

Messages from Barbara Dickinson

Hints and Tips from Barbara Dickinson

When you visit a physician for anything other than routine reasons, it's best to take someone with you who will be able to listen with you to what the doctor says. It's even better to take notes, and if the doctor will permit it, to tape his comments upon diagnosis. The reason for this is that later, you will want to talk over and consider exactly what was said. If you have just been diagnosed with a frightening disease, you won't be able to hear much beyond the stark words of the diagnosis.

There are two main questions that you want answered:

1. What's wrong with me?
2. What can you do for me?

The answer to the first question has to go beyond simply naming the disease. You need to know as much as you want to hear. If you are receiving a diagnosis of ALS, for example, what you want to hear is the full name of the disease (amyotrophic lateral sclerosis), spelled for you; its common name (Lou Gehrig's disease); and what the name of the disease means. This may be enough information for the first appointment.

The answer to the second question can under no circumstances be "nothing." Although there is still no known cure for ALS, there's plenty the medical system can do for a patient. If your doctor cannot help, ask for a referral to someone who can or contact The ALS Association.

ALWAYS GET A SECOND OPINION for a disease like ALS. It's tricky to diagnose.

Ideally, several professionals should be involved in the care of a patient with ALS: a neurologist, a pulmonologist, a physical therapist, a speech therapist, an occupational therapist, and a social worker. Consults with a nutritionist and a dentist can be helpful. The caregiver also needs some professional help: a mental health professional and/or a member of the clergy are essential. Support groups are also often very helpful. Most important is that the caregiver **MUST** find some way to get some respite.

The two smartest things that were said to my husband when he was first diagnosed were:

1. Don't read any statistics. This disease is now your personal possession. It will take its own course with you.
2. Don't concentrate on the big picture; it's out of your control. Take as much pleasure as you possibly can in every moment of your life. The small, sweet things will be your consolation.

The two wisest remarks that were made to me as a caregiver when my husband was first diagnosed were:

1. Don't run too far down the road. In other words, don't waste any energy anticipating what's going to happen. Get the practical details taken care of and then stay in the present. Promising research is going on.
2. A lot of people will be taking care of the patient. No one will be taking care of the caregiver. If you are going to be helpful, then you have to arrange for some caregiving for yourself.

The big thing to remember is that you as patient and caregiver are the consumers. You have the right to have your questions answered as fully as possible. If your doctor seems rushed, ask him or her to schedule your appointment at the end of the workday when he or she will be able to give you as much time as you need. This is not a favor, but your right as a consumer of medical services. You are entitled to a physician who is going to help you manage your disease.

Finally, you shouldn't accept statements like these easily, if ever:

1. There's nothing more I can do for you.
2. It's impossible. We can't do that/we don't do that.
3. Your request has been denied.
4. That's never been done before.