



MANAGEMENT FILE

by DR CHARLES SHEPHERD, our medical adviser

This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine .
MEA membership costs £18 a year for people living in the UK/BFPO.
For contact details, see foot of this page.



TEN KEY ASPECTS OF MANAGEMENT

This Management File brings together the 10 most important aspects of managing your ME/CFS and gives links to further sources of information or advice from the ME Association.

1

MAKE SURE THE DIAGNOSIS IS CORRECT. DON'T AUTOMATICALLY ATTRIBUTE NEW OR WORSENING SYMPTOMS TO ME/CFS

It is not always easy for a doctor to decide at what point in an illness it is appropriate to start using the term M.E. (myalgic encephalomyelitis/encephalopathy) or, as some doctors unfortunately prefer, CFS (chronic fatigue syndrome). As both names are commonly used, we have decided to

KEY SYMPTOMS OF M.E.

- Post-exertional malaise
 - Activity-induced muscle fatigue
 - Cognitive dysfunction
 - Sleep problems
 - Ongoing flu-like symptoms including sore throats and tender glands
 - Orthostatic intolerance
- Other common symptoms include:*
- Pain – muscles, joints and nerves
 - Problems with balance and temperature control
 - Gastro-intestinal symptoms
 - Sensitivity to light and sound
 - Alcohol intolerance

use the compromise term ME/CFS in our literature.

Where ME/CFS-like symptoms follow an acute infection, it's quite likely that a diagnosis of a post-viral/infectious fatigue syndrome (PVFS), or post-viral debility, will be used during the first few weeks.

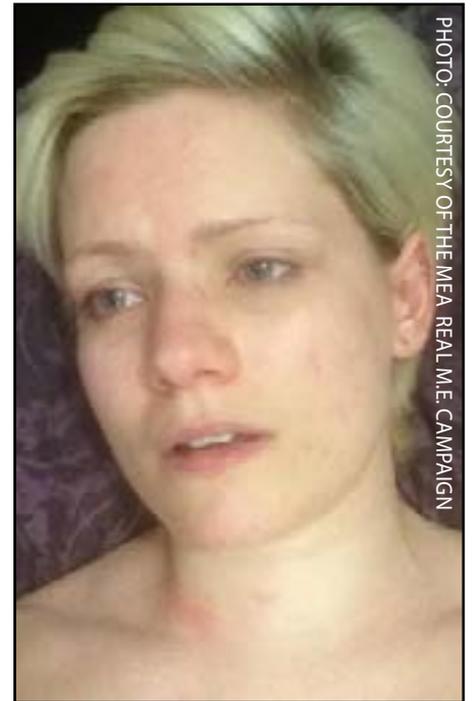
If the characteristic symptoms persist, a diagnosis of ME/CFS might then be made, or should certainly be given serious consideration.

The NICE (National Institute for Health and Care Excellence) clinical guideline recommends that a child or young person who has symptoms suggestive of ME/CFS should be referred to a paediatrician for assessment within six weeks of presentation (1.2.2.2).

Actual diagnosis should be confirmed within three months of symptom presentation in the case of a child or young person, and four months in the case of adults (1.3.1.1).

The NICE clinical guideline – which frames recommendations to the NHS – is being rewritten by experts and stakeholders, with publication of a new guideline expected in December 2020.

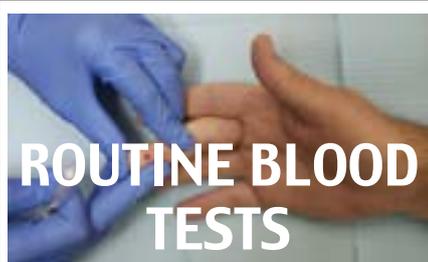
One of the reasons why some doctors find it difficult to make a diagnosis of ME/CFS is that this must be based on medical history alone – as there is no diagnostic blood test for this illness.



However, a number of specific blood and urine tests should always be checked before a doctor confirms the diagnosis (*see list on page 2*).

