



Managing ME-CFS

A guide for GPs in Scotland



Introduction

This Action for M.E. booklet is intended to support GPs in the treatment and management of ME-CFS.

It includes key knowledge about the condition, making reference to the *Scottish good practice statement on ME-CFS* (SGPS) for GPs¹ throughout. Produced in 2010, the SGPS, formally endorsed by the Royal College of General Practitioners (Scotland) and the Scottish Neurosciences Council, provides GPs with guidance on the differential diagnosis and clinical management of patients with ME-CFS.

You can read and/or download the SGPS, plus accompanying quick reference clinical guide and summary patient guide (*What someone should know if they or their doctor think they might have ME-CFS*) at www.show.scot.nhs.uk

In addition, we signpost you to sources of professional support and guidance that we hope will enable you to contribute to better outcomes for your ME-CFS patients.

The need for targeted support for GPs is clear: in early 2014, we asked 50 GPs in Dumfries and Galloway, Fife and Highland about their educational needs around ME-CFS.

A large majority (82%) said they had not undertaken any training on ME-CFS, while nearly two thirds (66%) told us they were not aware of the SGPS.

In addition, we undertook a major health and welfare survey² with 2,018 patients with ME-CFS in the UK; nearly 200 of these respondents live in Scotland. Of these, 74% said that having a better informed GP would make a real difference to their healthcare.

Our aim is that this booklet, plus its accompanying webinar series (see p 17), will help facilitate this.

We are enormously grateful to the Scottish Government for supporting our Inform M.E. project, which includes the production of this booklet and accompanying webinar series. Thanks also to our Scottish ME-CFS Collaborative partners, particularly Dr Gregor Purdie, specialist ME-CFS nurse Keith Anderson, and GPs Kate Down and Morag Calder.

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What is ME-CFS?

“ME-CFS is an illness characterised by persistent and fluctuating symptoms of fatigue, pain and loss of endurance to normal activities associated with conspicuous deterioration after exercise. It has been referred to as M.E. (Myalgic Encephalomyelitis/Encephalitis/Encephalopathy), CFS (Chronic Fatigue Syndrome) and sometimes as PVFS (Post Viral Fatigue Syndrome).” (SGPS, p 3)

ME-CFS, as we will refer to it throughout this booklet, affects an estimated 20,000 people in Scotland. Around 25% of those have severe ME-CFS, making them housebound or bedbound. There are a wide range of symptoms (see p 5) that affect many body systems, typically the nervous and immune systems.

In Scotland, there are approximately 2,000 newly diagnosed cases of ME-CFS per year. There is evidence³ that early diagnosis may aid recovery though this is not necessarily the case for those with severe ME-CFS (see p 15).

There is much debate about the underlying cause of ME-CFS, and what treatments do or do not work; there is currently no drug therapy directed specifically at the condition. Current theories about the cause of ME-CFS include autoimmune deficiencies, viral infections, autonomic/sympathetic/central nervous system dysfunction and genetic factors, amongst others.

Crucially, the NICE guideline³ recognises that ME-CFS:

- is a relatively common condition with complex symptoms
- is associated with altered neural functioning
- causes significant and, in some cases, profound disability.

As such, it places a substantial burden on people with the illness, their families and carers and on society.

Patients frequently tell us that they want general practitioners to be prepared to talk openly about what currently is and isn't known about ME-CFS. After years of little progress, this knowledge base is growing all the time.

Action for M.E. has co-funded the UK's first biobank for ME-CFS, an essential piece of research infrastructure. We also invest in small-scale pilot studies with a view to enabling medical scientists to develop competitive proposals for funding large scale projects through mainstream investment.

This is part of a sea change in ME-CFS, and developments within research and medicine are opening up significant opportunities in ways that have not been possible before now. We expect our biomedical knowledge of ME-CFS to grow substantially over next few years.

Symptoms

Symptoms of ME-CFS fluctuate in nature and severity over time, and are provoked by physical or mental exertion.

A key feature of ME-CFS is post-exertional malaise (sometimes referred to as a 'crash'), whereby mental or physical activity brings about an increase in symptoms anywhere between 24 and 72 hours later. Research⁴ conducted with women with ME-CFS shows that their responses to exercise are "distinctively different from those of sedentary controls."

