



Preparing information for your doctor

Description

Communicating your limitations

Many symptoms of ME/CFS can make communicating difficult. Some people who live with ME/CFS report that at times they struggle to recall information, lose their train of thought easily and find comprehending and processing new information difficult.

As your energy limitations are reached and your battery starts to run flat, these symptoms can get worse. This can make medical appointments stressful and remembering all the information you want to discuss with your doctor can be difficult.

Emerge Australia has put together some helpful ideas and tools to help you get the most out of your medical appointments. We will introduce you to the symptom severity and severity hierarchy scale, and the Activity-symptom tracker, and show you how to use the [NAM criteria](#) for diagnosis of ME/CFS.

Booking your medical appointment

Before you book your medical appointment, it is important to consider what support or preparation you may need.

If you have more than one or two topics to discuss, book a double appointment so you and your doctor have more time to cover each question you have. If possible, book your medical appointment at the time of day when you normally feel at your best.

Depending on the severity of your ME/CFS or the symptoms you are experiencing, you may need a quiet place to lie down while you wait for the doctor. You can organise this with the receptionist when you book your appointment. They can also let the doctor know that you may need to lie down during the appointment.

Bringing a support person to your appointment

Not everyone will need or want a support person to accompany them to their medical appointment. For those who do, it is a good idea to decide what role you would like the support person to take and talk with them about this before going to your appointment.

Before you talk to your support person, ask yourself:

- Do you want or need someone to drive you to and from your medical appointment?
- Will you want the support person to come into the waiting room or the doctor's room, or wait in the car?
- If your support person comes into the doctor's room, will you want them to advocate on your behalf, or just listen and take notes?

If you decide to bring a support person or advocate to your medical appointment, you may like to ask them to help you prepare. This will allow time for you to discuss their role and how they can support you.

You can find valuable information that Emerge Australia has created to support carers to advocate for fair and equitable treatment of people living with ME/CFS on the Emerge Australia website.

Once you have booked your appointment, use a diary to keep track of your appointment date, time, what information to bring and contact details of your healthcare team.

Think of each appointment with your team as a brainstorming session. You may want to seek a second opinion or connect back with your GP before making a decision. Unless the decision is time critical (an emergency), take your time to understand what has been recommended.

Find out what financial help is available

Medicare rebates change from time to time, so it is best to ask your GP what assistance is available to cover the costs of appointments, and what out-of-pocket expenses you should expect. You may also like to ask if there is a public waiting list that you could join.

Preparing information for your appointment

Having information for your appointment prepared beforehand can help you clearly communicate what you want to achieve during your appointment.

[Here is a sample template](#) for your appointment or feel free to create your own.

Symptom severity and severity hierarchy profile

For people who live with ME/CFS, recording symptoms can feel like a huge task and an overwhelming process. Emerge Australia recommends using the symptom severity and severity hierarchy profile to help provide an overview of your symptoms to your doctor in a simple and straightforward way.

This can help make sure that your doctor knows how many symptoms you have, how severe they are, and how to best manage your symptoms to improve your quality of life.

If you find completing the symptoms profile takes a lot of energy, try completing it over a few days or weeks, or ask for help from family or friends.

For information on how to fill in the symptoms severity and severity hierarchy profile visit the Emerge Australia [Stepwise Symptom Management page](#).

Sharing your record of activity

Many people who live with ME/CFS utilise activity-symptom trackers to support them in pacing. It can also be useful to show your doctor these records, to support them to understand how your symptoms are affecting your life and the level of activity you can complete over a week (or more if you choose.) You may want to share an example of one or two days, or a whole week with your doctor. Using simple entries into a calendar or diary is an easy way to record your activity.

Everyone deserves to be treated with respect

Doctors and their patients should work together in a professional manner. If you have concerns with the treatment of a healthcare professional, please contact the [Australian Health Practitioners Regulation Authority](#) (AHPRA), the agency that regulates health practitioners in Australia.

Additional Support

If you need additional support to prepare for an upcoming doctor's appointment, or when commencing with a new doctor, consider making an appointment with our Telehealth Nurse Service. We will do our best to connect with you with additional resources, or to talk with you about your goals and how to generate a plan for your appointment.

[Book a Telehealth Consult](#)

Category

1. Management

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Author

novadiem