

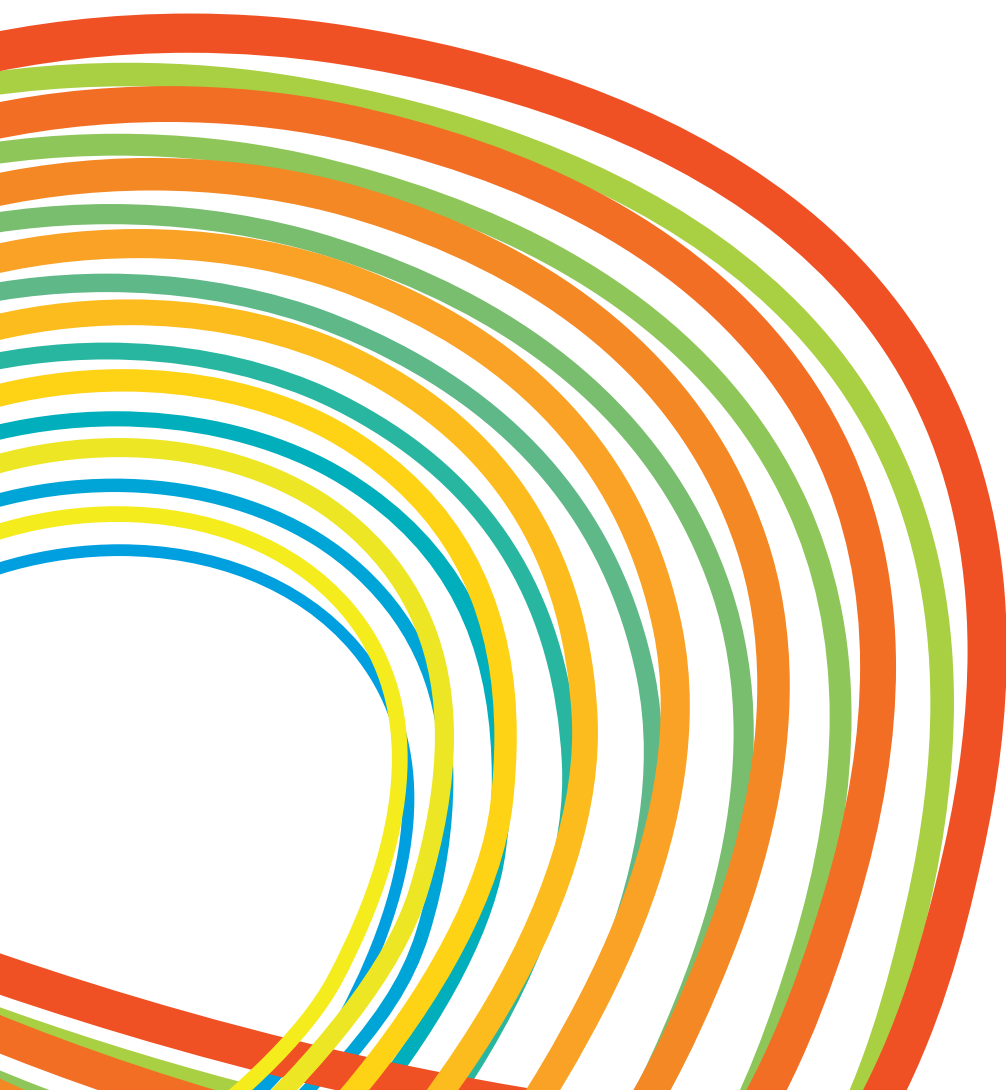


Newly diagnosed with M.E./CFS



Information and advice
for you and your GP





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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./CFS¹ 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.

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

There are some striking similarities between the symptoms of Long Covid and the symptoms of M.E./CFS, although there is no evidence to suggest they are the same thing. The term Long Covid is commonly used to describe signs and symptoms that continue or develop after acute Covid-19. This booklet may be used appropriately for people with a suspected diagnosis of Long Covid. You can also refer to NICE's 2020 *COVID-19 rapid guideline: managing the long-term effects of COVID-19*.³

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.'

Research⁵ 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 2021 NICE guideline¹ for M.E. advises that healthcare professionals: “help people with ME/CFS develop a plan for energy management as part of their care and support plan. Support them to establish realistic expectations and develop goals that are meaningful to them.” (Section 1.11.3)

Energy management - or pacing as it's more commonly know - can take time to learn, and there are many resources available to help you do this. Visit www.actionforme.org.uk/pacing for information, resources and signposting.

Symptoms

The 2021 NICE guideline notes four symptoms that should be present for a diagnosis of M.E. (Section 1.2.2):

- debilitating fatigue not caused by exertion, that's worsened by activity and not relieved by rest
- post-exertional malaise (see below)
- unrefreshing sleep or sleep disturbance (or both)
- cognitive difficulties (sometimes described as 'brain fog')

But it can also come with a range of other symptoms. Don't be alarmed by the long list 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.

Post-exertional malaise

- This is the worsening of symptoms after physical, cognitive and/or emotional activity, which is often delayed by hours or days, is disproportionate to the activity, and has a prolonged recovery time (may last hours, days, weeks or longer).