Along with post-exertional malaise, symptoms may include:

- persistent or recurrent fatigue
- myalgic and/or joint pain (in the absence of joint swelling or redness); can be widespread and migratory. The Scottish Intercollegiate Guidelines Network guideline on managing chronic pain⁵ may be useful here.
- sleep disturbance: some patients primarily have insomnia, others severely disrupted slow wave sleep. A referral to a sleep specialist, especially where sleep apnoea is suspected, may be useful.
- flu-like symptoms
- cognitive symptoms (difficulties with memory, concentration and information processing, often collectively referred to as 'brain fog')
- digestive and gastro-intestinal symptoms; reported food intolerances are common
- postural light headedness or dizziness: an increase in heart rate on standing of 30+ bpm or a standing heart rate of 120+ bpm suggests postural orthostatic tachycardia syndrome (POTS)⁶ which should receive specialist attention.

It is important to remember that "although fatigue and post-exertional malaise are universal symptoms of ME-CFS, they may not be the most severe symptoms in the individual case, where headaches, neurocognitive difficulties, pain and sleep disturbances can dominate, at least temporarily."⁷

Action for M.E.'s 2014 health and welfare survey² of 2,018 patients asked what their most frequent symptom was at time of responding. Commonly mentioned symptoms included:

- all over aches
- back pain
- balance problems
- cognitive problems
- difficulty walking
- dizziness
- fatigue/brain fog after activity
- inability to control temperature
- insomnia
- irritable bladder
- migraines
- muscle weakness
- nausea
- palpitations
- photophobia
- sleep reversal
- vertigo.

Vitamin D deficiency, which may develop over time, is also common.

Examination and investigation

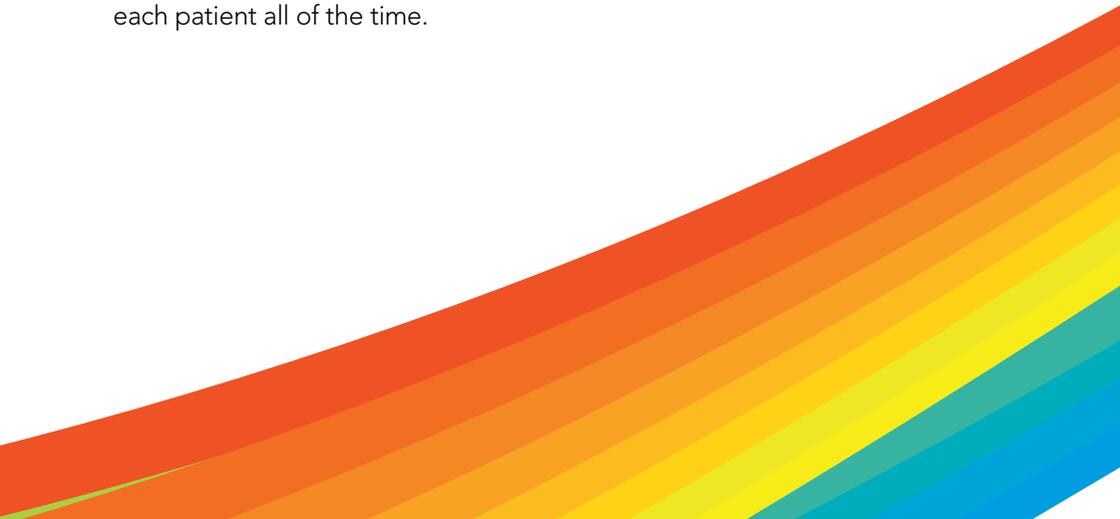
The SGPS states that the “The Scottish Public Health Care Network’s Health Care Needs Assessment of Services for people living with ME-CFS, has recommended the *pragmatic use* of the Canadian Consensus Document (2003) for the clinical, symptomatic definition of ME-CFS” with the provision “that neurological examination *must be done routinely in the differential diagnosis of ME-CFS*, to exclude specific neurological abnormalities such as: obvious muscle wasting, ptosis, upper motor neurone signs, ataxia, fasciculations, absent reflexes. If any of these abnormalities are present, neurological specialist referral is recommended for further investigation” (SGPS, p 33)

There is growing evidence⁸ from experts in the field of ME-CFS that a number of sub-groups exist within ME-CFS. Individuals in these sub-groups – which still need more research to be identified – differ in terms of their illness experience and the course their illness follows.

For example, a University of Utah project⁹ investigating gene expression in patients with ME-CFS concluded that “at least two subgroups of patients with CFS can be identified by gene expression changes following exercise.”

