street,
Perth PH1 5PP
Tel: 01738 451234
www.mereseearch.org.uk
www.mereseearch.org.uk/our-research
www.facebook.com/MEReseearchUK



PROVIDING SUPPORT AND CARE
TO PEOPLE WITH CFS/ME

The M.E. Trust is the UK’s only charity dedicated to funding and providing individualised patient treatment for people with M.E. /CFS. As well as listening, treating and caring for the needs of the whole person, we offer encouragement and support to families, carers and friends.

We help fund life transforming care [Kent University found ‘significant improvement in fatigue symptoms’], and we aim to create a Centre of Excellence, the first of its kind in the UK. Centre staff will have a deep understanding of the full spectrum of the illness and offer physical, emotional and spiritual care appropriate to individual need.

Our medical advisor trustee has more than 20 years’ experience of supporting people with the illness. The M.E. Trust aims to work with the NHS to ensure there are appropriate facilities for people with M.E./CFS, and with researchers to facilitate advances in treatment and care.

The M.E. Trust
16 Old Bailey, London EC4M 7EG
Email: info@metrust.org.uk
www.metrust.org.uk
www.facebook.com/themetrustuk



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reMEMber
The Chronic Fatigue Society

reMEMber gives information and support to those suffering from ME/CFS, particularly, but not exclusively, in Sussex - we have members all over the UK and beyond. Members meet for social contact and mutual support.

reMEMber campaigns locally and nationally for better services, and supports good biomedical research. We maintain strong links with the NHS and Healthcare Professionals.

Key resources include:

- self-management courses for ME/CFS patients
- ongoing self-management support
- one-to-one advice on accessing medical and other help.

reMEMber
PO Box 1647, Hassocks, West
Sussex, BN6 9GQ
Tel: 01273 831733
Email: me_cfs@hotmail.com
www.remembercfs.org.uk



The Young ME Sufferers Trust - Tymes Trust is the longest running support organisation for children and young people with M.E. It runs an Advice Line and Professionals Referral Service for families and professionals. In 2010 the Trust received the Queen's Award for Voluntary Service – the MBE for volunteer groups – for pursuing the educational rights of children with ME and advancing their care. 2014 marked our 25th Anniversary.

The Trust works with Nisai Learning which provides interactive virtual education for young people with M.E., funded by schools, Local Education Authorities and government agencies. The Tymes Trustcard is a pass card for children with M.E. when in school, launched by the then Education Minister Lord Adonis, endorsed by the Association of School and College Leaders and supported by Lord Clement-Jones CBE and Health Minister Earl Howe.

Tymes Trust
PO Box 4347, Stock
Ingatstone CM4 9TE
Tel: 0845 003 9002
www.tymestrust.org