

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.



HOW TO DEAL WITH YOUR DOCTOR

INTRODUCTION

Establishing a good relationship with your doctor is a vital part of any illness management plan. This is especially so when you have a complex long-term condition like ME/CFS.

When it comes to primary care, a good GP should normally be able to make an early and accurate diagnosis and deal with many aspects of routine management while making use of a hospital-based referral service for ME/CFS where one is available.

Your GP also acts as a gatekeeper to a range of health professionals and services that you may need to use. These include referral to a hospital specialist, physiotherapy and occupational therapy (OT) services, dietary advice and support/care social services.

A good GP will also provide supportive medical evidence for DWP benefit applications, insurance claims, ill-health retirement, home tuition, modifications at work, etc.

Unfortunately, what should happen in theory does not always happen in practice.

Some GPs are very helpful and knowledgeable (or keen to learn) when it comes to patients with ME/CFS. But others find this a very difficult illness to deal with and may then adopt a 'nothing can be done – so why are you here again?' kind of attitude.

A small but significant minority remain sceptical as to whether ME/CFS is actually a real illness. And a few are still

THE CHANGING FACE OF GENERAL PRACTICE

The NHS is seriously underfunded and there are major problems with GP recruitment. GP consultations have risen by 15% over the past five years and GPs are dealing with far more patients with complicated and long-term conditions like ME/CFS.

Many people do not have a 'family' GP any more – who knew all the members of the family and would talk to their patients face to face rather than making notes while looking at a computer screen. Today you are more likely to see whichever GP is available - who may not know anything about your previous medical history and can only briefly look at your medical notes.

There may be a team structure at the surgery and you will then see the most appropriate health professional. A practice nurse may be able to help with smaller/simpler problems and will refer to a GP if necessary. It is often easier to get an appointment with a nurse. Some GPs specialise in particular illnesses and it may be possible to ask for that GP. But this is likely to mean a longer wait.

In some places, you may have to wait a week or more for a routine appointment. If there is difficulty in arranging a surgery visit, you could ask for a telephone appointment instead. If you are dealing with an unresolved problem, it's sensible to try and see the same GP. If you feel that you need more time, ask for a double appointment. But you need to do this in advance – not on the day.

Home visits have declined dramatically in recent years. They are now normally reserved for patients who are so ill or frail that they cannot visit the surgery, or where the effort to do so would lead to a deterioration in symptoms. The surgery should have clear information on their home-visiting policy – check with their website or reception staff. Another option may be a Skype consultation.

Almost all GP surgeries now have a website where there should be up-to-date information on staff, surgery times, special clinics, and policies on things like home visits. Some surgery websites also allow you to book appointments on-line.

unpleasant or even hostile at the very mention of ME/CFS.

This Management File deals with most of the common queries and problems that arise when dealing with doctors. While concentrating on GP services, advice on dealing with hospital doctors is also included at the end.

HOW TO FIND A GP WHO IS HELPFUL AND SUPPORTIVE

Assuming that a diagnosis of ME/CFS has been made, and you are already registered with a GP surgery, you may find that there is a considerable variation in attitude amongst the individual

GPs. If the GP you are registered with, and/or the one you normally see, isn't being helpful the next step is to find out if there is another GP at the surgery who is better at dealing with ME/CFS. A tactful enquiry to the practice manager, or possibly the senior partner, is one way of taking this forward.

If there isn't anyone at the surgery who is interested in ME/CFS – as does happen – the only other NHS option is to change to a GP at another surgery, assuming that this is geographically possible.

Obtaining information about other GPs in the local area, who may be good, bad or indifferent when it comes to ME/CFS, is easier said than done. One source of information is a local ME support group – the MEA website has a full list of contact details for all the local ME groups in the UK. Or you could post a message on the MEA Facebook page.

HOW TO CHANGE TO ANOTHER GP SURGERY

This should be a relatively straightforward process – provided you have found another GP who is willing to accept you onto his/her list. You don't have to tell your current GP that you want to change. However, if you do, it could speed up the process of transferring your medical records.

