Newly diagnosed with M.E./CFS

Information and advice for you and your GP
Newly diagnosed with M.E./CFS

This information booklet supports some of the recommendations relating to diagnosis, shared decision making and general management in the NICE guideline on chronic fatigue syndrome/myalgic encephalomyelitis.

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What is this booklet for?

Healthcare professionals and people with M.E. alike tell us they would like more information and support about the diagnosis, symptoms and management of M.E.

This resource is intended to do just that. We hope that patients will share it with GPs, and that GPs will share it with colleagues.

We know that guidelines already exist that offer healthcare professionals information and advice about managing M.E., including the National Institute for Health and Care Excellence (NICE) guideline for M.E./CFS\(^1\) and the Scottish good practice statement on M.E./CFS\(^2\) (SGPS).

But we also know that, though useful, there is other information that GPs might helpfully consider.

The first part of this booklet offers key information about M.E., including guidance to help you be an active partner in your own care.

The second part suggests some key questions for you to ask your GP and offers information about existing guidelines. We know that it is unrealistic to expect every GP to be an expert in M.E./CFS; we also know that, according to Aviva’s 2013 Health of the Nation Index, 25% of GPs noted an increase in M.E. patient numbers over the past year, while 39% found M.E. to be the most challenging condition for referral. Action for M.E.’s 2014 survey of GPs in Scotland found that 82% had not undertaken any training on M.E./CFS, while nearly two thirds (66%) told us they were not aware of the Scottish good practice statement.

By offering evidence-based information and support, we hope to improve patient care for all those affected by M.E. in the UK.
What is M.E.?

Myalgic Encephalomyelitis (M.E.) is an illness with many names. Within the NHS it is commonly called Chronic Fatigue Syndrome (CFS or CFS/M.E.). Sometimes it is known as Myalgic Encephalopathy or diagnosed as Post Viral Fatigue Syndrome (PVFS). It’s possible that a number of sub-sets exist with M.E/CFS – see p 8. This can add to confusion for newly diagnosed patients and GPs.

M.E. is a long-term (chronic) fluctuating illness that causes symptoms affecting many body systems, more commonly the nervous and immune systems.

Many people with M.E. experience persistent pain or fatigue most of the time. This feels very different from ordinary tiredness.

Simple physical or mental activities, or combinations of activities, can leave you feeling shattered or struggling to function. You can also experience an increase in other symptoms.

You may feel the impact straightaway but it can typically take anything from several hours to two days to kick in. This is a key feature of the way M.E. affects people, and is known as post-exertional malaise or ‘pay back.’

Research\(^3\) has found that early management of symptoms such as post-exertional malaise is the most important factor in how the condition progresses (ie. how severe M.E. becomes). So it’s really important to learn as much as you can about how the symptoms affect you, and what you can do to help manage them.

The NICE guideline\(^1\) for M.E. says: “People with CFS/ME have reported pacing to be helpful in self-managing CFS/ME. However, healthcare professionals should advise people with CFS/ME that, at present, there is insufficient research evidence on the benefits or harm of pacing.”

However, people with M.E. tell us and other patient charities that they find pacing helpful. Action for M.E. can offer information and resources about this – see p 15.
Symptoms

M.E. is characterised by a range of symptoms. Don’t be alarmed by the long list of symptoms given here; you may only experience a few of them, and not all at the same time. Always get new symptoms checked by your doctor, as they may not be related to M.E. These can include:

Post-exertional malaise

- a key feature of the way M.E. affects people, this is the body’s inability to recover after expending even small amounts of energy; it’s sometimes also called ‘payback’ (see p 5).

Pain and/or fatigue

- many people with M.E. experience persistent pain or fatigue most of the time which feels very different from ordinary tiredness (see p 5)
- aching muscles or joints
- nerve pains or pins and needles
- headache or migraine
- twitching muscles or cramps
- abdominal pain (stomach or bowel problems)
- chest pain
- back pain

If pain, especially muscle pain, is more of a problem than fatigue, then you may have fibromyalgia in addition, or as an alternative diagnosis, to M.E.