Even those mildly affected can find that symptoms have a substantial impact on their life. Significant numbers of patients who answered our survey² told us they had stopped or reduced social contact (91.75% of respondents), household tasks (88.60%), sports and hobbies (87.73%) and paid work (86.69%).

Initial presentation of ME-CFS may be sudden or gradual, and follow an infection, typically but not always viral. Not all symptoms may be present in each patient all of the time.



The SGPS recommends:

- making a formal positive diagnosis three-four months into the illness, based on symptom pattern (see below), and excluding other conditions as appropriate
- making a full physical examination
- making a full mental state examination to identify patients with reversible co-morbid disorders
- asking about recent travel, tick/insect bites, unusual infections and drug/alcohol use
- reviewing current medication
- ordering tests including full blood count, urea, electrolytes and creatinine, liver function thyroid function, glucose, erythrocyte sedimentation rate, C-reactive protein, calcium, creatine kinase, ferritin and urinalysis (see p 8-9 of the SGPS for a full list).

The SGPS offers a severity rating guide (Appendix 3) and a sleep and pain profile (Appendix 4) that may be of practical use.

GPs should reconsider diagnosis if any of the following 'red flag' symptoms or signs are present:

- substantive unexplained weight loss
- neurological signs
- symptoms or signs of inflammatory joint disease or connective tissue disease
- symptoms or signs of cardio-respiratory disease
- symptoms of sleep apnoea
- clinically significant lymphadenopathy.



Key things to consider

- ME-CFS patients have low stamina for activities. Do not assume that if a patient appears better (or worse) at a given moment that this indicates a change in their overall condition.
- Generally, ME-CFS patients will need to space out their activities, including medical appointments, to avoid exacerbating their symptoms and may find that their capacity is generally greater at a specific time of day.
- Treatment approaches should be regularly reviewed, including home visits for those who are too severely affected to attend surgery.
- ME-CFS patients often require longer appointment slots, or a series of appointments focusing on complex specific symptoms.
- Encourage patients to record symptoms in a diary, which may help to overcome barriers to effective communication during their appointment.
- Do not assume that dizziness, palpitations, chest pains or breathlessness are symptoms of anxiety. These are likely to be symptoms of autonomic dysfunction in at least a sub-set of ME-CFS patients.
- People with ME-CFS often take a range of supplements. It is recommended to ask about these causing side-effects or interacting with prescribed medication.
- Patients should not be encouraged to undertake any form of vigorous exercise. Any attempt to increase activity should be cautious and gradual. For some this will be limited to gentle stretches. Others who are more mobile may be able to undertake very gentle yoga, pilates or short walks.
- Rest and relaxation are important aspects of managing ME-CFS. Some patients may benefit from advice around taking full, lying-down rest breaks, breathing exercises or mindfulness practice.
- General advice for ME-CFS patients includes drinking plenty of water to avoid dehydration, eating regular, small and well-balanced meals, and keeping caffeine and alcohol intake to a minimum (many people with ME-CFS experience alcohol intolerance so will generally self-regulate).
- Driving some or all of the time may be hazardous for patients with a high degree of cognitive or visual (eg. focusing) impairment.
- Pregnancy, childbirth and parenthood are concerns for many women with ME-CFS and their partners. Search for 'Mums and dads' at www.actionforme.org.uk for anecdotal information and support.
- People with ME-CFS may be eligible for a number of benefits. Claimants are increasingly expected to obtain their own supporting medical evidence, which can make a crucial difference to the success of a claim or appeal.

Treatment and management

While there is currently no cure, nor any pharmaceutical intervention targeted particularly at ME-CFS, a number of approaches have been found to help. Some are more successful than others for each individual, so “care of patients with ME-CFS must be specifically and carefully tailored to the symptoms, needs and circumstances of the individual patient.” (SGPS, p 3) This is particularly true of those who are severely affected (see p 15).

The SGPS offers an overview of management approaches that may be helpful, with evidence of effectiveness, including:

- pharmacological pain relief; more than three quarters of patients who responded to Action for M.E.'s survey² said that medication to ease pain, sleep and/or mood helped a little or a lot with their symptoms
- energy management and pacing; see p 11
- physical rehabilitation therapies; see p 11
- counselling and cognitive behaviour therapy (CBT); see p 12
- complementary approaches
- diet and nutrition.

It is important to note that some ME-CFS patients have unusually low tolerance to medication so it needs to be started with low doses and carefully monitored.

