

For the Provider: Working with Patients with ME/CFS and their Caregivers

by Lynn Fuentes, PhD

Many patients with ME/CFS, particularly those who are most severely ill, may not have the energy to adequately describe their symptoms and needs or engage in needed discussions about care and treatment. The full extent of symptoms is not obvious in a short meeting, but it is important to be aware that you may need to communicate with a caretaker or note taker to ensure that all necessary information has been communicated to you and that instructions you offer are understood and recorded.

SOME USEFUL FACTS ABOUT ME/CFS PATIENTS:

1. A patient who has had ME/CFS for a long time will have adjusted to a new normal. Thus, responses like “I’m okay, thanks,” need to be interpreted as expressing what is normal for them and not what would be okay for someone who suddenly contracted this illness and was reporting on it the next day.
Similarly, if patients are asked to record symptoms on a chart, they are likely to note their level of exhaustion at a 3 when to anyone else it would be a 7.
2. The effects of exertion on a patient are often not apparent until a couple of days later. Thus, a patient who has rested up to come to an appointment will be at the highest end of their functioning and not demonstrating their usual functioning.
3. Patients with ME/CFS often do not have the energy to prepare questions for their appointment. Thus, it is important to ask them or a caregiver to note questions as they occur and to bring in these notes to the appointment.
4. Patients with ME/CFS often cannot easily retain information. Thus, they may forget information shared during the appointment within a short time if it is not written down.
5. Patients with ME/CFS are used to trying to act ok when they are with other people. Thus, it is hard to tell how they are feeling. They may often get so tired during the appointment that they will zone out and not really hear what is being said even though they appear to be fully present.
6. Because they are so exhausted (often from getting cleaned up and traveling to the appointment), they often do not have the energy to discuss options or, if they disagree with something that is said, to dispute it, so it may seem that they are agreeing when in fact they may not be.
7. Patients with ME/CFS have often been treated dismissively, disbelieved, and talked down to. As a result, they are often wary of speaking up again.

For all of these reasons, it is important to have a caregiver, or at the very least a note taker, at any appointment.

Be aware that the caregiver may need to do a lot of the talking. This does not represent an attempt to take over from the patient; it is a practical way to convey information that the patient needs to have communicated when he or she is not able to effectively do it themselves.

SOME WAYS TO HELP:

- If possible, have a place where ME/CFS patients can lie down if they will have to wait for an appointment, ideally with dim lighting.
- Ask questions to determine the actual functional ability of the patient. Very often they are much sicker than they appear.
- Allow patients extra time for responding to questions.
- Write down important conclusions and recommendations and give a copy to the patient.
- If the caregiver is not present during the appointment, and the patient agrees, speak to the caregiver before or after the appointment to ensure that needed issues are being covered and treatment protocols are understood.

Thank you for all you do!