

Can we talk?

How to communicate with your doctor

by Catherine L. Shaner MD FAAP, Fibromyalgia AWARE, Sept-Dec 2002

Small talk, baby talk, girl talk. We fill our lives with conversation. Sometimes, though, we need to go beyond the chatter - we need to communicate. Communication involves the exchange of ideas and requires listening as well as speaking. In healthcare, good communication provides the best outcomes with the least mistakes. As a bonus, it creates happier and less frustrated patients and physicians.

Establishing excellent communication with your doctor is important. Why is it, then, we sometimes leave our doctor's office feeling that a lot was said but nothing was accomplished? Or we feel as if we conversed in two different languages? For example:

Patient-talk: "I fell out, Doc."

Doctor-talk: "You've sustained a syncopal event, Mr. Smith."

They both mean: Mr. Smith fainted.

Were the doctor and patient talking? You bet. Were they communicating? No way! How can you assure smooth communications with your doctor?

Before The Visit

Organize ahead of time

Keep a list on the refrigerator, by your bedside, or in your purse. Jot notes about symptoms or questions as soon as they arise. A day or two before your visit organize your notes. Be as specific as possible. For "my arm hurts", you might describe the problems holding your arms up for hair drying, lifting children, or hanging laundry. Highlight the items that are particularly worrisome.

Identify goals for the visit

What do you hope to accomplish with your doctor? A diagnosis? Referral to a specialist? Report new symptoms?

Prioritize your goals, listing your primary reason for this appointment first. How many problems should you talk about at a visit? Two to five, depending on the time allotted and the complexity of the problems.

Other notes to make

Make as many lists as you need to organize all the information and questions you need to communicate to your doctor:

- Current medication list: including prescription, over-the-counter, herbal supplements, vitamins, topical medications, alternative medications and treatments; allergies and previous adverse reactions; prior medications and why they didn't work.
- Problem list: a complete but concise summary of your medical history. Rank conditions in order of importance, with the most important first. Give dates, if possible. Example: Fibromyalgia - 1990, migraines - 1992, gall bladder removed - 1986.
- Specialist list: summarize latest recommendations. Example: Gynecologist - August 2002

- hormone replacement started.
- Recent tests: include dates and locations. Always ask for copies of your test results so you can have them for your own files.
- Changes in symptoms since your last visit
- Questions for today
- Refills needed
- Forms to be completed (with an SASE for return or sticky note with your telephone number)

Bring your lists! If you forget, ask the receptionist for paper and start writing while you wait. Keep copies of your problems and medication lists in your purse or car in case of emergency and update them regularly.

At The Doctors Office

Speak up: Being part of a team requires trust and clear, open communications. Be frank, even if it's embarrassing. Hand your doctor your lists, so he knows what you want to discuss today. Remember your goals for this visit. Voice your ideas. It is best to ask questions as soon as they arise.

Clarify: Use words such as "exactly" or "specifically". Ask: How will this help me? What will happen if I don't do this? When you say to increase activity, exactly what kind and how often? Does exercise mean weights or walking? What do you mean by "come back if not better"? When and how much better?

Negotiate: Request a cheaper drug or one with fewer side effects and less risk. Ask for an easier regimen or a less painful procedure. If a suggestion is unrealistic for you, say so - don't leave discouraged because you can't do it all. Doctors can simplify or adjust treatments so you can live with the recommendations. And remember: it's okay to think about your decision or change your mind. Never be pressured or scared into an action. Short of a life-threatening emergency, there is always time to think things through.

What can get in the way?

Knowing the factors that impede effective communication is half the battle. Emotions, communication style, differing expectations, and lack of time all work against us. When emotions are high, logic is low. The shock of a new diagnosis, fear, embarrassment, resentment, intimidation, and forgetfulness (fibrofog) can all jumble our thoughts. With pain and fatigue, you might not be functioning at your highest level. If you find emotions interfering with your visit, honestly state how you feel. Naming the emotion takes some of the punch out of it. Ask for a moment to compose yourself, count to 10 and breathe slowly and deeply. Begin again if you are able or wait for another time. Consider also that a chronic illness frustrates doctors as well as patients. Although your doctor wants to help, he may feel there is little he can do for you.

Poor communication frequently results when we assume too much. Just as "straighten up your room" has both a parent and a teen interpretation, failure to clarify medical directions may result in differing expectations for you and your physician. For example, assuming your test results will be normal unless you are called could be a deadly mistake. Rather than assume, specify. Request a simpler explanation. If you learn best by seeing or reading rather than hearing information, ask your doctor to draw a diagram or give you a brochure. Ask him to slow down or confirm details. Repeat any instructions he gives you and write everything down or tape record it.