Feeling generally unwell

- having flu-like symptoms (often called ‘general malaise’ by doctors)
- recurrent sore throat, with or without swollen glands

Sleep disturbance

- unrefreshing sleep
- difficulty getting off to sleep
- waking for long periods in the early hours
- light, dreamy, restless sleep
- sleep reversal (for example sleeping from 4am till midday)
- hypersomnia (sleeping for a long time)
Problems with concentration, thinking and memory (‘brain fog’)

- reduced attention span
- memory problems
- word-finding difficulties
- inability to plan or organise thoughts and/or speech
- loss of concentration

Problems with the nervous system

- poor temperature control
- dizziness on standing or sitting up
- hyper-sensitivity to light and sound
- sweating
- loss of balance
- poor circulation

Digestive problems (which can also be Irritable Bowel Syndrome)

- nausea
- loss of appetite
- indigestion
- excessive wind/bloating
- cramps
- alternating diarrhoea and constipation

Intolerance and increased sensitivity, eg:

- bright lights, sounds and smells
- some foods (for example dairy or wheat)
- some medications
- alcohol.
What do we know?

M.E. affects an estimated 250,000 people in the UK. There is much debate about its underlying cause, treatments and what does/doesn’t work and there is currently no drug therapy directed specifically at M.E. Current theories about the cause of M.E. include autoimmune deficiencies, viral infections, autonomic/sympathetic/central nervous system dysfunction and genetic factors, amongst others.

M.E. is a physical illness of uncertain duration that is defined by the World Health Organisation (G93.3) as neurological. There are a wide range of symptoms (see page 6) that affect many body systems, typically the nervous and immune systems.

Within the NHS, a diagnosis of Chronic Fatigue Syndrome (CFS) or CFS/M.E. is often given. M.E. is sometimes also diagnosed as Post-Viral Fatigue Syndrome (PVFS). This can make it confusing for many. Action for M.E. uses the terms M.E., CFS and M.E./CFS because we do not wish to withhold support from those who have been given a diagnosis of CFS, as opposed to M.E.

Impact of symptoms

Within this characteristic range of symptoms there is a wide spectrum of severity, from mild to moderate to severe and very severe (International Consensus Panel, 2012). Everyone who experiences M.E. has a different pattern of illness. Symptoms fluctuate and change over time.

Even in its mildest form, M.E. can have a significant impact on an individual’s life, and not just on their health. A lack of understanding and awareness about M.E. means patients can experience disbelief, and even discrimination, from friends, family, health and social care professionals and employers.

Sub-groups

Experts increasingly think that a number of sub-groups exist within M.E., on the basis that individuals within these sub-groups differ in terms of their illness experience and the course their illness follows over time.

The likelihood of multiple sub-groups within M.E. may explain the huge variation observed by doctors in the progression of the illness and underlines the difficulty of making a prognosis.
The experience of doctors specialising in M.E. is that some people recover completely (the rate is higher for young people), some report improvement over time, and some do not improve or report a decline in their health. Some people also experience a slow onset form of M.E. which develops progressively. Identification of sub-groups will, it is hoped, help doctors to personalise treatments and improve outcomes for people with M.E.

Some people do remain ill for many years, even decades. A proportion, estimated at 20-25%, of people remain severely ill and as a result can be housebound or bedbound for lengthy periods. In some cases, even those whose lives have been seriously restricted by M.E. for a long time can experience some form of improvement.

Diagnosis

As there is no specific single test to detect M.E./CFS, diagnosis is made after other possible known causes for symptoms have been excluded. This should be a positive clinical diagnosis made on a well-characterised constellation of symptoms.

You may need to make several visits to your doctor before a final diagnosis is made. The NICE guideline¹ says: “A diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for:

- 4 months in an adult
- 3 months in a child or young person; the diagnosis should be made or confirmed by a paediatrician.”

The SGPS² says: “The aim should be to make a diagnosis three to four months into the illness.” Further guidance for GPs in Scotland (building on the SGPS²) is provided in Action for M.E.’s booklet, Managing ME-CFS: a guide for GPs in Scotland.

In addition to the diagnostic criteria specified by NICE, there are other diagnostic criteria preferred by groups of specialist clinicians/researchers, including the Fukuda/CDC criteria (1994), the Canadian consensus criteria (2011) and the ICC primer (2012).

While there is currently no pharmaceutical cure for M.E. there are a number of conventional medical approaches and complementary therapies available which may help to alleviate symptoms. Action for M.E. can provide information on these (see p 15).

