

NHS healthcare for people with M.E.

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Introduction

The family doctor or General Practitioner (GP) is usually the first point of contact for health advice or treatment. GPs work as part of a team, known as a primary healthcare team, which may also include practice nurses, community nurses, health visitors, pharmacists and other healthcare professionals.

Sometimes it may be necessary for your GP to refer you to a specialist. A visit to a specialist is known as 'secondary' care and can only be arranged through your GP.

This information sheet is for people with M.E. (also known as Chronic Fatigue Syndrome or CFS). It explains what help is available from primary and secondary care and how to make the most of this. For information on healthcare for children see *Further Information* at the end.

It is worth noting that the medical profession generally use the term Chronic Fatigue Syndrome (CFS). Even if you prefer the term M.E. it may be useful for you to use Chronic Fatigue Syndrome when visiting your doctor.

What can I expect from my primary healthcare team?

Ideally your primary healthcare team should be able to manage your illness in the same way that they would other chronic health problems, such as diabetes or asthma. However not all GPs are confident and experienced with the diagnosis and management of this complex illness.

A GP who has the experience of other patients with M.E./CFS may be able to provide an appropriate management programme, working together with other members of the healthcare team. This might include treatments and strategies to help control symptoms and improve your quality of life.

Your GP should be able to diagnose M.E./ CFS but it may take several appointments to achieve. You might first be given a provisional diagnosis. Sometimes a referral to a specialist may be necessary.

If you have had a diagnosis of M.E./ CFS for some time it is still important to visit your GP. This will help to ensure that your condition is monitored and that any medication you are taking is reviewed on a regular basis. If you experience significant setbacks or relapses, or need help or assistance with benefit and insurance claims, it is helpful if you and your GP have an established relationship.

If your GP has limited experience in the management of M.E./CFS, Action for M.E. has produced a helpful publication for GPs: *Guidance on the management of CFS/M.E.* The government's Chief Medical Officer has informed GPs about this publication. Alternatively there may be another GP within the same practice who is more experienced or interested in the management of M.E./CFS, so do ask.

How can I make the most of appointments with my GP?

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

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.

It can help to write down questions you want to ask your doctor. Be sure to tell your GP about all the symptoms you are experiencing, even if they seem unrelated. They may be able to see a link which is not obvious to you. If you develop any new 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./CFS or are caused by something different.

You could try keeping a simple diary of your symptoms and problems to help you and your GP see a pattern and assess how your condition may be fluctuating. This can also be a helpful prompt if you see another healthcare professional or if you are filling out forms for benefit claims.

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.

Advice by telephone

GPs are often happy to give advice on the telephone as it can save time for both you and them. Check with your surgery to find out if this is possible and if they have set times when they prefer patients to telephone. This could be convenient if you need specific advice but don't feel well enough to visit the surgery. If your GP is unavailable, you may be able to leave a message asking for them to call you back when they are able to.

Seeing a different GP

There is often more than one GP in a practice and you can ask to see any of the GPs in the practice where you are registered. However, it is a good idea to try and see the same GP each time so that you can build a relationship with them.

Second opinion

You can ask to have a second opinion, but you are not automatically entitled to this. Before asking for a second opinion, it is a good idea to ask your GP or consultant to go over anything you didn't understand or are unhappy about. This may clarify any issues or concerns you have.

Home visits

Your GP will decide if, and when, a home visit is required on the basis of your medical condition. This can be particularly important if you are severely affected with M.E. If you are unable to get to the surgery because you feel too ill to leave your home, it may be helpful to discuss this with your GP on the telephone or get a friend to do this for you. It may be possible for the district nurse to visit you, or for a friend or relative to go to the surgery on your behalf to discuss your condition. In this situation you would need to write a letter to your GP giving them permission to discuss your case.

Managing at home

Local social services departments are responsible for providing home care services (formerly called home help) for people who need help at home with personal care, for example washing and dressing. There is normally a means-tested charge for these services. The amount of help on offer varies across the UK. You can find the details of your local social services in the phone book, from Directory Enquiries, or you can ask at your local library or Citizens Advice Bureau.

Aids for people with disabilities are available from your doctor; other health care professionals involved in your care; local authority social services departments and a number of voluntary organisations, including the British Red Cross. If your problems are severe it may be appropriate for you to be assessed by a community occupational therapist in order to receive modifications to your home such as ramps and stairlifts.

If you are experiencing significant problems with your diet and struggling to maintain an adequate food intake, discuss the possibility of a referral to a dietician with your GP or hospital specialist.