Streamline your visit

No doubt about it, time is a huge factor in poor communications for today's healthcare providers. In an ideal world, a doctor would have enough time to answer all questions clearly. Since this

rarely happens, how can you use your time with your doctor wisely? Studies show that you have 23 seconds to speak before the doctor interrupts, so weed out the irrelevant details. For example, state, "I passed out last night. They took me to the emergency room." Stop right there! Don't add, "And it was really cold in the ER and the nurse looked at me like she'd never heard of fibromyalgia and..." Unless you have more symptoms to add, let your doctor ask you questions. Refer to the list of concerns you brought with you to make sure you have all of them covered.

If there is not enough time to cover everything, request handouts and brochures that will provide you with information. Then schedule another visit with more time to fully discuss your concerns.

Before you leave

Ask the doctor for written instructions. Summarize and make sure to clarify anything you aren't familiar with. Don't leave without fully understanding your diagnosis and treatment. If the doctor has left the room, ask a nurse.

Outside The Office

I forgot to ask...

Realistically speaking, questions come to mind outside of the office. If your problem is urgent, call the office right away. Otherwise, check first to see if your question can be answered in a brochure given to you by your doctor. Consult your pharmacist for medication questions. Are you tempted to ask your chat room support group for advice instead? The Internet is a great place for researching information to discuss with your doctor, but relying on online information for medical answers can be dangerous.

Communicating by telephone

The office RN can handle most questions. Call early in the day, but be aware that your call may not be returned until the end of the day. It is helpful to compose a one sentence description of the problem, including symptoms and dates. Have medication bottles handy as well as your pharmacy phone number. Write down your questions and have a paper and pencil handy to record instructions. Inform the office if family members may receive information.

Communicating by e-mail

The majority of families with computer access want to communicate with physicians via email. Physicians generally are less comfortable with that route. Both sides have concerns about confidentiality. Some benefits of email include: ending telephone tag, speed, cutting costs, more detailed medical records, fewer medical errors, and improved compliance. Risks include: privacy and security, as well as physician concerns of staff workload, reimbursement and malpractice liability. More importantly, access to care might be determined by computer literacy. At present, most doctors do not offer email communication, but it pays to ask.

Communicating by Fax

Transmitting messages via Fax provides many of the same advantages as email. Access to a fax machine (or directly from your computer with PC-fax software, allows you to send detailed, accurate communications. Fax is an especially good method when you have multiple requests and is an excellent way to receive your lab results from the office. Bear in mind that confidentiality is an issue when using shared office equipment.

You have the right to remain silent - but don't!

Communication is a two-way street and it starts with you. Speak up! You have the right to understand your diagnosis, your symptoms, tests, procedures and all the risks and options. Your doctor has the responsibility of treating you with respect, listening, addressing embarrassing questions, educating, informing and considering your opinions and concerns. You are responsible for coming to scheduled appointments, taking your medication as prescribed, reporting adverse effects, becoming knowledgeable about your disorders, informing your doctor about your

symptoms, progress, questions and concerns. Communication is an especially important skill for fibromyalgia patients. Make every word count!

Pointers For Successful Communications

Pointer 1: Talking about pain

Mention where, how much (use a scale of 1-10), what makes it better or worse, description (tingly, achy, knife-like), medications used and, most importantly, the impact on your daily functioning. Decide on your pain management goals. "I need better pain control" could mean completely pain-free (but possibly sleepy) or it could mean enough pain control to be able to play with your grandchildren, work 20 hours a week, or sleep comfortably. You and your doctor need to be working towards the same goals.

Pointer 2: Talking about tests

Discuss the reason for the test (diagnosis? Change in treatment?), method, accuracy, preparation, pain involved, when to expect results and insurance coverage. Test results are written in medical-ese, language that can be misinterpreted by non-medical people and well-trained medically knowledgeable friends. Ask your doctor to explain the wording in simple terms. Do not settle for a glossing over such as "that's nothing to worry about."

Pointer 3: Talking about medication

Know the medication's purpose, how to take it (with food, time of day, when to stop), adverse effects, interactions with other medications, when it should take effect, and cost. Make sure you can read the prescription: if you can't, the pharmacist might not be able to either. To minimize errors and complications, it's a good idea to have one doctor all of your prescriptions, even specialty medications.

Pointer 4: Talking about alternative/complementary therapies (ACTs)

Present articles from reliable sources, discuss pros and cons, and determine compatibility with your medications. Understandably, doctors are hesitant to advocate ACTs without scientific testing. However, your doctor may agree to a trial if the treatment has not been shown to be harmful. Obtain a prescription or letter of medical necessity, if possible, because insurance companies sometimes covers alternative therapies.

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