You don't have to tell the new GP surgery why you want to change either but you will need to fill in a registration form. A request will then be made to your current GP for your medical records to be transferred to the new GP surgery.

If you cannot find another GP, but still want to leave your current GP, you can ask NHS England Customer Contacts Centre to find you another doctor – but this could actually mean going from bad to worse.

- ◆ More information on how to find a GP or change your existing GP can be found on the NHS Choices website:
<https://tinyurl.com/ya37neka>

RIGHTS AND REQUESTS

As with any relationship, doctors and patients have to work together in a process that involves both rights and reasonable requests.

The General Medical Council (GMC) produces very clear guidelines relating to professional conduct. In practice, this means that doctors have to treat patients with respect and involve them in the decision-making process.

At the same time, patients have to accept that there are limitations to what a doctor can or cannot do, or be expected to know about ME/CFS. So patients cannot make unreasonable demands regarding investigations or treatments.

In relation to DWP benefits, GPs do not have to write letters to support benefit applications and may charge to do so. If the DWP asks for a report they will pay for this to be completed.

- ◆ Guidelines on good professional conduct can be found on the GMC website:
<https://tinyurl.com/ya5clwng>

MAKING A DIAGNOSIS OF ME/CFS

A diagnosis of ME/CFS should never be made without your doctor first taking a detailed clinical history, performing a full physical examination, and making sure that a number of routine blood and urine tests have been arranged (to exclude other possible causes of ME/CFS-like symptoms) and reported as normal.

This is not something that can be done in around 10 minutes – the average time for a GP consultation. So, if you need more time to discuss diagnosis or management issues, ask if you can have an extended or double length appointment.

In some cases, further investigations may be necessary to rule out other causes of an ME/CFS-like illness and this may involve being referred to a hospital based service.

In our current state of knowledge, costly investigations such as brain

scans and immune function profiling are research-based investigations that do not normally help with diagnosis or management of ME/CFS. So there is no point in expecting that they will be arranged by a GP – unless there are sound reasons for doing so.

Both NICE and the Chief Medical Officer's Working Group report on ME/CFS made very specific recommendations on the way in which a diagnosis of ME/CFS should be made with the aim of establishing an accurate diagnosis in most cases within three months of the onset of symptoms in children and adolescents and four months in adults. Unfortunately, this is still not happening in practice with patient evidence collected by the MEA indicating that only 18% of people are being diagnosed within 6 months of onset and over 60% waiting a year or more for a confirmed diagnosis. Diagnostic delay also has an important impact on all aspects of management and lack of appropriate management advice early on is likely to play a key role in making ME/CFS more persistent and severe.

- ◆ The MEA has an information leaflet covering all the key points relating to making an early and accurate diagnosis of ME/CFS. This includes all the first line blood tests that should be arranged and the timeline. This information can be downloaded from the MEA website:
<https://tinyurl.com/j53t9sw>

GENERAL MANAGEMENT OF ME/CFS

Here are some tips on how to make the best use of what may be a very time limited appointment with a GP:

- Remember that the doctor may not have read all your medical notes before you go into the surgery.
- Explain your symptom with a small amount of detail – i.e. how long you have suffered from this, how severe it is. Be as explicit as you can but keep it short and to the point. Making a written list may help – again, keep it short.

- Deal with the main symptom/problem first – if you have more than one you want to discuss.
- If you can, tell the doctor what you are expecting from the consultation – e.g. a medicine, a referral, a test, etc.
- Your doctor may ask you what treatment/help you are expecting. If you can answer this question, be as clear as you can. If you feel that specialist help or tests would be useful then ask your doctor if this would be possible.
- Have realistic expectations of how your GP may be able to help – e.g. symptomatic relief.
- If you think an examination may be needed then do wear appropriate clothes and shoes.
- Towards the end of your appointment, the doctor is likely to suggest how he/she feels they are able to

help you. If you disagree then it is OK to ask a question or to briefly say what you had hoped for as far as help is concerned.

