

TEN KEY ASPECTS

THE TEN MOST IMPORTANT
FACTORS OF MANAGING
YOUR ME/CFS

NOVEMBER 2023



TEN KEY ASPECTS OF MANAGEMENT

INTRODUCTION

This leaflet brings together the 10 most important aspects of managing your ME/CFS.

It provides links to further sources of information or guidance from the ME Association and elsewhere and is consistent with the recommendations in the October 2021 NICE guideline on ME/CFS.

The new NICE guideline explains how health professionals working in both primary (i.e. general practice) and secondary (i.e. hospital) care should be diagnosing and managing people with ME/CFS. The NICE guideline places special emphasis on the importance of listening to and believing people who have ME/CFS.

We are also here to help and support people with Long Covid who have symptoms that overlap with ME/CFS – especially fatigue, cognitive dysfunction/brain fog and dysautonomia (orthostatic intolerance and PoTS).



More information on the NICE guideline on ME/CFS

NICE Clinical guideline on ME/CFS – An ME Association Summary:

<https://meassociation.org.uk/9d0l>

1: MAKE SURE THE DIAGNOSIS IS CORRECT AND 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 ME (myalgic encephalomyelitis/encephalopathy) or, as some doctors unfortunately prefer, CFS (chronic fatigue syndrome). As both names are commonly referred to, we use the compromise term ME/CFS in our literature.

Where ME/CFS-like symptoms follow an acute infection – as they often do – it's possible that a diagnosis of a post-viral/infectious fatigue syndrome (PVFS), or post-viral debility, will be initially used in people who are failing to return to normal health after two or three weeks.



Ten Key Aspects of Management was written by Dr Charles Shepherd, Trustee and Hon. Medical Adviser to The ME Association.

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DISCLAIMER

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or dentist about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor or dentist.



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If the characteristic symptoms of ME/CFS persist for two to three months after an infection, or another triggering event occurs such as a vaccination, a diagnosis of ME/CFS should then be suspected.

The new NICE guideline on ME/CFS recommends that a diagnosis should normally be confirmed within three months of the onset of symptoms. You should then be referred by your GP to a specialist ME/CFS service for confirmation of the diagnosis and multidisciplinary help with management.

One of the reasons why doctors sometimes find it difficult to make a diagnosis of ME/CFS is that this has to be based on medical history alone – as there aren't usually any abnormal findings on clinical examination and 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 5). This is because there are many other illnesses – endocrine/hormonal, infectious, immunological, neurological, rheumatological – that can produce symptoms that are 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 when an existing symptom (such as joint pain) becomes significantly worse, or changes in character. Do not automatically assume that this is just another aspect of your ME/CFS.

Common triggers for causing significant exacerbations in symptoms or relapses include infections and overdoing activity – mentally and physically. Stress and traumatic physical events can also cause an exacerbation or relapse – as can vaccinations.

MEA information leaflets:

■ **Blood tests explained:** Contains 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. The MEA 'purple book' has a differential diagnosis section covering conditions that need to be considered before a diagnosis is confirmed.

<https://meassociation.org.uk/xyhr>

Key diagnostic symptoms of ME/CFS

- Post-exertional malaise, or symptom exacerbation – this is essential for diagnosis
- Debilitating physical fatigue that is activity-induced
- Cognitive fatigue and dysfunction or 'brain fog' – problems with short-term memory, concentration, information processing and retrieval, etc
- Sleep problems – including unrefreshing sleep
- Ongoing flu-like symptoms including sore throats and tender glands
- Orthostatic intolerance - difficulty remaining in a standing position

Other common symptoms include:

- Pain involving muscles, joints and nerves
- Problems with balance and temperature control
- Irritable bowel-type symptoms
- Sensitivity to light and sound
- Alcohol intolerance
- Headaches



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■ Importance of Early and Accurate Diagnosis

<https://meassociation.org.uk/mwta>

■ Conditions that can have very similar symptoms to ME/CFS: **Fibromyalgia, Lyme Disease, and Thyroid Disease.**

Fibromyalgia and ME/CFS: <https://meassociation.org.uk/t4zv>

Lyme Disease - The Facts: <https://meassociation.org.uk/ldxn>

Thyroid Disease and ME/CFS: <https://meassociation.org.uk/mdwb>

■ Just Diagnosed – We Are Here To Help

<https://meassociation.org.uk/36pe>

■ Explaining ME/CFS To Other People

<https://meassociation.org.uk/5t5e>

■ Relapses, Exacerbations and Flare-ups: information on why relapses sometimes occur and how to deal with them.