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.

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. 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. Around one in four people with M.E. 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.

The 2021 NICE guideline for M.E. recommends that healthcare professionals diagnose M.E. when someone has had key symptoms (see p 6) for three months, and they cannot explained by another condition (section 1.4).

While there is no single pharmacological cure for M.E., there are a number of medications that your doctor can prescribe that may help with individual symptoms. In some cases, this may include those licensed primarily for other health conditions.

For example, some tricyclic antidepressants are prescribed in low-doses to help with sleep or chronic pain. Using antidepressants does NOT mean that M.E. is the same as depression, or that it is a mental illness. The doses used to help with sleep and pain are much lower than the doses used to help manage depression.

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.

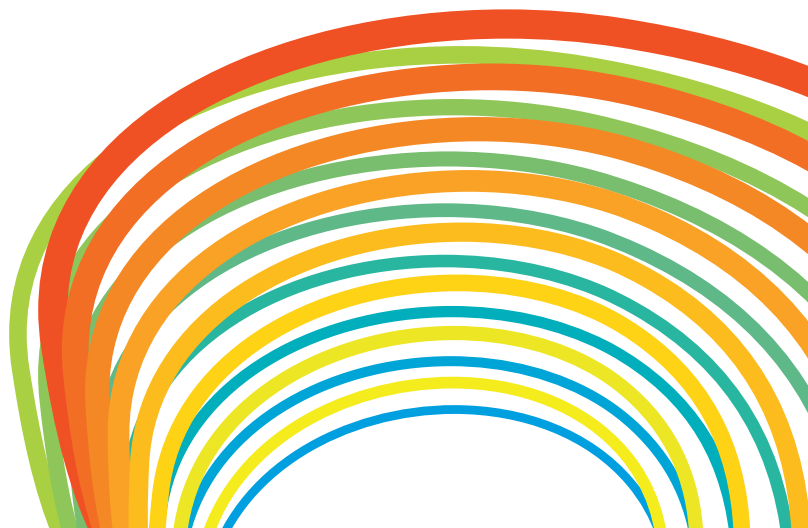
In summary, try to:

- 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
- be realistic about what you can and can't 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.

UK charity The Patients Association (Tel: 0800 345 7115.

www.patients-association.org.uk) offers specialist information and guidance to help you access and make sense of the health and social care services you are entitled to.



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.

The 2021 NICE guideline on shared decision-making⁴ says that healthcare professionals should: “support shared decision making by offering interventions at different stages, including before, during and after discussions, so that people are fully involved throughout their care; [and] tailor the methods used to support shared decision making to the care setting and context in which the decision is being made, including whether the discussion is happening in person or remotely by video or phone.” (Section 1.2)

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 feedback from people with M.E., telling us what works for them.

Alice says: "I first noticed something was wrong when I was about 20 years old. I became ill a few weeks before Christmas with what I thought was the flu. I felt so weak, I couldn't move, and my throat was so sore I couldn't swallow. I ended up going to the out-of-hours surgery in the middle of the night because I was in so much pain. The doctor said I had a bacterial infection and just told me to continue to take ibuprofen and paracetamol. After a few weeks I got better, but from then on my health started to deteriorate little by little. I felt exhausted constantly, and my doctor said I had low vitamin D and iron levels so put me on tablets for those. I kept getting sore throats down my left side, so I saw an ear nose and throat specialist who said they couldn't see anything wrong and so just sent me away. I still felt awful and every day I would get to around 4pm and crash - I would have to nap, and if I didn't I would become almost zombie like, I couldn't function. I went back to the doctors

Helen says: "It took me many years to accept my M.E. and the situation with my health and try to stabilise my health (learning to pace!). I have tried anything and everything to improve my health. I decided to set up my Instagram page (@the.invisibleme) to share what I have learnt and the challenges I face as I continue to fight invisible illness one day at a time. Today my health is relatively stable; it's not great but it's stable! now happily use a wheelchair (a huge step) to conserve energy and despite what many have said I now know that chronic and invisible illness is well and truly real."

Christopher says: "Action for M.E. has helped just by being there, showing that pervading ignorance is not all-pervading. I enjoy reading the updates and feeling encouraged by various developments. Certainly, once I had my diagnosis, it helped me to identify myself in that regard and that in turn helped me get a handle on what I was going through. My advice for those recently diagnosed with M.E. is to take it easy, one day at a time. Tell people you don't need sympathy, but you want understanding. M.E. changes your life so much and you need to be willing to roll with it. Forgive people their ignorance but do not stand for people kicking you when you're down."

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
- 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**
- CPD-accredited online learning that you can share with your doctor on diagnosing and managing the symptoms of M.E. at **www.actionforme.org.uk/learn-about-me**

Keeping you and your GP up to date with M.E. research

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

In 2022, the M.E./CFS Priority Setting Partnership worked with people with M.E., carers, clinicians and researchers to identify the Top 10+ M.E. research priorities to influence future research funding (www.psp-me.co.uk). This followed the launch of DecodeME, the world's largest genetic study into the disease (www.decode.me.org.uk).