The SGPS also offers specific guidance on managing symptoms of:

- sleep disturbance
- headaches
- abdominal problems
- balance problems.

A growing body of research⁸ points to ME-CFS being a heterogeneous illness, which may explain why patients respond so differently to individual treatments. There is a clear need for more research to help us better understand which phenotypes respond to which treatment approaches.

The SGPS presents a care pathway, guided by the key principles of working in partnership with the patient, and mutually agreeing all treatments.

Pacing

More than 84.65% of patients who took part in Action for M.E.'s 2014 survey² said that pacing – ie. managing physical, mental and emotional activity and rest – helped a little or a lot with when it came to managing symptoms.

A recent critical evaluation¹⁰ of pacing research found that it “offers practitioners an additional therapeutic option which is acceptable to the majority of patients and can reduce the severity of the exertion-related symptoms of ME-CFS.”

Pacing can also be a valuable self-management technique that is free and accessible to all, including the considerable number of people who do not have access to a specialist NHS service.

Action for M.E. produces a self-management booklet, *Pacing for people with M.E.*, which can be downloaded from www.actionforme.org.uk or ordered from the Action for M.E. office (see p 18 for contact details).

Physical rehabilitation therapies

Published the year after the SGPS, a large-scale randomised controlled trial (known as the PACE trial¹¹) showed that, when combined with specialist medical care, some people with mild/moderate* ME-CFS had, at 52 weeks, moderately improved after taking part in graded exercise therapy (GET) or CBT.

*People with ME-CFS who were house or bedbound, ie. the more severely affected, did not take part in this trial.

However, several large surveys of ME-CFS patients by Action for M.E. and other ME-CFS organisations show that many patients reported that GET and, to a lesser extent CBT, caused them harm. Clearly there's a discrepancy here which could be caused in part by the physical therapies referred to in previous surveys not being so clearly defined or professionally provided. It is also possible that therapies such as GET are only suitable for a specific sub-group of patients.

Feedback from patients includes being told to undertake activities that are inappropriate given their condition such as joining a gym or pushing themselves beyond their physical capabilities too hard or too soon. **Therapies for people with ME-CFS should only be applied by appropriately trained professionals who have experience in dealing with the illness.**¹²

Experienced therapists tell us that most people they see with ME-CFS are undertaking too much for their physical state and require support to draw back on activities and pace. Specialist ME-CFS clinics (see p 12) such as those in Lothian and Newcastle are now offering GET and CBT strongly underpinned by pacing support.

Their approach is to start patients on a very low, stable baseline of activity before cautiously introducing small increases in gentle movements and activities for those who wish. Although commonly called GET, this approach is more akin to graded activity management than to the rigid programmes to which ME-CFS patients have sometimes been exposed.

Specialists such as Dr Nancy Klimas are increasingly focusing on the exercise threshold at which people with ME-CFS energy producing metabolism switches from aerobic to anaerobic (where the body's demand for oxygen outstrips supply). This threshold can be extremely low for people with M.E. and research¹³ suggests that oxygen depletion and the build-up of lactic acid in muscles associated with frequent switching may be key elements of the PEM experienced by ME-CFS patients.

CBT

It's important to reassure patients that offering CBT does not imply that the underlying cause of the ME-CFS is psychological. The therapist delivering CBT must have an up-to-date understanding of ME-CFS and its impact on patients.

CBT can be particularly helpful for those who find it difficult to pace their mental and physical activity. It can also help them to find ways of coping with issues such as demoralisation, frustration, guilt, anxiety, panic and depression, and to feel more in control of the illness rather than controlled by it.

Referral for specialist treatment

At the time of writing, the following ME-CFS services exist in for patients in Scotland Please note that no services within Scotland currently provide a diagnostic or full specialist ME-CFS service.

NHS Lothian

Therapist led rehabilitation service at Astley Ainslie Hospital offers time-limited, flexible support to adults who are able to attend the clinic. Programmes include a combination of pacing, CBT and gentle GET/GAT with advice on topics such as sleep and managing stress.

Contact ME-CFS Service

Department of Clinical Psychology, Astley Ainslie Hospital, 133 Grange Loan, Edinburgh EH9 2HL. Tel: 0131 537 9139

NHS Fife

A specialist ME-CFS nurse runs a clinic and undertakes home visits for severely affected patients.