This is because there are many other illnesses – endocrine/hormonal, infectious, immunological, neurological, rheumatological – that can produce symptoms very similar to ME/CFS.

It is also important to check with your doctor when a new symptom appears, especially what doctors call 'red flag' symptoms (for example weight loss, joint swelling, persisting fever or raised temperature), or an existing symptom (such as joint pain) becomes significantly worse, or changes in character. Do not automatically assume that this just another aspect of your ME/CFS.



Routine blood tests that should be arranged to exclude other possible causes of an ME/CFS-like illness:

- ESR and C-reactive protein (markers for inflammation and infection)
- Haemoglobin, red blood cell indices and serum ferritin (for anaemia and iron status)
- White cell count and differential (markers of infection)
- A range of biochemical tests including calcium, urea and electrolytes (sodium and potassium), total protein, blood sugar and Hb1c (for diabetes)
- Liver function tests
- Serum creatinine (kidney function test)
- Thyroid function tests
- Creatine kinase (muscle function test)
- Immunological screening test for coeliac disease
- ◆ The MEA has a leaflet covering Early and Accurate Diagnosis – available as a [free download](#) from our website. We also have leaflets about three conditions that can have very similar symptoms to ME/CFS: Fibromyalgia, Lyme Disease, and thyroid disease.
- ◆ We also have leaflets entitled Just Diagnosed – We Are Here To Help, Explaining ME/CFS To Other People and Relapses, Exacerbations and Flare Ups. The latter provides information on why relapses sometimes occur and how to deal with them. Our leaflet on flu jabs is updated every year. Browse through the leaflets in our website shop [here](#).

Known triggers for significant exacerbations in symptoms or relapses include infections and these can also occur after overdoing things mentally or physically. Traumatic physical or emotional events can play a part here and the same advice applies – to go and see your GP – even when you have a significant relapse or exacerbation of symptoms and there is no obvious trigger.

Vaccinations have also been reported by some people with ME/CFS as a trigger factor for the condition and/or a

cause of symptom exacerbation.

A full description of all the blood tests that should be checked before a diagnosis of ME/CFS is confirmed, along with other tests that may need to be arranged to exclude other conditions, can be found in our leaflet entitled [Blood Tests Explained](#) and in section 6.6 of [our guide](#) for health professionals. This guide has a 'differential diagnosis' section covering conditions that need to be considered before a diagnosis is confirmed.

2

WHAT CAN HEALTH PROFESSIONALS DO TO HELP?

NICE recommends that care for people with ME/CFS is led by primary health-care professionals. In most cases, this means your GP or, in for children and young people, a paediatrician – with referral to an NHS specialist service where necessary.

However, many GPs lack the time, confidence and expertise to deal with this condition. And, sadly, some health-care professionals still hold unhelpful or hostile attitudes..

Decisions about any aspect of care should be properly discussed with the health professional involved and mutually agreed – following the rules of informed consent produced by the General Medical Council and those set out in the NICE guideline (see [General Principles of Care](#)).

If there is a query over diagnosis, or help is required in relation to any aspect of management or you have a GP who just isn't interested in ME/CFS, you can ask for a referral to a hospital-based specialist or ME/CFS service.

If you are severely affected – i.e. wheelchair-bound, house-bound or bed-bound – you should be assessed by a doctor with expertise in ME/CFS at least once. Preferably you should be under the care of a hospital-based team. Ideally, they should visit you at home.

For children and adolescents who are sufficiently unwell to be continually away from school, on-going care should also involve a paediatrician.

Putting this advice into practice isn't always easy because there are still parts of the UK – especially in Scotland, Wales and Northern Ireland – where it is very difficult to find a hospital-based specialist, or a multidisciplinary team, with the necessary expertise. If there isn't a local ME/CFS service, or the local service is not suitable, the Countess of Mar has established through a [parliamentary question](#) that doctors can make a referral to any other suitable service or consultant.

