

1. Introduction

Building a trusting relationship with your doctor is an important part of any illness management plan. This is especially the case when you have a complex and long-term illness like Myalgic Encephalomyelitis /Chronic Fatigue Syndrome and may also have other comorbidities.

ME/CFS can be a challenging illness for doctors. They may not have received any training in ME/CFS, nor be aware of the current clinical guidance. Also, ME/CFS can present differently in each person and there are limited treatments available. This situation can lead to frustration for both the doctor and the patient.

An informed GP with a good understanding of your situation, may be able to refer you to other health services and can provide medical evidence for a range of financial supports from Work and Income and employers.

The following tips may help you to partner with your doctor, to share the lived experience, and to ensure that the doctor is aware of current and emerging evidence-informed practice.

2. Prepare for your appointment.

- a. **Make a list of items to talk about.** Having things written down can help ensure you do not miss anything during your appointment and help you to be clear about what you want to share and how you want to say it.

Bullet points are a good way of providing as much information as possible while keeping it brief. Your doctor may need to ask you what the top priorities are for the appointment, and it is likely to be easier to select from a list, than from your memory.

- b. If you develop a **new symptom**, take note of when it started, whether it is constant or fluctuates, and whether anything makes it better or worse.
- c. **Consider making a double appointment**, so that you have time to talk about several issues.

Not all medical centres will allow you to make a double appointment. For those that do, it is likely to cost you double, but having a longer appointment may result in better outcomes for you than two single appointments.

- d. **Bring a support person.** Whether it is one of our Registered Nurses, a friend or a family member, having a support person with you can make a difference. It can be helpful for your doctor to hear another person's perspective as part of the information gathering process. A support person can also help you remember and reflect on what was said during the appointment.
- e. **Let your doctor know if you cannot afford your appointments.** Some practices are now part of the reduced fees scheme that allows people with a Community Services Card to pay a lower amount.

If your medical centre is not part of this scheme, or you still cannot afford your appointments, talk to your practice and they may be able to negotiate something with you. There is funding available that your doctor may be able to apply for in these situations.

3. At the Appointment...

- a. **Be as concise and precise as possible.** It is not necessary to know or use medical jargon, but it is important to report your symptoms clearly and avoid vagueness as much as possible.

It is better to use concrete examples like “My heart rate increases to 140 when I have a shower, and I need to lie on the bed for one hour afterwards” rather than “I am exhausted all the time and I can’t do much”.

Do your best to keep it short and to the point.

- b. **Share the lived experience** as much as possible to help your doctor understand what you are experiencing. Share your current functionality level, what activities you have identified are manageable, and what aren't.

Explain what happens when you have exceeded your energy limits and you experience post-exertional malaise.

For example, you might say “I have found I can manage an outing once a week if I have a quiet day the day before, and if I lie down and rest for an hour before hand and afterwards. If I don't do these things, my brain fog, fatigue and pain increase for several days, and I feel like my glands are swollen.”

Activity and Symptom logs can help make this visible too.

- c. **Check that the doctor knows about the Health Pathways** website, which is provided by Te Whatu Ora Waitaha (formerly the CDHB) for medical professionals. This has clinical guidance for doctors about ME/CFS based on the IOM 2015 Diagnostic Criteria. We have a letter about this for doctors that you can ask for.
- d. **Take notes.** Taking notes during your appointment can help ensure you do not forget anything that was said during the appointment. Or alternatively, ask the doctor to write key points down.
- e. **Remember that the doctor may not have had time to read your notes.** Our doctors are incredibly busy, and you may also see someone who is not familiar with you from time to time.

You might find it useful to keep an updated sheet of your key diagnoses and health concerns, medications and management approaches, ready to share with any medical professional who is new to you, or who needs a reminder.

The Health and Disability Commissioner has developed a Health Passport booklet which you may find useful to hold information about you and how you want to be supported when using health services. This can be downloaded from the www.hdc.org.nz website, or you can request a booklet from MECFS Canterbury.

4. Connect with your doctor regularly.

Catching up with your doctor regularly helps to build a relationship with your doctor and helps your doctor to understand what your baseline is so that they have something to compare to if things change.