Contact Keith Anderson

Ladybank Clinic, Commercial Road, Ladybank KY15 7JS. Tel. 01337 830398

Email: keithanderson1@nhs.net

NHS Greater Glasgow and Clyde and NHS Highland

The Centre for Integrated Care in Glasgow offers some holistic self-management support. Referral to this type of service is not equally beneficial to all patients and should be considered on an individual basis.

Contact Centre for Integrated Care

Glasgow Homeopathic Hospital, 1053 Great Western Road, Glasgow G12 0XQ

Tel: 0141 211 1600

Specialist clinical referral

ME-CFS patients may be referred out-of-area to the North of Tyne CFS/ME Service, but this would need to be approved by your Health Board on an individual basis.

Contact Dr Gavin Spickett

Consultant Clinical Immunologist, Newcastle Hospitals NHS Trust,

Royal Victoria Infirmary, Queen Victoria Road, Newcastle upon Tyne NE1 4LP

Tel: 0191 282 5517. Email: gavin.spickett@nuth.nhs.uk

POTS referrals

It is important to note that POTS symptoms overlap substantially with ME-CFS symptoms. Treatment (to lower heart rate) can result in substantial improvements in capacity and quality of life for patients. Tilt table testing is available in Scotland, but you might consider referring to M.E. researcher and clinician Prof Newton for a more specialist approach. Again, this would need to be approved by your Health Board on an individual basis.

Contact Prof Julia Newton

Royal Victoria Infirmary, Queen Victoria Road, Newcastle upon Tyne NE1 4LP

Tel: 0191 282 4128. Email: (secretary) chanel.hains@nuth.nhs.uk

Other referrals

It may be appropriate to refer ME-CFS patients in your area to a diet specialist, specialist sleep support or chronic pain services.

ME-CFS research

There has been considerable under-investment in ME-CFS research by mainstream funders. This desperately needs to change and, over the past couple of years, we have seen momentum gaining. You can keep up to date with new research and emerging evidence about ME-CFS in several ways.

Conferences

Action for M.E. hosts an annual conference in November focusing on ME-CFS research, inviting patients, carers and professionals to hear and discuss the latest developments. For more information, contact Action for M.E. (see p 18).

The UK CFS/M.E. Research Collaborative (see below) and Invest in M.E. (www.investinme.org.uk) host annual conferences for professionals and patients.

Professional bodies

Established in 2013, the UK CFS/M.E. Research Collaborative promotes high-quality evidence-based and peer-reviewed research. Professional membership costs £20 per year; £15 for research students. For more information, visit www.actionforme.org.uk/cmrc

The British Association for CFS/M.E. is a multidisciplinary organisation which exists to promote and support the delivery of evidenced-based treatment for children, young people and adults with ME-CFS in the UK. Membership costs £15 per year. For more information, visit www.bacme.info

The International Association for CFS/M.E. publishes *Fatigue: Biomedicine, Health and Behaviour*, an interdisciplinary online journal which regularly features papers on ME-CFS. For more information, visit www.iacfsme.org

Online resources

Action for M.E.'s YouTube channel features presentations from our research conferences and events. Go to www.tinyurl.com/actionformeyoutube

Perth-based charity ME Research UK funds biomedical investigations into the causes, consequences and treatment of ME-CFS, and publishes useful summaries of up-to-date research. Visit www.meresearch.org.uk

Cort Johnson's Health Rising blog offers a review of key research developments in ME-CFS, with useful context and comment. Visit www.cortjohnson.org

Severe ME-CFS

You may see patients whose ME-CFS is severe, though because of the nature of their symptoms mean that they are far less likely to be able to travel to a surgery or health centre.

Research¹⁴ has found that risk factors for severe ME-CFS include family history (including a strong association with having a mother who has ME-CFS) and being female. Early intervention “appeared also to be a major determinant of severity, with all but one of the variables in the final logistic regression model pertaining to the management of the condition in its early stages.”

Unfortunately the evidence base for effective management of severe ME-CFS is almost non-existent. The SGPS¹ acknowledges this, while providing useful guidelines for the holistic care of patients with severe ME-CFS.

Responses from severely affected patients who took part in Action for M.E.'s 2014 survey² indicate that the following approaches were more helpful than others in helping them cope with symptoms:

- medication to ease pain, pain and/or mood
- pacing
- rest, including bed rest
- dietary changes
- vitamin/mineral supplements
- meditation/mindfulness.