Because of the complexity of the illness, its fluctuating nature and the wide spectrum of symptoms, different things work for different people. Some, particularly those who are more severely affected, unfortunately find currently available therapies of little benefit.
What you can do to empower and support yourself

Make the most of your relationship with your GP

Keep a diary of your symptoms (see p 6) to take to GP appointments with you. A diary will help you to understand what is going on and enable you to reflect on your own particular circumstances. The effects of ‘overdoing it’ may not show up for a day or two but your diary may help you to identify what triggered your symptoms.

Because time will be limited when you see your GP, it is helpful to clarify the purpose of your visit and what you want to achieve at the beginning of the appointment.

When you visit your doctor you can choose to take a friend or relative with you. There can often be a lot of information to remember, so it can be helpful to have someone with you to listen to what is being said and to make notes.

Sometimes it is possible to book a double appointment if you have a number of things you want to discuss.

Ask the right questions – see p 18 for key questions to ask your GP about you and your M.E. – and write them down before you go in. Make sure you understand everything your GP has told you before you leave the surgery. Don’t be afraid to ask them to explain anything you’re not sure about. It is important that you understand how to manage your care.
If you develop any new symptoms or health problems it is important that you discuss these with your GP so that they can assess whether the symptoms are part of your M.E. or are caused by something different. They may be able to see a link which is not obvious to you.

In summary, try to:

• respect the 10 minute consultation – be brief, to the point and prepare what you want to say in advance

• be accurate and concise about your symptoms (exaggerating or underplaying them isn’t helpful) – this is why a diary can be useful

• ask for a double appointment if you think it necessary

• see your GP little and often – it works better that way

• talk to your GP about booking appointments to focus on identifying management options for specific types of symptom such as pain, sleep or digestive problems; this may involve a specialist referral in some cases

• try to be positive about what you can do.

Remember that your GP is experienced at pain relief and other symptom management – you may just have to remind him/her that some people with M.E. are more sensitive to drugs, so you may need to start with a lower dose than usual.
Know about your right to shared decision-making

Because of the complexity of M.E., its fluctuating nature and the wide spectrum of symptoms, different management strategies work for different people. Action for M.E. (see p 15) can provide you with information and evidence about the strategies that other people with M.E. find most useful, which you can discuss with your GP.

This is what section 1.1 of the NICE guideline\(^1\) has to say about shared decision making:

“Shared decision-making between the person with CFS/ME and healthcare professionals should take place during diagnosis and all phases of care. The healthcare professional should:

- acknowledge the reality and impact of the condition and the symptoms
- provide information about the range of interventions and management strategies as detailed in this guideline (such as the benefits, risks and likely side effects)
- provide information on the possible causes, nature and course of CFS/ME
- provide information on returning to work or education
- take account of the person’s age (particularly for children younger than 12 years), the severity of their CFS/ME, their preferences and experiences, and the outcome of previous treatment(s).
- offer information about local and national self-help groups and support groups for people with CFS/ME and their carers (see also the NHS Expert Patients Programme).
“Healthcare professionals should be aware that – like all people receiving care in the NHS – people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting other aspects of their care, or future choices about care.”

Unhelpful stereotypes and myths are sometimes perpetuated about the illness and this can, unfortunately, impact on the support that people with M.E. receive from friends, families and even professionals.

If you feel that your care is being influenced by stereotypes or prejudices then it is right that you should challenge this. You can contact Action for M.E. to explore how best to address the situation.

It’s important to remember that there are many good healthcare professionals who are not influenced in this way and provide excellent support and care.

The SGPS² on M.E. makes it clear that “the normal general practice principles of empathetic listening, mutual respect and shared decision making between a person with ME/CFS and health care professionals are essential during all phases of care in the NHS.”
Know that you are not alone

Below is a selection of feedback from people with M.E., telling us what works for them.

Judy says: “You need to investigate, take responsibility for and become the expert of your own illness. If you don’t feel heard, try writing what you want to say in a letter. Don’t be browbeaten into treatments that don’t feel right for you. Trust your instincts. Investigate alternative therapies, don’t believe any promise of cure and try what you feel drawn to.”