- Occasionally a doctor may say that he/she feels you are anxious or depressed. Explain to the doctor that when you are not well and need to work/look after a home and family, etc. So it is understandable that you may appear anxious or upset. But it is your symptoms you would like help with.

Make the most of your 10 minutes!

DRUG TREATMENTS

When it comes to the use of prescription-only drugs at a GP level, this is very much limited to the treatment of key symptoms such as pain, sleep disturbance, irritable bowel and depression (if it occurs).

Without knowing more about the underlying disease process, and the

safety and effectiveness of speculative forms of treatment, GPs are unlikely to prescribe drugs that do not have a license for use in ME/CFS or an official (ie NICE) recommendation for use in ME/CFS. This is partly because, if anything goes wrong with a speculative form of treatment, this could have serious legal consequences for the doctor who prescribed it.

So it's highly unlikely that a GP is going to be willing to prescribe an antiviral or immunomodulatory drug, or even something like vitamin B12 injections. These sort of treatments are only likely to be available on a research or clinical trial basis through a doctor working in a hospital-based service with expertise in dealing with ME/CFS.

When seeing your GP it's worth mentioning any over-the-counter medicines and supplements you are taking – as they can interact with prescription-only drugs.

REFERRAL TO A HOSPITAL-BASED ME/CFS SERVICE

If you feel that your GP isn't able to deal with either diagnosis or management of ME/CFS, then it's perfectly reasonable to ask if you can be referred to a hospital-based ME/CFS service/clinic.

Some GPs are still not aware that these services exist (most of which are in England) and should be quite happy to receive this information. The MEA website has a full list of ME/CFS clinics, along with their contact details:

<https://tinyurl.com/yxo6gjwo>

However, in some parts of the UK there isn't a hospital-based referral service. In this case, you can still ask to be referred to a service or consultant of your choice outside the local area. This is a process that isn't always straightforward or known about. If there is a problem getting a referral, you could point out to the GP that this has been raised in the form of a parliamentary question from the Countess of Mar:

<https://tinyurl.com/zj3h8k8/>

If there is a long waiting list for an appointment it's worth contacting the

clinic direct to see if this could be speeded up – for example by being willing to take a short-notice cancellation.

ONLINE DOCTORS

It is now possible to consult a doctor online. One example is Push Doctor: www.pushdoctor.co.uk. This service is staffed by off duty GPs and offers an appointment within minutes. Prescriptions can be emailed. Top Doctors also provides on-line consultations: www.topdoctors.co.uk.

There is a free online GP service being trialled by the NHS called GP At Hand: www.gpathand.nhs.uk. This service currently only operates in parts of London but if successful it will become a 24/7 service. For people who register, the service may become their registered GP.

Downsides to on-line consultations include the fact that the doctor may know little or nothing about ME/CFS and some issues can only be sorted out in person – so really require a

face-to-face consultation.

Always check that the service is regulated by the Care Quality Commission: www.cqc.org.uk. And do be careful when searching for symptoms and medical information on some general websites. Use the MEA website: www.meassociation.org.uk and the NHS Choices website:

<https://tinyurl.com/ybkpkxl2>

PRIVATE DOCTORS

A growing number of private GPs and specialists, as well as private health providers like BUPA, see fee-paying patients. This is an option to consider if you are having difficulties with your NHS GP and can afford to go privately. However, there is no guarantee that you are going to find someone who knows any more about ME/CFS than your GP – even though you may end up with a more understanding doctor who is able to spend more time with you.

There are also a small number of private doctors who either specialise in ME/CFS, or see private patients in addition to their NHS work. If you do decide

to go privately, you will normally need a referral letter from your GP – who should be kept informed about any results or treatments that follow. A first-time consultation with a private specialist is likely to cost around £200 – the cost of blood tests and other investigations is extra and can quickly mount up.

