CFIDS Association of America

working to make CFS widely understood, diagnosable, curable and preventable

Improving Communication Between Doctors and YPWCs

By Sharon Walk

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All too often, doctors and patients fail to communicate effectively. They go their separate ways after office visits, each unaware of the other's thoughts and concerns. Sharon Walk and other young persons with CFIDS (YPWCs) have joined efforts here, suggesting ways for doctors and patients to bridge the gap of miscommunications and understand each other better. -The Editors

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For Our Doctors: Ways to better understand and communicate with YPWCs

1. **Make time to listen to our concerns.** So often we feel rushed through appointments and don't get to ask the questions we have. Please make sure your appointment scheduler understands that we may occasionally ask to arrange for longer visits when we have severe relapses or confusing treatment problems. Try to make sure that near the end of an appointment you take a minute to ask if we have any further questions and if we have understood everything that was discussed. If you need to keep track of the time, you might hang a clock in your line of vision so you can see it without your patient noticing. When you glance at your watch repeatedly, we hesitate to take your time with our questions and concerns.

2. **Talk so we can understand you.** Try to remember that you are talking to a younger person and take the extra time to explain medical terms. Of course, how much you need to do this will vary depending on the ages of your patients and the amount of CFIDS and general medical knowledge they have.

3. **Talk to us without our parents during each appointment.** Often those of us who are younger CFIDS patients come to appointments with our parents. Try to set aside at least a few minutes to talk to us by ourselves. Sometimes we have questions and concerns that we might not want to discuss in front of our parents, but that we really need to address with our doctors.

4. **Let us be part of the decision-making process.** As YPWCs, we often feel that we lack control over our lives. It sometimes seems that all of our decisions about treatments, school and social life are dictated by our doctors, schools or parents. As a doctor treating YPWCs, you can help return some of that control to us. Try not to tell us what we have to do; rather, suggest something that you would like us to do and ask us how we feel we can make it work. By giving us choices and listening to our opinions, you may have happier and more secure patients.

5. **Encourage us to think of creative solutions to problems.** What works for one YPWC may not work for another, even if they appear to be similarly affected by CFIDS. Give our parents and us opportunities to share ideas for increasing our social and activity levels and improving our quality of life. We'll work together to create individualized treatment and schooling plans.

6. **Show trust in us.** As YPWCs, we are constantly facing people who do not believe we are sick and do not understand CFIDS. It helps us to feel that we are trusted and believed by our doctors.

7. **Understand and help us through our fears about not being believed.** Sometimes we assume that if we are successful at doing one thing we will be expected to continue to push ourselves until we near a relapse. Some of us fear that our parents and doctors will push us until we question our own judgment about whether or not we're really sick. This comes, in part, from our experiences with doctors, teachers and parents prior to being diagnosed with CFIDS.

   Many of us were often told that we weren't sick and that all we needed to do was to "do more" and get back into the world. Sometimes we still associate someone wanting us to try to do more with being told that we're not really sick, or with being pushed harder than is good for us, and having to fight to say "no."

As a CFIDS doctor you can help us avoid this. From the first appointment, emphasize to the newly diagnosed YPWC that you believe what we are going through is real, and that you are going to do your best to improve our quality of life. Tell us whether you have seen cases like ours before. Listen to our reactions with care and understanding, and know that we are usually eager to socialize and attend school as much as we are physically able.

8. **Don't be afraid to say, "I don't know. "** We understand that most doctors, including those knowledgeable about CFIDS, have experiences when they are perplexed by a patient. Maybe the patient in their care has unusual symptoms or isn't responding to a treatment as expected. But when this happens to us, we often leave our doctors' offices feeling that they think we aren't following their recommendations or just don't want to get well. That makes us feel awful about ourselves. Be willing to admit if you just don't know why a treatment isn't working as expected, or why we have an unusual symptom or problem. CFIDS confuses us, too, and we will respect you for your honesty.

For YPWCs: Ways to better communicate with your doctors and increase their understanding of your life with CFIDS

1. **Make sure your appointments are the length you need.** If you expect to need a longer appointment than usual, perhaps because of new symptoms or a confusing relapse, it's important to be considerate and tell that to the appointment scheduler. Otherwise, your visit may be rushed and not as helpful as you need and your doctor will likely be late for appointments with other patients.

2. **List your three worst symptoms.** Before seeing your doctor, decide which three symptoms have been most disabling for you since your last visit. Be sure to discuss them with your doctor, so you can work together to prioritize your treatment plan.

3. **Make a list of the questions you have for your doctor.** It helps to write down the questions and concerns you think of between visits. Before your appointment arrange them in order of importance and consider adding a brief explanation. That way, if you are having a difficult day, you can hand the list to your doctor and he or she will understand what you wanted to know.

4. **If you have questions about your CFIDS treatments, ask them!** When your doctor suggests trying drugs or other treatments, feel free to ask him or her to explain what each is and what symptoms he or she hopes it will help. This will help you to understand and participate in your treatment plan, and help to prevent misunderstandings.

   For example, antidepressants are used to treat many different conditions - not just depression. If your doctor prescribes one and you leave without asking questions, you may find yourself wondering whether your doctor thinks you're depressed. You may not find out until your next visit that antidepressants are often used to treat sleep disorders and chronic pain. Misunderstandings like this can be prevented by asking your doctor to explain what your new medicines are, and what you should expect while you take them.

5. **Tape record your visits with your CFIDS specialist.** When a YPWC goes to see a CFIDS doctor, there are often many questions answered, research breakthroughs explained and details to remember. If you record your appointments, you can listen to them again and better understand what your doctor said. (Before you tape record a visit, ask your doctor for his or her permission.)

6. **Tell your doctor if you're having problems with people who don't understand CFIDS.** It is common for YPWCs to have difficulties with school personnel, and sometimes even their parents, not understanding their illness and the limitations it places on their lives. Your doctor can help resolve this if you tell him or her what is happening. Ask for his or her assistance in explaining your disability and how others can support your efforts to lead as normal a life as

possible.

7. **Tell your CFIDS doctor if you are depressed.** Many YPWCs go through periods of depression as they adjust to living with a chronic illness. Your doctor will know that in most cases, depression is a result of illness, not the cause of it, and will help you get through it. If you're concerned about deep or prolonged feelings of sadness or helplessness, don't be afraid to tell your doctor about them, and to ask for a referral to a health psychologist or therapist or counselor.

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