Hospital-based specialist services and management

Information about where to find hospital-based referral services, details about NICE recommendations and the MEA position on management, can be found in the [NHS Services Directory](#) on the MEA website.

The directory offers guidance that can help you decide if you should request or accept a referral to your local NHS specialist service. Careful consideration should be given to any subsequent advice to try either cognitive behaviour therapy (CBT) or graded exercise therapy (GET).

We have grave reservations about both therapies based on consistent patient feedback published in survey reports and from published research evidence and reviews.

CBT may help some people cope with the emotional consequences of living with a long-term condition – as it does for people with cancer and MS, for example – but it should never be considered as a treatment for ME/CFS.

GET is a form of activity management that can involve regimented exercise protocols that make many people with ME/CFS feel worse and can cause devastating relapses in health. GET is not recommended by the ME Association.

NHS specialist services do offer other forms of management advice including Pacing (where you try and balance activity with rest and listen to what your body is telling you) and practical tips that can help you live with ME/CFS. This is an approach that is recommended by the ME Association (see Section 4 below).

It is often the case of trying things for yourself and seeing if the advice provided by NHS specialist services can help, given your own particular circumstances. But it pays to be cautious.

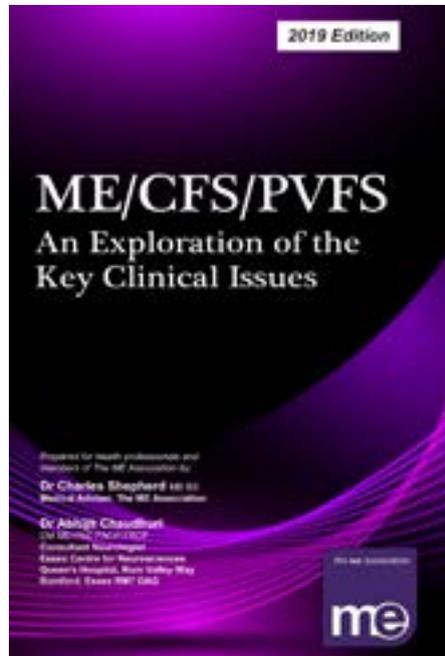
■ We have a guide that covers energy management (Pacing) and many other leaflets that deal with specific drugs (and other options) that might help alleviate some of your symptoms and which could be considered in consultation with your GP.

■ We also have leaflets entitled *How to Deal with your Doctor* and *Referral to Specialist Services*. Browse through the leaflets in our website shop [here](#).

DRUGS CAN HELP RELIEVE SYMPTOMS – BUT WE DON'T YET HAVE A CURE

At present, there are no drug treatments that can successfully treat or cure the underlying disease process. Until we know a lot more about what keeps this illness going, a successful drug treatment is some way away.

A number of drugs that are designed to treat possible cause rather than symptoms are now being, or have been, assessed in clinical trials.



The latest edition of our clinical and research guide. Buy it here:
www.meassociation.org.uk/shop/books/

Examples include hydrocortisone, modafinil (a central nervous system stimulant), low dose naltrexone, rituximab, and valganciclovir (an anti-viral drug). Although some of these drugs appear to benefit some sub-groups of people with ME/CFS, their use is still highly speculative. None are therefore licensed for use in ME/CFS and they would not normally be prescribed outside a research setting.

There are, however, a number of drugs that can help to provide relief from some of the key symptoms found in ME/CFS – in particular pain, sleep disturbance, irritable bowel, and depression (where this occurs).

Examples include the use of a low dose of a sedating antidepressant drug called amitriptyline for pain and sleep disturbance, and gabapentin or pregabalin for more severe pain.

◆ We also have information leaflets on the drugs that may be prescribed for pain relief in ME/CFS – amitriptyline, duloxetine, gabapentin and pregabalin.

◆ The ME Association also have leaflets that consider management of all the main symptoms and about the drugs that may be prescribed in consultation with your GP. Visit the [website shop](#) for more information.

The latest edition of our clinical and research guide is pictured left.

