

Effective communication

is at the top of everyone's wish list when it comes to the **patient-doctor relationship**. Here are some strategies to enhance communication with your medical team and avoid leaving the doctor's office feeling frustrated and depressed.

Doc Talk

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Have you ever fantasized about having a heart-to-heart gripe session with your physician about the care you're receiving? Did you leave your doctor's office after your last visit frustrated and less than satisfied? Are you sick of not getting the respect and compassion you deserve from your health care providers?

If so, you're not alone. In an era of managed health care, many patients and physicians are reporting a decline in satisfaction with the patient-doctor relationship. That's especially unfortunate because there is mounting scientific evidence showing that the effectiveness of the patient-physician relationship directly impacts your health outcome.

When you suffer from an illness such as chronic fatigue and immune dysfunction syndrome (CFIDS), the situation can be even more complex. Patients are frustrated when they encounter health care providers who don't know much about CFIDS, or who believe the illness is primarily psychological in origin. Even with a sympathetic doctor who is committed to helping them, patients can lose their cool when treatment after treatment fails and no progress is made toward helping them recover their former active lives.

For the physician's part, they have frustrations of

their own. It can be difficult treating CFIDS patients and others who suffer from illnesses with no known cause or cure. Doctors are human, just like you, and they enjoy getting personal and professional fulfillment from successfully treating, even curing, diseases. But with CFIDS, they can become just as frustrated as patients are when they can't help you as much as they'd like. Add to this the fact that it often requires more time during each office visit to examine and talk with a CFIDS patient than the six to nine minutes that is standard in managed care today, and the situation is further complicated.

So what can PWCs do to strengthen their relationships with their doctor and other health care providers? First, find a doctor who is willing to work with you and listen to you. Usually you can tell how a physician and staff will treat you within a few visits. It's important to evaluate the doctor's attentiveness and effectiveness within a few visits. Although this is no guarantee of the future, if you make this determination early, you can save yourself a lot of grief and time.

The second item that tops the list of strategies to enhance the patient-doctor relationship is effective communication. That's the topic we'll discuss in this article.

When you went for your first visit, you were probably asked to fill out paperwork and provide detailed

information about your medical history. This identifies a starting point for a good treatment plan. If you haven't already done so, be sure all your health care providers have the following information:

- History of your illness
- Allergies to food, medication, supplements, etc.
- Exposure to infectious diseases
- Work history
- Activity level and tolerance level for activity
- Family history if known
- Complete list of all past surgeries and major hospitalizations
- List of all past major illnesses or conditions
- List of all medication and supplements you're taking, and the dosage

You may want to make copies of this list and keep it updated so you'll have it for other physicians and specialists to whom you're referred. This aids the doctor in determining what else might be contributing to your condition. It also helps avoid negative interactions with new medications or supplements you're taking.

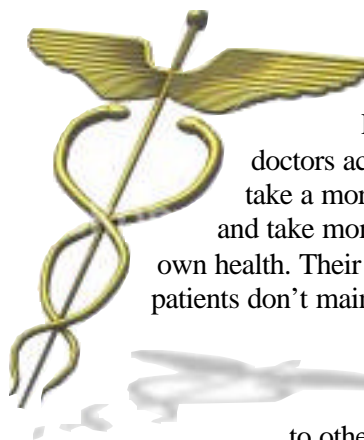
During your office visit be sure to share the following other information:

- Tell them the purpose for the visit if it's not a routine follow-up visit.
- Give any new information you have about your condition or symptoms to the nurse or receptionist on arrival or when they take you to the examining room.
- Reference symptoms to how you felt before the condition appeared vs. how you feel now.
- Sometimes it's helpful to take a picture with you. If you're having trouble with energy or walking, take a picture that shows how active you used to be. If you have gained weight, a picture could reference how much. Sometimes pictures really *are* worth a thousand words.
- Share one or two of the best articles you've read about CFIDS since your last visit. Don't inundate your doctor with material, but if you read a wonderful article that accurately describes what you're going through, it's okay to share it.

To enhance the relationship with your doctor, it's important for you to be an integral part of the process. Communication is a two-way street. It's your responsibility to keep track of the treatment, its outcome and any new developments. We strongly recommend that you keep a journal or "illness diary" and share it with your doctor. The journal should:

- Chronicle how you feel each day and what activities you are—or are not—able to do.