Seeing your doctor regularly also means you can discuss issues as they come up instead of waiting until you have a list of things to talk about. Focusing on one or two issues at a time means that the issues can be discussed more thoroughly and allows a stepped approach to developing a management plan for you.

a. **Ask if your medical centre provides any online services.**

Many medical centres now offer telehealth appointments (by telephone or video call) that significantly reduce the amount of energy needed to attend from that needed for an in-person visit. These don't suit everyone though.

Your medical centre may also provide online services for patients to book appointments, order repeat prescriptions, and check your lab results.

If you need help with working online, talk to the receptionist at your medical centre or get in touch with MECFS Canterbury and ask if there is someone that can be assigned to assist you.

b. **Ask if you can email your doctor between appointments.** Email can be a great way to stay in contact with your doctor if you have a brief question, want to follow up on something, or want to share something concisely without emotion. Ask your doctor if you can email them between appointments.

Some medical centres prefer that all communication is sent to the practice nurses initially, so that it can be reviewed before sending onto the doctors. Find out what your centre prefers.

5. Play an active role in your treatment.

It is important that you play an active role in deciding on the treatments and supports that you receive. It is likely you are more knowledgeable on ME/CFS than your doctor and more aware of the current research. If there are treatments or medications that you want to try, let your doctor know so you can discuss them together.

a. **Make sure you understand your doctor's recommendations.** It is important to ask any questions you may have and clarify anything you are unsure of. Another good strategy is repeating back what the doctor has said back to them to make sure you are both on the same page.

If you have been prescribed a new medication, ask about the possible side effects. You can also discuss this with your pharmacist.

If your doctor refers you to another service, make sure you understand the purpose of the referral and what you should expect from the service.

b. **Remember that our Registered Nurses are available to advocate for you with your GP.** Most doctors have not had training on ME/CFS, so it can be very helpful to have a medical professional sitting in the appointment with you who is familiar with the clinical guidance and management protocols.

c. **Provide resources for your doctor.** If your doctor is open to it, provide them with information on ME/CFS and possible management approaches. There is a lot of information available online, and it can be difficult to distinguish what is credible and what is useful for a doctor to know. If this is something you need help with contact our office or our Registered Nurse Service.

Avoid overloading your doctor with information. They may be interested but simply do not have the time to read a 20-page research paper every three months.

Ask our office what material we currently have for doctors. For example, we have copies of the NZ Doctor article "How to treat: ME/CFS".

d. **Be aware of what you are entitled to.** Knowing what you are entitled to can ensure that you receive as much support as possible to manage your illness. If you want information on things like disability allowance, disability parking permits, reduced taxi fares or applying for the supported living payment you can look online, talk to others with ME/CFS or contact MECFS Canterbury.

6. Make a formal complaint when something goes wrong.

While this may sound counterintuitive to building a relationship with your doctor, it can be helpful for your doctor to know that you are unhappy with the service they provided.

- a. It may encourage the medical centre to get familiar with the latest guidance for ME/CFS.
- b. Making a complaint also ensures that there is a record of what happened and ensures that it will be investigated.
- c. Contact MECFS Canterbury, or the National Health and Disability Advocacy Service www.advocacy.org.nz, if this is something you need advice on.

7. When to look for a new doctor.

Continuity is important when managing any chronic illness and changing doctors too often can lead to more frustration as it can take time to build a relationship with a doctor. But sometimes, despite our best efforts, it may be necessary to look for a new doctor.

- a. **Ask for recommendations.** If you are looking for recommendations for doctors it can be good to talk to other people with ME/CFS. You could do this at our Monthly Group Support Meetings or in our Facebook Group or talk to our Registered Nurses.
- b. **Book an appointment with the doctor you are considering,** before you move practices. This gives you an opportunity to discuss your medical history and what your expectations of them are. If you decide they are the right fit and move practices, it will still take time to build a relationship with them.
- c. **Be aware of non-enrolled patient costs.** It costs more to visit a doctor if you are not enrolled in their medical practice.

MECFS Canterbury

Ways to get in touch with us:

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