STRIKING THE RIGHT BALANCE BETWEEN ACTIVITY AND REST

Energy management – achieving the correct balance between activity and rest – remains the most important part of ME/CFS management. This is because the key biological defect in this illness is the inability to produce energy to carry out and sustain mental and physical activities.

Energy management has to involve

physical, mental and emotional activity – all of which require some form of energy production and can worsen ME/CFS symptoms when carried out beyond a person's limitations.

In practice, this should involve an individual activity management programme that takes account of three factors: stage of your illness, severity of your illness, and to what extent your symptoms fluctuate. Basically, this involves finding a baseline of activity that you feel comfortable with and then carrying out physical and mental

activities in small, flexible amounts. Gradual increases in physical and mental activity levels should only be introduced when you feel comfortable doing so and does not result in any form of symptom exacerbation.

Pacing is a flexible approach to activity management. We believe that it is the best and safest method of managing your ME/CFS. If you speak to your GP and obtain a referral to a ME/CFS specialist service, you can learn how this method works in practice.

However, not all specialist services

offer Pacing and you will need to decide what works best for your circumstances (see below). You may also find that flexible management programmes can be obtained from physiotherapists or occupational therapists – but you need to ensure that they understand ME/CFS and can tailor an approach to suit you.

Unfortunately, finding a health professional with a good understanding of energy management may not be possible – so this often has to be left to finding out from self-help literature or from other people with ME/CFS.

The ME Association do not believe that graded exercise therapy (GET) is appropriate for people with ME/CFS. This is because it is based on the flawed theory that decreased mobility is mainly due to deconditioning and fear of exercise, and it imposes progressive and inflexible increases in activity regardless of how a person is coping or feeling.

We believe that Pacing is far more helpful to people with this condition and that it provides a safe and effective form of management (*for more information about this and other forms of activity management visit the [website shop](#)*).

Feedback on activity management to the 2002 Chief Medical Officer's Report found that, while nearly 90% found Pacing helpful, only 35% reported benefit from GET – with almost 50% reporting that GET had made them feel worse.

Similar results were reported in the MEA Report on CBT and GET and in the 2019 Forward ME Group survey of CBT and GET. These reports can [all be downloaded](#) from the MEA website.



DEALING WITH EMOTIONAL AND MENTAL HEALTH ISSUES

As with any other chronic illness, people with ME/CFS can develop emotional and mental health problems.

The reasons for this are complex but probably involve both internal factors (i.e. the effects of the illness on brain function and brain chemical transmitters) and external factors (i.e. losses and problems relating to benefits, doctors, family, finances, friendships, work).

ME/CFS is a life-changing illness that involves significant losses to almost every aspect of normal life – friends, family and social life, employment, education and financial security.

But it can also sometimes result in changes that, for some people, help to lessen the negative load – for example, being able to do things that you can manage like hobbies, gaining friendships and support from other people with ME/CFS, or spending more time with your family, partner or children.

It can also sometimes result in changes that, for some people, help to lessen the negative load - for example, being able to spend more time with your partner and children.

So it may be helpful to prepare a list of your losses and gains, and then work through how you are going to try and deal with these issues.

To do so, you may find it helpful to talk to a professional counsellor, especially if you are having difficulty in coming to terms with sudden and dramatic losses in so many important aspects of normal life.

Alternatively, an approach known as cognitive behaviour therapy (CBT) can be helpful for people who are finding it difficult to cope with all the lifestyle adjustments and losses that come with having ME/CFS.

But take note – CBT is not a treatment for M.E. If you feel anxious or depressed, as opposed to just being 'fed up', you must talk to your GP and make use of whatever help is appropriate and available.

Any form of significant clinical depression would normally require treatment with CBT and/or anti-depressant medication – symptoms include poor appetite, loss of interest, loss of self-esteem, worthlessness, being tearful at times and even suicidal thoughts or intentions.

If antidepressant drugs are prescribed, it should be noted that people with ME/CFS tend to be sensitive to drugs that act on the central nervous system. So anti-depressants need to be used with care and probably started at the lowest possible dose, with gradual increases until an optimum dose is achieved.