Prescription costs

Most people have to pay for their prescriptions although there are some exemptions. Leaflet HC11, available from your main post office, will tell you whether you need to pay. If you need medication on a regular basis you can reduce costs with a pre-payment certificate. You can find out more about this in Leaflet HC12 which is also available from main post offices, or visit www.dh.gov.uk.

Complaints

If you have concerns, speak to someone directly involved in your care (GP, nurse, practice manager, receptionist), as they may be able to sort out the problem quite easily. If this doesn't resolve the matter, each GP surgery has a complaints procedure and you can speak or write to the person who deals with complaints.

Sometimes you might want to talk to someone who is not directly involved in your care. The new Patient Advice and Liaison Services (PALS) that is available in all NHS and Primary Care Trusts, or the Independent Complaints Advocacy Service (ICAS), should be able to help you. Alternatively, you can phone NHS Direct on 0845 4647 for advice on how to make your complaint or visit www.nhsdirect.nhs.uk.

Will I need specialist care?

If your GP has any doubt about your diagnosis or the management of your illness, a referral to a specialist in secondary care may be appropriate. You may also be referred to a specialist if you have severe or long-standing symptoms, or if your case is particularly complex. Discuss with your GP whether referral to a specialist would be helpful.

Specialists are usually based in hospital outpatient departments. They may be a specialist in another medical condition but have an interest in M.E./CFS. Your referral may not be to your nearest hospital and it is also very likely that there will be a waiting list.

How can I prepare for my visit to a specialist?

To reduce stress and minimise the delayed fatigue that can so often be experienced with M.E. try to allow plenty of time for the journey to your hospital appointment. It is also important to allow yourself time to rest afterwards.

It is often helpful to be accompanied, for some or all of the appointment, by a carer or friend. They can help provide additional information or perspective during the consultation if needed. They can also make notes of any key points discussed during the appointment.

Your GP should send any relevant test results and other related information with your referral letter. You might find it helpful to prepare for the appointment by writing a simple summary of what has happened to you medically. This can be particularly helpful if your story is complicated and will be a useful prompt for you. A list of your main symptoms and how they affect you; an outline of your current level of activity and of your main concerns can help to focus discussion and make best use of the available time.

It is important to have a record of any other health professionals you have seen or are currently seeing. List any medication that you are taking currently or that you have taken in the past, including the dose and whether you have felt any benefit or experienced side effects. It is also a good idea to ensure that the specialist is aware of any complementary therapies you are using or have tried.

What can I expect at the appointment?

The specialist will want to make a full assessment of your situation, leading to a diagnosis. They should also outline an overall plan of management and how it will be achieved, and provide a rough idea of what the initial timescale and goals will be. This will be given as advice to you in person and in a letter to your GP. The plan may include advice on managing physical and mental activity, lifestyle changes and adjustment and coping. The details will depend on individual circumstances.

The specialist may discuss treatments. This may be medication or the use of other approaches that can help alleviate symptoms such as pain, sleep disturbance, mood disturbance, gut symptoms, dizziness, etc. If medication is suggested, this may be prescribed at the appointment or recommended to your GP for you to try later.

They may discuss the necessity of a referral to another specialist or professional for some specific aspect of your symptoms or condition. This could involve professionals such as physiotherapists, occupational therapists, dieticians, social workers, counsellors or clinical psychologists. Depending on the nature of the problem and the best options for treatment, further referrals might not be conducted at the same hospital and there may be a waiting period. If you do see another professional they will assess you and then plan further visits if necessary. They will also keep your GP and specialist updated.

Issues about benefits, employment and/or education may need to be addressed. The specialist may be able to write letters in support, if appropriate.

What can I expect after my appointment with a specialist?

The specialist will decide with you and your GP the most appropriate medical supervision and follow-up arrangements. Your GP will be the main person for supervising your ongoing care, and will normally be the first point of contact for any problems that arise.

Please remember that if you decide to see a specialist privately it is important that they keep your GP and any NHS specialist informed so that your treatment is managed effectively. Action for M.E. has an information sheet, *Guidance on seeing a private practitioner*, which highlights issues you need to be aware of before starting any private treatment.

Where can I find further information?

See *How we can help* for details of the information and support Action for M.E. can provide.

We can also provide your GP with Action for M.E.'s *Guidance on the management of CFS/M.E.* and more detailed information about M.E. services. Your GP can email admin@afme.org.uk to request a copy of the guide.

Important differences exist between children and adults in the nature and impact of the M.E. and its management. However, the principles of care of children and young people with M.E. are common to many chronic conditions. For further information see Action for M.E.'s *Children and Young People's Guide to The Chief Medical Officer's Working Group Report on CFS/M.E.* and our guide for GPs.