Other useful resources

Acknowledging the “specific care needs” of people with severe ME-CFS, section five of the SGPS (the complete version, not the quick clinical reference guide) offers guidance on impact of symptoms and principles of care.

The NICE guideline³ includes information and guidance on severe ME-CFS, with a chapter highlighting “where there are additional needs or additional caution is required.”

Severe M.E./CFS: a guide to living by Emily Collingridge is designed to be a definitive reference tool for anyone affected by severe ME-CFS, personally or professionally. For more information, visit www.severeme.info

Children and young people

ME-CFS is a “relatively common and serious condition in children and young people, having a significant impact on their physical, emotional and cognitive well-being [...] Early diagnosis and appropriate multi-disciplinary intervention facilitate recovery.”¹⁵

However, research¹⁶ shows that that young patients can experience barriers in accessing care, including, according to their parents, “negative attitudes and beliefs towards the child’s condition when they consulted GPs, paediatricians and child psychiatrists.”

This can have a knock-on effect with their education, preventing families from getting the support they need. It’s imperative, therefore, that health professionals “establish a supportive and collaborative relationship with the person with CFS/M.E. and their carers. Engagement with the family is particularly important for children and young people.”³

In the absence of specific guidance for children and young people, the SGPS offers “summary, interim guidance only” which is nevertheless useful.

Other useful resources

The SGPS has specific guidance on children and young people: see section four of the full guide (not the quick clinical reference guide).

The NICE guideline³ refers throughout to diagnosing and managing ME-CFS in children. It states that a diagnosis should be made after symptoms have persisted for three months (four in an adult), and that prognosis in children and young people is more optimistic.

Action for M.E. and the Association of Young People with M.E. (www.ayme.org.uk) have produced a booklet, *Your child and M.E.*, which parents and carers may find useful. This can be downloaded from www.actionforme.org.uk or ordered from the Action for M.E. office (see p 18 for contact details).



Support for professionals

Action for M.E. webinars

Action for M.E. is hosting a series of webinars for GPs in Scotland in 2013-15, led by health professionals, covering aspects of diagnosing and managing ME-CFS, including severe ME-CFS. You can watch recordings of these at www.tinyurl.com/actionformeyoutube and/or register to take part in future webinars by contacting Action for M.E. (see p 18 for contact details).

Accessing other expertise

Albert is an online resource where GPs can develop their knowledge and expertise, including asking other GPs questions and sharing practice documents, policies, procedures and clinical protocols. It is facilitated by national GP federation Quality Practice. For more information, visit www.qualitypractice.co.uk

US website the ME-CFS Knowledge Centre offers a number of short films, made by expert health professionals such as Dr Nancy Klimas, covering topics including diagnosis, laboratory testing and sleep problems. For more information, visit www.cfsknowledgecenter.com/expert-assistance.php

Assessment of needs

The Health Care Needs Assessment of Services for People with ME-CFS (2010) "describes the views of key stakeholders on what can be done to meet needs," based on evidence from researchers, clinicians and patient groups. You can read and/or download it at www.scotphn.net



Useful contacts

Action for M.E.

For information, support and publications
call 0845 123 2380 (Monday to Friday 9am to 5pm)
write to Action for M.E., 272 Bath Street, Glasgow G2 4JR
email admin@actionforme.org.uk
or visit the Online M.E. Centre at www.actionforme.org.uk

For the Welfare Advice and Support Service
call 0845 122 8648 (Monday, Tuesday and Thursday 10am to 12.30pm
and 2pm to 4pm, Wednesday 2pm to 4pm)
or send an online enquiry via www.actionforme.org.uk/get-help/welfare-rights

Neurological Alliance of Scotland

Aims to work closely with healthcare professionals and others to improve care of people affected by neurological conditions; offers support for management of long-term conditions, including ME-CFS.

Mansfield Traquair Centre, 15 Mansfield Place, Edinburgh EH3 6BB
Email: info@scottishneurological.org.uk
www.scottishneurological.org.uk

Carers Scotland

Offers information and local support services for carers.

The Cottage, 21 Pearce Street, Glasgow G51 3UT
Advice line: 0808 808 7777
www.carersuk.org/scotland

Scottish Independent Advocacy Alliance

Signposts to local services that can help individuals or groups access the services they need.

London House, 20-22 East London Street, Edinburgh EH7 4BQ
Tel: 0131 556 6443
www.siaa.org.uk

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To download and/or print copies of this booklet free of charge, go to www.actionforme.org.uk/gpbookletscotland



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