Remember that there are supposed to be clear boundaries between private medicine and NHS medicine. So, if you opt to go and see a private specialist, you won't normally be able to divert back to the NHS for expensive tests and drugs that may be required.

HOSPITAL DOCTORS

If you've been referred to a hospital-based ME/CFS service, you should come under the care of a doctor who is interested in ME/CFS and has built up a considerable amount of practical clinical experience dealing with ME/CFS patients. As doctors from a wide range of -ologies see people with ME/CFS – immunologists, neurologists, psychologists, psychiatrists, virologists – it's inevitable that they will hold differing views on causation and management.

So it's worth finding out what sort of specialist is leading the local service and what sort of management approach is being used before asking for a referral. Again, a local ME/CFS group is likely to have this kind of information. Or you could use MEA Facebook to obtain feedback.

PHARMACISTS

You can also consult your local pharmacist – many of whom now have a separate consulting area where you can have a confidential discussion. Pharmacists should be able to offer sound advice on most minor ailments, know when you need to see a GP about a symptom, and deal with any queries relating to drugs or supplements you are taking.



However, they may not know very much about ME/CFS.

COMPLAINTS ABOUT DOCTORS

Hopefully, this is something that will not occur. However, if you believe that some aspect of your doctor's approach falls below an acceptable standard, then a complaint may be the only way forward.

Depending on the issue involved, this may require nothing more than a well written letter to the GP surgery or hospital concerned pointing out what went wrong and asking for your complaint to be looked into. All GP surgeries should have a written complaints procedure. You can find this at the reception or on the practice website.

Alternatively, you can complain to the commissioner of the service – either NHS England or the local Clinical Commissioning Group (CCG).

You can get help and advice on procedure from your local Patient Advice and Liaison Service (PALS) and your local Independent Complaints and Advocacy Service (ICAS)

PALS provides confidential advice, support and information on health-related matters to patients, their families and carers. PALS can give you information about the NHS complaints procedure, including how to get independent help. You can find your nearest PALS office by calling NHS 111 or by using the directory on their website: www.pals.nhs.uk

ICAS is a national service supporting people who want to make a complaint about their NHS care or treatment. The Department of Health website has more information about ICAS. You can contact your local ICAS office through PALS.

If you make a verbal complaint, a member of staff should record your complaint in writing. They should give you a copy of this written record or send one to you. Whether you complain verbally or in writing, you should receive an acknowledgment from your surgery

within three working days .

If you're not happy with your surgery's reply, you can refer your complaint to the Parliamentary and Health Service Ombudsman.

If the complaint is really serious, or about professional conduct, it may be appropriate to make a complaint to the General Medical Council. If legal issues are involved, you will need to consult a solicitor who deals with professional injury cases and/or medical litigation.

◆ More information on complaints about GPs and all other NHS services can be found on the NHS Choices website:

<https://tinyurl.com/t9wk8ue>

REMOVAL OF A PATIENT FROM A GP LIST

Most GPs have a few patients who they find challenging. But removing a patient from their list is usually a last resort. If a GP removes a patient, this should be done in line with GMC ethical guidelines and in a way that meets their contractual obligations.

Justifiable reasons for removing a patient include violence or threatening behaviour, discriminatory abuse, and repeated unreasonable or inconsiderate actions.

However, it would be unreasonable to remove a patient because they had made a complaint, their disruptive behaviour is caused by a medical condition, there are concerns about resource implications to the practice caused by their care or treatment, or they have a medical condition that puts the doctor at risk. Having ME/CFS, or any other long-term complex medical condition, is not a valid reason for removal.

Where removal is being considered, the GMC expects doctors to do what they can to restore the professional relationship. If this fails, the doctor should warn the patient in writing that this is happening and explain what arrangements are being made for their care until a new GP can be found.