<https://meassociation.org.uk/42mz>

2: WHAT CAN HEALTH PROFESSIONALS DO TO HELP?

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

The new NICE guideline recommends that the diagnosis, management and care for people with ME/CFS should involve both your GP and primary healthcare team and a multidisciplinary specialist referral service.

If help is required in relation to any aspect of diagnosis or management, or you have a GP who lacks the confidence or knowledge to deal with ME/CFS, you should ask for a referral to a specialist ME/CFS service. The new NICE guideline lists all the different health professionals who should form part of this multidisciplinary team.

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. You should also be under the care of a hospital-based team who should, ideally, be able to visit you at home or arrange virtual consultations.



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For children and adolescents who are sufficiently unwell to be continually away from school, on-going care should also involve a paediatrician with knowledge and experience of dealing with ME/CFS.

Putting all this into practice isn't always easy because there are still parts of the UK – especially in Scotland (where NICE guidelines do not formally apply), 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 established through a parliamentary question that doctors can make a referral to any other suitable service or consultant:

<https://tinyurl.com/mua6e5ap>

Further information

■ Contact details for all the specialist referral services throughout the UK can be found in the NHS Services Directory on the MEA website.

3: DRUGS CAN HELP TO RELIEVE SOME ME/CFS 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 in ME/CFS. 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 the possible causes of ME/CFS rather than individual symptoms are now being, or have been, assessed in clinical trials. Examples include hydrocortisone, immunoglobulin, modafinil (a central nervous system stimulant), low-dose naltrexone, 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, nor are they recommended in the NICE guideline, and would not normally be prescribed outside a research setting.

Routine blood tests

The following blood tests should be done 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
- 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



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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-type symptoms, 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.

In addition to the management of key ME/CFS symptoms, there may be other symptoms that are linked to what are called co-morbid conditions. These are conditions that are more common if you have ME/CFS. More important ones include irritable bowel symptoms, interstitial cystitis, joint hypermobility, migraine-type headaches and postural orthostatic tachycardia syndrome (PoTS).

Further information:

The MEA has information leaflets covering

- A-Z of Symptom Relief

<https://meassociation.org.uk/kd84>

- Drugs that may be prescribed for pain relief in ME/CFS – amitriptyline, duloxetine (Cymbalta), gabapentin (Neurontin) and pregabalin (Lyrica).

- Management of all the main symptoms – eg cognitive dysfunction, cold hands and feet, headaches, sleep disturbance

- Management of co-morbid conditions – fibromyalgia, irritable bowel symptoms, PoTS

<https://meassociation.org.uk/me-association-shop>

4: PACING - STRIKING THE RIGHT BALANCE BETWEEN ACTIVITY AND REST

Energy and activity 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 a defect in the body's ability at a cellular level to produce enough energy to carry out and sustain mental and physical activities. Living with ME/CFS is rather like having a battery that is consistently under performs, rapidly runs out of power, and does not successfully recharge.



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Energy management has to involve physical, mental and emotional activity – all of which require some form of energy production and can quickly exacerbate ME/CFS symptoms when carried out beyond a person's limitations.

In practice this should involve an individual activity-management programme known as pacing. This should take account of three factors: stage of your illness, severity of your illness, and to what extent your symptoms fluctuate.

Pacing involves finding a baseline of physical and mental activity that you feel comfortable with and is not exacerbating symptoms. Physical and mental activities should then be carried out in small, flexible amounts with longer periods of rest or relaxation in between. Gradual increases in physical and mental activity levels should only be introduced when you feel comfortable doing so and are not resulting in any form of symptom exacerbation. It's important to stick within your energy limitations at all times and not do anything that results in post-exertional malaise/symptom exacerbation.

Pacing is a very flexible and individual approach to activity management. We believe that it is the best and safest method of managing your ME/CFS. Feedback on activity management to the 2002 Chief Medical Officer's Report found that while nearly 90% found Pacing helpful almost 50% reported that an approach called graded exercise therapy (GET), which involves progressive and structured increases in activity, made their condition worse or much worse. Similar results were reported in the MEA Report on cognitive behaviour therapy (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.

If you speak to your GP and obtain a referral to an ME/CFS specialist, you should (in theory) be provided with expert information and guidance on how Pacing works in practice. You may also find that suitable advice on activity management can be obtained from private or NHS physiotherapists or occupational therapists away from a specialist ME/CFS centre. But you need to ensure that they understand ME/CFS and can tailor an approach to suit your individual circumstances.