Jennifer says: “You will get better more quickly if you take things more slowly – don’t try to rush or force recovery. Accept it will happen in its own time. Accept you have to change your lifestyle and prioritise differently. Essentials are: daily quiet time, healthy diet, lots of rest, putting yourself first, learning to say no or cancelling rather than pushing yourself, giving up exercise (gentle walking/stretching are OK) and avoiding stressful people/situations.”

Sue says: “There is no quick fix. When starting any treatment plan it can take months before real improvement can take effect. Pacing activity works but you must work out a baseline – the activity level where symptoms are at a minimum – before starting to increase activity. When a therapist says ‘Do what you enjoy,’ only do if it doesn’t increase symptoms.”

Laura says: “Be kind to yourself and keep your hope up. Let yourself cry. Keep visualising the future you want for yourself but never ever push yourself. I take vitamin supplements, herbal medicine and gentle bodywork. I recommend the book 50 Stories of recovery from CFS by Alex Barton. It gave me hope (but read it in small bits!). I also recommend mindfulness meditation.”
Contact Action for M.E. for information, support and useful resources

Contact us by telephone, post, email or social media (see back cover) to find out more about our printed and online information, including:

- lots of details about symptoms, diagnosis, management approaches and living with M.E., from medical professionals and from other people with M.E. at www.actionforme.org.uk
- support specifically for those newly diagnosed with M.E. at www.actionforme.org.uk/living-with-me/newly-diagnosed
- guides to managing your energy, with lots of practical tips and help
- information about aids and adaptations that can help with independent living
- advice for carers and family members
- advice for people with M.E. who are trying to stay in, return to, or leave work, including information they can share with their employer
- our Welfare Advice and Support Service – call our welfare advisor on 0800 138 6544 or visit www.actionforme.org.uk/living-with-me/welfare-benefits
- factsheets on a range of topics including welfare benefits and life with M.E.
- articles on many aspects of living with M.E. from our membership magazine, InterAction
- a friendly forum where you can chat to other people with M.E. at www.actionforme.org.uk/forum
- a services directory where you can look for specialist NHS M.E. services and support groups in your area.
Keeping you and your GP up to date with M.E. research

Research relating to M.E. is growing...

There is growing evidence from experts in the field that a number of sub-groups exist within M.E. 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.

Evidence is emerging for possible phenotypes relating to:

- postural orthostatic tachycardia syndrome (Newton et al, 2013, *Journal of Internal Medicine*)
- brain dysfunction (Natelson, 2013, *Frontiers in Physiology*)
- gene expression changes following exercise (Light et al, 2012, *Journal of Internal Medicine*).

Key papers have been published on:

- defining post-exertional malaise and sudden onset of M.E. (both Jason et al, 2015, *Journal of prevention and intervention in the community*)
- discriminative validity of metabolic and workload measurements (Van Ness et al, 2013, *Journal of physical therapy*)
- brain inflammation (Nakatomi et al, 2014, *Journal of Nuclear Medicine*)
- loss of capacity to recover from acidosis on repeat exercise (Jones et al, 2012, *European Journal of Clinical Investigation*)
- using the DePaul Symptom Questionnaire to assess symptoms (Brown and Jason, 2014, *Biomedicine, Health & Behavior*).

To keep up to date with the latest published research on M.E., visit www.actionforme.org.uk/research
...but diagnosis can still be problematic

An evaluation of referrals made by GPs to the specialist clinic at Bart’s Hospital found that 49% did not have a diagnosis of M.E..

A study of patients referred by GPs to the Newcastle NHS M.E. Service found that 40% were diagnosed with conditions other than M.E.. Of these:

- 47% were found to have fatigue associated with a chronic disease, including metabolic syndrome, neurological disorder, connective tissue disorder/autoimmune disease and fibromyalgia
- 20% had a primary sleep disorder
- 15% had a psychological/psychiatric illnesses, most commonly depression, anxiety and post-traumatic stress disorder
- 13% of patients had fatigue for which the cause remained unexplained
- 4% had cardiovascular disorders.
Guidelines for your GP

Key questions for your GP about you and M.E.

Don’t forget to take your symptom diary, if you’ve made one.