EDUCATING DOCTORS ABOUT ME/CFS

The wide range of views held by doctors about cause and management of ME/CFS often dates back to what they were told (or not told) about the illness at medical school, and then in hospital medicine, before becoming a GP or hospital doctor.

Sadly, many will not have seen a patient with ME/CFS during their entire medical training and may have received little or nothing in the way of lecture-based education on the subject.

A significant proportion will have been given information based on the psychosocial model of causation (ie abnormal illness beliefs and behaviour plus deconditioning) and management (CBT and/or GET) and remain ignorant of the research which has established that ME/CFS is a complex multisystem neuro-immune disease.

So many people with ME/CFS have to

become 'expert patients' and acquire far more medical and research information about their illness from charities and the internet than their GP.

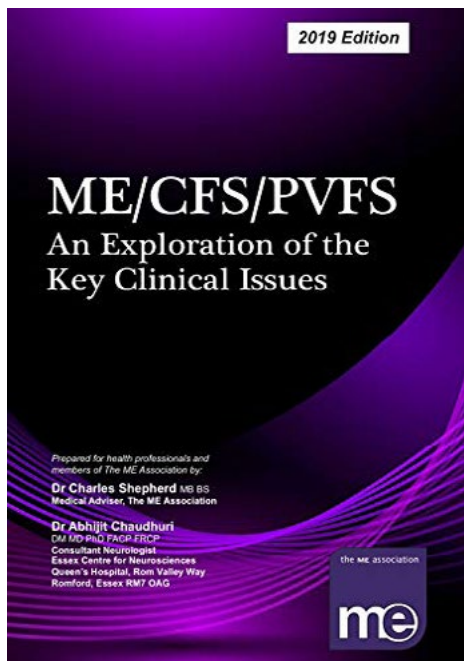
A good GP should be willing to listen and learn from his/her patients. At the same time, it's important to remember that doctors suffer from 'information overload' – so there is no point in expecting them to plough through lots of complicated information that has been printed off the internet. Some of my medical colleagues have an almost instant allergic reaction to 'information off the internet' – so keep it simple and accurate.

The MEA has a wide range of patient-based literature relating to all aspects of management. This is written in a way that should make it acceptable to health

professionals. A good source of fully referenced evidence-based information on research, clinical assessment, diagnosis and management is the MEA purple book (*ME/CFS/PVFS: An Exploration of the Key Clinical Issues*). We have funds in the MEA education budget to send out free copies to any GP who wants one.

Through our involvement with the Forward ME group we have met representatives from the GMC, Royal College of General Practitioners (RCGP) and the Royal College of Paediatrics and Child Health to try and improve both undergraduate and postgraduate medical education on ME/CFS. This initiative is starting to have an effect – one example being the preparation of a review covering diagnosis and management of ME/CFS for the RCGP journal.

Medical information contained in this leaflet is not intended to replace medical advice or treatment from your doctor. We recommend that you always consult your doctor or healthcare professional about any specific problem. We also recommend that the medical information we provide is shown to and discussed with your doctor, as appropriate.



The ME Association's 'Purple Book'

"We have funds in our education budget to send out free copies to any GP who wants one." Just email the full name and surgery address of your GP to admin@meassociation.org.uk or phone 01280 818 963 during weekday office hours.

THE ME ASSOCIATION



ME CONNECT

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

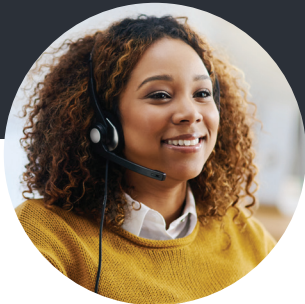
3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



Freephone
0800 538 5200

Monday to Friday 10am - 6pm
(Late night until 9pm on Thursdays)

Saturday & Sunday
10am - 12 noon & 7pm - 9pm



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!



MEConnect@meassociation.org.uk



[X.com/meassociation](https://x.com/meassociation)



facebook.com/meassociation



instagram.com/meassociation

meassociation.org.uk