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



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Graded exercise therapy (GET) used to be recommended by NICE in their previous (2007) guideline. Having assessed all the evidence for both benefit and safety in the process of preparing the new NICE guideline on ME/CFS, the NICE guideline committee concluded that the evidence of benefit was very low and there were significant problems with safety. Consequently, GET is no longer recommended for people with ME/CFS and should not be prescribed.

Further information

The MEA has a new and very comprehensive guide covering all aspects of Activity and Energy management and Pacing:

<https://meassociation.org.uk/h8qj>

5: DEALING WITH EMOTIONAL AND MENTAL HEALTH ISSUES

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. So it's not surprising to find that it can sometimes trigger mental health problems as well.

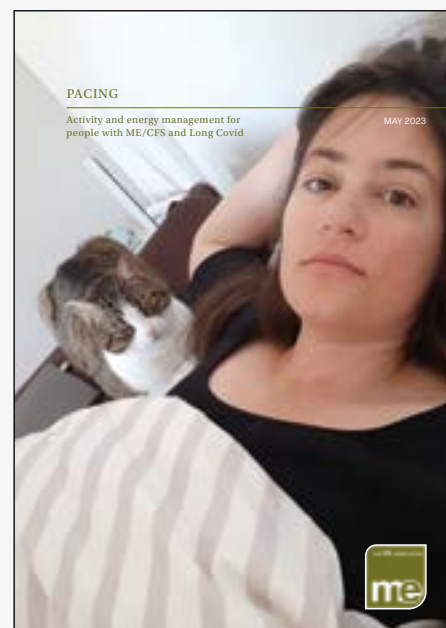
The reasons for this are complex but probably involve both internal factors (i.e. the effects of the illness on brain function and brain chemical transmitters) and external factors (i.e. problems relating to benefits, doctors, family, finances, friendships, work).

On the other hand, ME/CFS can sometimes result in changes that help to lessen the negative effect – for example, being able to spend more time with your family, partner or children.

So it can 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



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ME/CFS. The new NICE guideline makes it clear that CBT should no longer be used as a treatment for ME/CFS that is based on the theory that it is caused by abnormal illness beliefs and behaviours. However, CBT can help people to cope – as it is sometimes used in other long-term illnesses.

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 antidepressant medication. Symptoms of true clinical depression 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 antidepressants have to be used with care and probably started at the lowest possible dose, with gradual increases until an optimum dose is achieved.

Further information

The MEA has a range of leaflets available: **Anxiety and Panic Attacks**; **Depression – Antidepressants and other treatment options**; **Managing your emotions**; **Stress and how to deal with it**:

<https://meassociation.org.uk/mhme>

6: 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 – where input from a paediatrician can be especially helpful if there are problems about attendance or obtaining home tuition.



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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 for those in employment.

ME/CFS is an illness that is covered by the 1995 Disability Discrimination Act and by section 6 of the 2010 Equality Act. This latter legislation provides 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 to stay in work or return to work. It is also relevant to education. You may also be 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. These organisations will normally provide free legal and employment advice to their members.

Further information

The MEA has information leaflets covering: **Employment and occupational health**; **Ill health retirement**; **Going to University**:

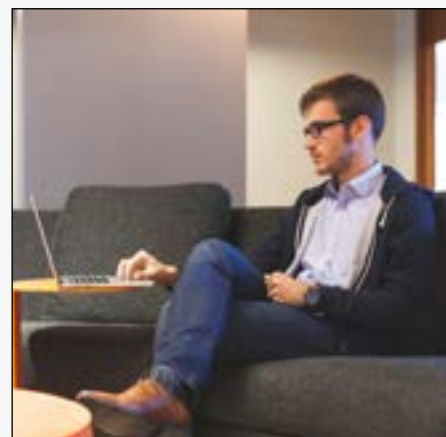
<https://meassociation.org.uk/9mme>

7: 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 can be problematic when it comes to people with fluctuating medical conditions like ME/CFS.

Decisions on benefit entitlement should primarily be made on the degree of disability and ill health and not the diagnostic label. Neither is it appropriate for participation in a particular type of treatment programme to be made a condition for claiming or continuing to obtain sickness or disability payments.

The process of claiming state benefits may sometimes seem like jumping over a never-ending series of hurdles, with far too many



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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 people are unable to perform both mental and physical tasks in a regular, reliable and sustained manner and without causing harm to either themselves or other people. So do make use of the fact that the DWP accepts that you must be able to carry out the WCA descriptor tasks reliably, repeatedly, safely and in a timely manner.