• Which tests have you (and any specialists involved in my diagnosis) carried out and what were the results? Is this the full list of tests recommended in the guidance? NICE recommends a list of tests in section 1.2.2 History, examinations and investigations of its guideline for M.E.1

• Are all my symptoms related to M.E. or could I have an additional (co-morbid) condition or illness?

• Have you ruled out other conditions before giving me a diagnosis of M.E.?

• Not all symptom-management approaches are effective for all patients. How do we know what’s right for me?

• Are there medications that might help alleviate the symptoms that are troubling me particularly at the moment?

• Does a specialist NHS M.E. service exist locally that you can refer me to? If not, is there a local consultant with an interest in M.E. who could see me?

• Are there any self-management courses available through the NHS locally for people with M.E. or long-term conditions?

• Is there any equipment, aids, adaptations or similar eg. a wheelchair, disability travel pass, Blue Badge or stair lift that could help me maintain my independence?

• Would a referral to the local authority social services department for advice and an assessment be helpful?

• What can I do to help me self-manage my symptoms?

• After my diagnosis has been formalised and my treatment/management plan has been established, how frequently should I come back for monitoring and review?

• Are there any ‘red flag’ symptoms I should alert you to straight away if they develop or get worse?
Guidelines for symptom management in England, Wales and Northern Ireland

The NICE guideline¹ says: “Advice on symptom management should not be delayed until a diagnosis is established. This advice should be tailored to the specific symptoms the person has and be aimed at minimising their impact on daily life and activities.

“A diagnosis should be made after other possible diagnoses have been excluded and the symptoms have persisted for:

• four months in an adult
• three months in a child or young person; the diagnosis should be made or confirmed by a paediatrician.

“Healthcare professionals should proactively advise about fitness for work and education, and recommend flexible adjustments or adaptations to work or studies to help people with CFS/ME to return to them when they are ready and fit enough. This may include, with the informed consent of the person with CFS/ME, liaising with employers, education providers and support services, such as:

• occupational health services
• disability services through Jobcentre Plus
• schools, home education services and local education authorities
• disability advisers in universities and colleges.

“Any decision to refer a person to specialist CFS/ME care should be based on their needs, the type, duration, complexity and severity of their symptoms, and the presence of comorbidities. The decision should be made jointly by the person with CFS/ME and the healthcare professional.

“An individualised, person-centred programme should be offered to people with CFS/ME. The objectives of the programme should be to:

• sustain or gradually extend, if possible, the person’s physical, emotional and cognitive capacity
• manage the physical and emotional impact of their symptoms.”

There are a number of specialist NHS services for M.E. for adults and children across England. You can find your nearest by searching Action for M.E.’s services directory at www.actionforme.org.uk/find-local-services
There are no specialist M.E. services in Wales or Northern Ireland. Instead GPs can refer to services for specific symptoms, eg. pain and fatigue management services.

At the time of writing, a report by the M.E./CFS and Fibromyalgia Task and Finish Group set up by the Welsh Government had made a number of recommendations, including that each health board should:

- identify an appropriate clinical lead or leads for M.E./CFS and fibromyalgia by April 2015
- identify a “home” for services for M.E./CFS and fibromyalgia
- develop effective local pathways for children and adults with M.E./CFS and fibromyalgia.

At the time of writing, a February 2015 workshop meeting had been scheduled for the Minister for Health, Department of Health decision makers and others to discuss service provision for M.E. and fibromyalgia in Northern Ireland.

A pilot condition management programme was set up in the Northern Trust in 2014 and assessment of how effective this was is underway.

**Guidelines for symptom management in Scotland**

There are very few specialist services for people with M.E. in Scotland. GPs and/or nurses should offer a care plan with the following objectives:

- treat individual symptoms as far as possible (eg. sleep, pain, orthostatic intolerance, irritable bowel syndrome); this may involve specialist referral for some and/or trialling medication
- provide support with managing the condition, including the emotional impact
- monitor symptom treatment and management and pick up any alternative diagnosis, referral requirement or new symptoms which may present over time.
References


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- members of our Patient and Carer Reference Group
- GPs and other healthcare professionals
- M.E. support group representatives
- people with M.E. who shared what worked for them (see p 14).
If you have found this resource helpful, please consider making a donation to help us help more people affected by M.E.

Visit www.justgiving.com/actionforme or call 0117 927 9551. Thank you.