

Symptom tracker:

Date	Symptoms you're experiencing:	On a 1-10 scale, how severe is it?	How long?	What seems to make them worse or better?	Treatments you've tried	What else could it be?	Other/ feedback from family members?

Other notes or questions for your health care provider:

--

Advice from rare disease advocacy organizations

Speak up and ask questions. If you experience new symptoms that *defy explanation*, do not hesitate to bring up your concerns to your doctor. Even if your family doctor cannot determine a diagnosis, you may be referred to a specialist who can narrow down – or broaden – the search for answers.

Be an assertive, proactive patient. Much of the battle will be in finding a doctor who will listen to your accurate description of symptoms. If a doctor does not seem to take into account *all* of your symptoms of concern, seek a second opinion.

Be organized. Your description of symptoms is only the beginning. Once a doctor has an idea of what might be the cause of your symptoms, diagnostic tests will likely be done. **Ask for and keep copies of any diagnostic test that is done.** With Gaucher disease, for instance, simple blood tests and genetic analysis may be all it takes to make the diagnosis. Same goes for any other paperwork or prescriptions you receive. *Start a file for all materials related to your pursuit of a diagnosis. Another good thing to keep on hand and up-to-date is a family medical history, including information about any relatives who died in infancy or under mysterious circumstances.*

Be aware. Keep track of not just your paperwork, but also how your condition progresses. Record each symptom you note, including the time and date when it happens, a ranking from 1 to 10 of how severe it seems, as well as any recent treatments, medications, or other potentially relevant information (e.g., stress level, life changes).

Search smart. Use your symptoms as search terms, including those symptoms that may seem unrelated to one another. The internet is a powerful tool overflowing with information – not all of it perfect or credible, but it could take you a step in the right direction if you know where to look. The National Organization for Rare Disorders (NORD) and the Canadian Organization for Rare Disorders (CORD) are great places to start.

Accept support. A trusted friend or family member who escorts you to doctor visits can provide moral and emotional support and can also help you to remember and understand all of the new information you might be receiving.