Anyone who is 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

Alongside other charities, the MEA has worked with the DWP to try to increase the number of successful first-time benefit claims from people with fluctuating medical conditions. This has included producing recommendations to improve the Work Capability Assessment part of the ESA. The WCA is once again being reviewed with the aim of providing more help to people who are able to return to some form of work. However, it's difficult to know whether this is going to help people with ME/CFS or make obtaining ESA even more difficult.

Further information

■ The MEA has a range of information leaflets covering all the main DWP benefits and one covering income protection/permanent health insurance. A full list can be found in the Benefits section of the MEA website shop.

<https://meassociation.org.uk/iqgm>



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8: 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.

If you do require this sort of help in the home you should ask for a social care needs assessment from your local Social Services department.

Loss of social contacts and networks locally or at work is not unusual if you have ME/CFS. This may mean that you 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 all 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 DWP Carers Allowance if he/she regularly cares for you at least 35 hours per week and you receive Attendance Allowance, the daily living component of PIP or some other benefit.

Further information

■ For information and advice on practical aids, contact your nearest Centre for Independent Living:

www.ncil.org

■ Carers UK is an excellent source of support and advice for carers:

www.carersuk.org

■ The MEA has information leaflets covering Blue Badge applications, Carer's Allowance, Care and Support Plans, and Disability Aids and Appliances. We also have a **To Whom It May Concern** letter that can be used to support applications for disability aids and appliances.

<https://meassociation.org.uk/me-association-shop>



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9: VITAMINS, MINERALS, SUPPLEMENTS AND NUTRITION

People with ME/CFS have enough restrictions in their lives without adding an unnecessarily restrictive diet to the list. However, a number of sensible dietary changes may be helpful in some circumstances.

Besides having a healthy, balanced diet containing fruit, vegetables, etc, 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 (i.e. problems with remaining in an upright position) or low blood pressure.

If you have irritable bowel symptoms, 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 to ensure adequate nutritional intake. Trying what is called a FODMAP diet may also be helpful.

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. There is now good evidence to indicate that we should all be taking a regular small dose of vitamin D every day, especially during the low sunlight winter months.

Apart from vitamin D, there is very little scientific evidence to show that people with ME/CFS have significant deficiencies in vitamins or minerals – including iron. 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 a good quality vitamin and mineral supplement is a sensible precaution.

Further information

■ The MEA has a range of information leaflets covering diet, nutrition and muscle energy supplements. These include a leaflet on Vitamin D.

<https://meassociation.org.uk/curr>



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10: 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 to find a reputable practitioner who is not making unproven therapeutic 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’.

The MEA reports companies and therapists to the regulatory authorities for making unproven therapeutic claims. You can check on the products and practitioners that we have reported by using the search facility on the MEA website.

Please note that the Lightning Process is not recommended by either the ME Association or the new NICE guideline.

Further information

■ The MEA information leaflet on Alternative and Complementary Therapies:

<https://meassociation.org.uk/acam>



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INFORMATION AND SUPPORT FROM THE ME ASSOCIATION

■ The MEA website shop has details on information leaflets covering all aspects of the management of ME/CFS:

<https://meassociation.org.uk/me-association-shop>

■ **The ME Connect helpline** provides information and support seven days a week from 10am to 12 noon, 2pm to 4pm and 7pm to 9pm. Calls cost the same as other standard landline numbers starting 01 or 02. Call: 0344 576 5326.

There is an ME Connect email service as well. Please email meconnect@meassociation.org.uk

<https://meassociation.org.uk/me-connect>

■ The Medical Matters section on the MEA website contains a library of frequently-asked Questions and Answers from ME Essential magazine.

<https://meassociation.org.uk/medical-matters>

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. We will provide you with a regular ME Essential magazine which is simply the best magazine available. It will keep you informed of developments, it shares personal stories and the latest medical information, with an Ask the Doctor feature in every issue.

<https://meassociation.org.uk/nmrs>



“Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful.”



THE ME ASSOCIATION



ME CONNECT

The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

Contact ME Connect by phone, email
or social media private message



0344 576 5326

10am-12 noon, 2pm-4pm, 7pm-9pm
every day of the year



HERE TO LISTEN

We are here to listen,
validate and empathise
with any issues you might
be facing.



VITAL SUPPORT

We are here to help
you reach an informed
decision.



SAFE ENVIRONMENT

We provide a safe,
confidential, and
understanding
environment where
you can be heard
and understood.

We're here for you!



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