◆ We have leaflets that deal with emotional and mental health issues. They can be downloaded [here](#).

SORTING OUT WORK, EDUCATION AND FAMILY RESPONSIBILITIES

Many people with ME/CFS, especially during the very early stages, find they are no longer able to continue with their normal work, education, domestic or family responsibilities.

In the case of work, it's important to

stay in touch with key people at work (i.e. a personnel/human resources manager and/or occupational health department) to keep them informed about how you are progressing.

The same applies to a child or young person at school or university – because input from a paediatrician can be especially helpful if there are problems about attendance or obtaining home tuition.

As time goes on, you may find yourself

in a position where some form of limited return to work or education becomes possible. For others, the outcome is much less certain, and retirement on the grounds of permanent ill health may need to be considered.

ME/CFS is an illness that is covered by the 1995 Disability Discrimination Act and by section 6 of the 2010 Equalities Act. These laws provide important provisions in relation to modifications to hours, duties, travel, etc that an employer would be expected to make to enable a sick or disabled employee stay in work or return to work. You might also be

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OBTAINING STATE AND PRIVATE SECTOR BENEFITS

The Department of Work and Pensions (DWP) has made it clear that people with ME/CFS are entitled to claim the full range of state sickness and disability benefits – provided you meet the eligibility criteria. Unfortunately, the way in which eligibility for these benefits is assessed is problematic when it comes to people with fluctuating medical conditions like ME/CFS.

It's worth noting that decisions on benefit entitlement should primarily be made on the degree of disability and ill health and not the diagnostic label. Official reports have pointed out that it is not appropriate that participation in a particular treatment programme is made an absolute condition for continuing sickness / disability payments.

However, the process of claiming state benefits may sometimes seem like jumping over a never-ending series of hurdles, with far too many people still only being successful after going to reconsideration or an appeal.

For those unable to work, the way in which this is assessed for Employment and Support Allowance (ESA), through the Work Capability Assessment (WCA), still causes major problems when it comes to conditions like ME/CFS where

able to make use of this legislation if you are being threatened with dismissal on the grounds of continuing ill health.

People with ME/CFS who are in work may experience all kinds of difficulties with their employers. So it's normally sensible to remain a member of your trade union or professional body while off sick. Normally these organisations will provide free legal and employment advice to their members.

◆ For MEA literature about employment issues, ill-health retirement and life and study at university, please [browse our website shop](#).

people are unable to perform both mental and physical tasks in a regular, reliable and sustained manner.

So do make use of the fact that the DWP now accepts that you must be able to carry out the WCA descriptor tasks **reliably, repeatedly, safely and in a timely manner**.

Anyone more severely affected from the point of view of mobility or care needs should consider applying for a Personal Independence Payment – which has replaced Disability Living Allowance.

Claiming on an income protection policy (also known as permanent health insurance) can be just as difficult. If an internal appeal fails to resolve a dispute, you should take legal advice or refer your case to the Financial Ombudsman www.financial-ombudsman.org.uk

With other charities, the MEA has been working with the DWP to try to increase the number of successful first-time benefits claims from people with fluctuating medical conditions. We produced recommendations to improve the Work Capability Assessment part of the ESA. Unfortunately, our proposals for a better WCA, which would measure both fluctuation and severity, and which were assessed in an evidence-based review, were not accepted.

◆ To improve your chances of making a successful claim, download our helpful benefits guides. Visit [our website shop](#).

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HOW TO OBTAIN SOCIAL AND PRACTICAL SUPPORT, AND HELP FOR CARERS

If you are more severely affected, you may be entitled to various forms of practical assistance such as a wheelchair, adaptations to the home, or a home help. If you have very limited mobility you may be entitled to a Blue (car parking) Badge – but do note that the eligibility criteria relating to restrictions on mobility are quite strict and some people with ME/CFS find it very difficult to get a Blue Badge.