- List any new symptoms you have and how the latest medication or treatment is affecting you.
- Describe your emotional state and whether or not medications affect your emotions.
- List questions and concerns you want to discuss during your next doctor's visit.
- Describe any changes that have occurred in your health or lifestyle.



If you're reticent about taking the journal with you, don't be. Recent studies show that doctors actually want patients to take a more active role in their care and take more responsibility for their own health. Their chief complaint is that patients don't maintain and share a personal health file on their conditions, including lab results, visits to other doctors and decisions to

discontinue a treatment or medication that has been prescribed. Without a true exchange of detailed information, it's hard for you and your doctor to reach mutually satisfying decisions. Although it sounds time-consuming to share all this with the doctor, coming prepared actually saves time.

Because CFIDS can often make it exhausting to handle the activity level of getting ready to go to the doctor, traveling to the office and then waiting for a prolonged period of time when the doctor is running behind, it's your job to communicate this to the nurse or doctor so they can make accommodations for you whenever possible. Similarly, if cognitive problems make it difficult to concentrate during your visit, ask if you can tape record the discussion with your doctor so you can play the audio back at home to make sure you understand any instructions you're given. If your physician refuses, it's a good indication you may need to find another doctor.

Remember that a patient's attitude toward the doctor is also important. If you're adversarial and angry during every visit, it will negatively impact the relationship. Your doctor may not want to listen to you, let alone treat you. Don't let your frustrations with the illness compromise this vital relationship. Make sure you recognize the difference between being assertive and being too aggressive.

It's okay to expect that your medical team will stay current on "best medical practices," but it's unreasonable to expect that they have read every piece of literature or study ever published about CFIDS. It's reasonable to

DID YOU KNOW?

If you're establishing a relationship with a new physician, or trying to improve your current patient-doctor relationship through better communication, it is perfectly acceptable to ask questions like these:

- What sort of approach do you take to patient education? Do you offer printed resources about CFIDS to patients, or refer them to various on-line resources?
- Do you encourage patients to seek out information on their own about their illness? Are you open to patients' efforts to share such information with you? If I bring key articles about CFIDS to you, would you read them?
- What methods do you use beside one-on-one visits to communicate with patients? Do these include e-mail and phone communication, Internet access, written instructions or other means?
- Under what circumstances would you suggest a second opinion? Would you be offended if a patient questioned your judgment?
- Do you encourage patients to ask direct questions?
- Do you want patients to be active in the decision-making process?
- How do you feel about alternative therapies and medicines?
- If I had a choice between treatments, how would we work together to make a decision? Will you instruct me on the benefits and risks of all reasonable diagnostic and therapeutic options, even if some options aren't covered by my insurance?
- If I maintain and bring in an "illness diary" (personal medical record) to ensure that you understand how my CFIDS is affecting me, would you consider this an effective communication tool?

expect your doctor to recall key elements of your medical history and past treatments, but it's unreasonable for you to get furious if he or she suggests a treatment you've tried before unsuccessfully, but it was 10 years ago and with another doctor. It's okay to expect your health care providers to remain objective when you ask about trying alternative or nontraditional treatments. It's not okay to expect them to sanction the use of treatments that are so experimental or controversial that they fear for your safety.

If you're unsure of the proper boundaries, you should initiate a discussion that clarifies mutual expectations. You can do this in person or in an e-mail, but again, don't make this adversarial. (See the box on this page.)

If you find you have serious disagreements with your doctor or feel the treatment is inappropriate, it will be up to you to take the initiative to either correct the situation or find another doctor who is a better fit for you and your condition. Talk honestly with your friends or support group if you're having difficulties communicating with your doctor. Many times they can be a sounding board and can identify the source of the communication problem. They may also be able to suggest strategies to enhance communication with your health care team that have worked for them, or they may offer referrals on other physicians.

It's important to realize your doctor may have some beefs with you too. You need to be a partner in creating an atmosphere where those

concerns can be shared. One of the main complaints doctors express is that patients don't make the behavioral changes that are critical to a good outcome. These changes include therapeutic lifestyle changes and adherence to treatment recommendations.



Doctors agree.

You should assume ultimate responsibility for managing your condition.

dations. Another key complaint is that some patients still buy into the Marcus Welby model of patient care where the kindly TV doctor takes your hand and leads you step-by-step back to health. Today's model, physicians say, requires improved patient self-care.

This article has offered suggestions for you to use that have worked for other PWCs. If you have more ideas or comments about effective communication strategies, please contact us at www.lifequestcoach.com or send an e-mail to jo@lifequestcoach.com. ■

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