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 changes and correlation with symptoms (Zeineh et al, 2014, *Radiology*)
- brain inflammation (Nakatomi et al, 2014, *Journal of Nuclear Medicine*)
- using the DePaul Symptom Questionnaire to assess symptoms (Brown and Jason, 2014, *Biomedicine, Health & Behavior*)
- metabolic phenotypes (Hoel et al, 2021, *Journal of Clinical Investigation*)
- altered endothelial dysfunction (Blauensteiner et al, 2021, *Scientific Reports*)
- red blood cell deformability (Saha et al, 2019, *Clinical Hemorheology and Microcirculation*) B cell receptors (Sato et al, 2021, *Brain, Behaviour and Immunity*).

To keep up to date with the latest published research on M.E., visit

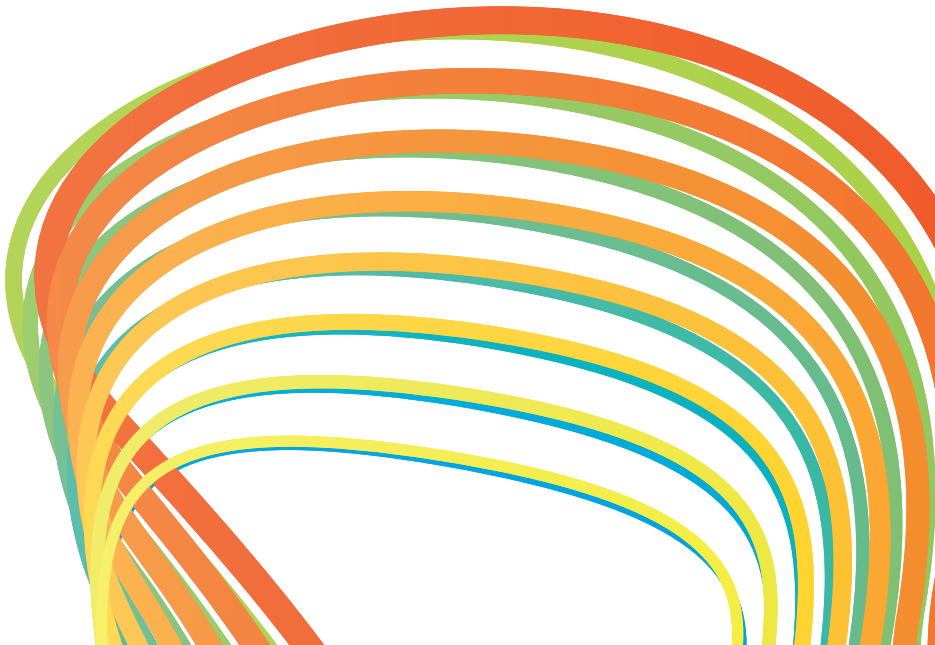
- Science for ME (www.s4me.info), an independent, patient-led, international forum for people with M.E./CFS and the carers, clinicians, scientists and advocates who support them
- ME/CFS Research Review (www.mecfsresearchreview.me), an insightful blog by Simon McGrath who has lived with M.E./CFS for more than 20 years.

...but diagnosis can still be problematic

An evaluation of referrals⁶ made by GPs to the specialist clinic at Bart's Hospital found that 49% did not have a diagnosis of M.E.

A study⁷ 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 test recommended in the guidance? The 2021 NICE guideline¹ for M.E. advises which tests should be carried out along with a medical assessment (including symptoms and history, comorbidities, overall physical and mental health), physical examination and an assessment of the impact of symptoms on psychological and social wellbeing.
- 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

The 2021 NICE guideline says (section 1.2.6): “When M.E./CFS is suspected, give people personalised advice about managing their symptoms. Also advise them:

- Not to use more energy than they perceive they have – they should manage their daily activity and not ‘push through’ their symptoms
- To rest and convalesce as needed (this might mean making changes to their daily routine, including work, school and other activities)
- To maintain a healthy balanced diet, with adequate fluid intake.”

With your informed consent, healthcare professionals can liaise on your behalf with employers, education providers and support services.

Once a diagnosis of M.E./CFS has been obtained – see p 9 of this booklet – you should be referred to a specialist clinician who can confirm the diagnosis and support you to develop a care and support plan.

The NICE guideline says: “The personalised collaborative care and support plan is developed by the ME/CFS specialist team based on a holistic assessment. It is the basis for other assessments and plans in areas such as social care, energy management, physical activity, physical functioning and mobility, cognitive behavioural therapy and dietary management.”

There are a number of specialist NHS services for M.E. for adults and children, along with consultants working in related settings (eg. pain management), plus the option of private healthcare, with some providers taking NHS referrals.

Unfortunately access to specialist provision across the UK is patchy, and there are very few specialist M.E./CFS services outside of England. If your GP suggests a referral to a specialist, it is your choice whether or not you would like to be referred.

You may be eligible for welfare benefits support, and/or social care services. Action for M.E.’s Information & Support Services (contact details are on the back page of this booklet) can help you think about the options available to you, and prioritise things so they feel less overwhelming.

References

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Acknowledgements

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- Dr Alastair Miller
- 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.



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