Loss of social networks locally or at work is not unusual if you have ME/CFS. This may mean that you may find yourself becoming increasingly dependent on a partner, or even a child, for both emotional and practical support.

For a carer, having to make all kinds of social, emotional and financial adjustments is often very stressful. So it's important to think about the needs of those who care for you – because they may not have anyone else who is able to speak up for them.

Your carer may be able to claim a Carers Allowance if he/she cares for you at least 35 hours per week and you receive the daily living component of PIP.

◆ For information and advice on practical aids, contact your nearest Centre for Independent Living – www.ncil.org. Local authority adult social care departments can advise on home helps and agencies who can put you in touch with volunteers. Carers UK – www.carersuk.org – is an excellent source of support and advice for carers.

◆ Visit [the MEA website shop](#) to explore our wide range of leaflets about all manner of subjects to do with ME/CFS. These include benefits leaflets and guides, and leaflets about severe ME/CFS, caring for someone with the illness and getting help from social services.

VITAMINS, MINERALS, SUPPLEMENTS AND NUTRITION

People with ME/CFS have enough restrictions in their lives without adding a restrictive diet to the list. But a number of sensible dietary changes can be made.

Besides having a healthy balanced diet, it's a good idea to include complex carbohydrates – things like pasta – which help to ensure that blood sugar levels remain steady throughout the day.

It's also important to keep the body well hydrated with water, especially if you have orthostatic intolerance (ie problems with remaining in an upright position) or low blood pressure.

If you have irritable-type bowel, excluding certain groups of foods may be helpful. These can be identified through trying an exclusion diet, where different foods, or food groups, are removed in rotation – preferably guided by a qualified dietitian. Trying what is called a FODMAP diet may also be help.

Some aspects of ME/CFS – for example lack of sunlight, inactivity, dietary restrictions – may increase the risk of vitamin D deficiency as well as osteoporosis. If this is so, you need to discuss taking extra calcium and vitamin D with your doctor or dietitian. Many doctors now believe that we should all be taking a regular small dose of vitamin D every day.

There is very little scientific evidence to show that people with ME/CFS have significant deficiencies in vitamins or minerals. So supplements need to be used with care – especially those that contains high doses of certain ingredients. But, if your diet is in any way unbalanced, taking vitamin and mineral supplements is a sensible precaution.

- ◆ A patient [information leaflet](#) on essential fatty acid supplements, including eicosapentaenoic acid (EPA), which some people report might be beneficial, is available from our website shop.
- ◆ Browse [our website shop](#) where we have a wide range of leaflets on dietary, muscle energy and vitamin supplements and information about how to maintain a healthy diet.

ME CONNECT
We're here to help

Do you need to talk?

CALL 0344 576 5326

any day of the week
between these hours:
10am-12noon,
2-4pm and 7-9pm

Calls cost the same as other standard landline numbers (starting 01 and 02). If you have a call package for your landline or mobile phone, then calls will normally come out of your inclusive minutes.

ALTERNATIVE AND COMPLEMENTARY APPROACHES

If you have faith in an approach such as acupuncture (perhaps for pain relief), meditation, osteopathy or homeopathy, these may be worth a try – even though there is no sound scientific evidence that any of these approaches work in ME/CFS. But do try and find a reputable practitioner who isn't over-hyping their claims and check you can afford the fees.

The Health Professions Council has details of qualified and properly registered dietitians and other practitioners in some of these areas: www.hpc-uk.org.

The downside here is that all kinds of bogus and extremely dubious claims for approaches such as anti-candida programmes, immune-boosting supplements, and even talking therapies are aimed at vulnerable people – including those with ME/CFS. Some people have lost a great deal of money chasing the latest 'miracle cures'.

- ◆ You can [download the MEA leaflet](#) on alternative and complementary therapies from our website shop.

DISCLAIMER

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your own doctor.

The MEA recommends that you always consult your own doctor or healthcare professional about any specific problems.

We also recommend that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor or dentist.