

A guide to patient-physician education

By James P. Sutton, MD

▪ Introduction

Have you ever left the doctor's office, only to realize that you did not get the help you needed? Did it seem like the doctor was not paying attention to you? Did your doctor focus on one problem when you really wanted help with something completely different?

An important but neglected issue in the management of any chronic illness is that of communication between patient and physician. This is particularly important when dealing with neurological illness. At Pacific Neuroscience Medical Group we know that good communication is essential in order to ensure quality care. We are committed to communicating as effectively and clearly as possible with our patients, whether it involves answering questions during their visits, returning their phone calls promptly, or explaining complicated treatment plans in clear language they can understand.

In 1999 Dr. James Sutton, Medical Director of Pacific Neuroscience Medical Group, was invited by the Parkinson's Institute to speak on Physician-Patient Communication. The following is a summary of the key points from his presentation. It is our hope that wherever you decide to go for your care, this information will help you to communicate better with your neurologist.

▪ Plan for your visit

Have you ever waited weeks for an appointment, finally see the doctor, and only get 10 or 15 minutes with him? How can you possibly get anything out of such a short visit?

One answer to this problem is to prepare for your visit. You will get more out of your appointment if you get a few things ready ahead of time. Here are some tips:

- Bring a list of all your medications.

Write down the name and strength of any medications you take, the number of pills that you take each time, and the times that you take them. This can save a lot of time at the doctor's office, and make your visit more productive. It can also help to avoid errors. Here is one way to record your medications in a simple table:

My medications

Name	Strength	7AM	11 AM	3 PM	7 PM	10 PM
Sinemet	25/100 mg	1	½	½	½	½
Mirapex	1 mg	1	1	1	1	1
Ecotrin	325 mg	1				
Ativan	1 mg	As needed, up to 3 a day				

You may ask: "why not just bring in the containers. If you want to be really careful, bring in a list **and** the pill containers. Medication containers have important information printed on them, such as medication names, strength of tablets, and how to take the medication. However, even though the medication and tablet strength in a bottle will not change, your doctor's instructions will often change between refills.

Although he will have notes in the chart about new instructions, your doctor and his staff rely on what you say at the time of your visit. Don't just hand a bag of prescription bottles to the nurse, especially if the instructions you follow have changed. Otherwise, your doctor may get the wrong information, you may get the wrong medical advice, and you may get the wrong instructions the next time you get a refill.

Make sure that at every visit, the information your doctor gets from you lets him know how you *really* take your pills!

- Decide ahead of time what to tell the doctor.

If you have a problem that you want to discuss at an upcoming visit, make notes about the problem, so you don't have to remember everything when you are sitting in the exam room. Try using the P-Q-R-S-T system that doctors learn in medical school:

- P** **Palliative/provocative factors.** In plain English, what makes it better (massage, medications, etc.), and what makes it worse (stress, walking)?
- Q** **Quality.** If it hurts, is it a dull pain, or sharp, or throbbing? How else might you describe your problem?
- R** **Region.** What part of your body is affected? Legs? Arms? Head? Neck?
- S** **Severity.** How bad is your problem? Is it mild, moderate, or severe? Is the pain the worst you've ever had, or just a nuisance?
- T** **Time.** When did your problem start? Is it getting better or worse? If it comes and goes, how many times does it happen each day, how long does it last each time, and when do the episodes occur?

The time you spend with your doctor will be more productive if you have this information at your fingertips, instead of having to recall it. In addition, the information will be more accurate if you make notes when the problem is fresh in your mind.

- Did the last intervention help?

Often, you will be seen in follow-up after a medication addition or change. Your doctor is going to want to know if this change made you better or worse. Keep notes about the effect of the last medication adjustment or other treatment, and bring these with you to your visit. This will help your doctor evaluate your response. This information is the best measure of how you are doing; your examination only helps confirm what you yourself have observed.

Be prepared to answer the following questions:

- Did you follow the recommendations made at your last visit?
- Did these recommendations help?
- Did you have any side effects from a new medication?
- Did you have to stop the medication?
- If so, how long did you take it for, and what else did you notice
- Was it too expensive?
- Focus on the most important problems.

At any given appointment only a few problems can be evaluated thoroughly. Before your visit decide what you would like to tackle; if at all possible pick **one** problem to work on. Tell the doctor what your chief problem is **at the beginning of the visit**. It could be pain or a worrisome new symptom. It could be a possible side effect of your medication such as constipation or bladder problems. Or you might just need someone to talk to. Your doctor will be able to help you best if you focus on what you need help with the most.

- **Ask questions**

Do you ever feel like your doctor doesn't explain things? Do you feel like all he does is write prescriptions? Do not let him get away with that! Ask questions!

Doctors love to explain things, believe it or not. If you want to know why you are taking Neurontin or Sinemet, or how it works, ask. If you want to know which pain medication is the safest, ask. There is no such thing as a stupid or silly question.

- Ask questions about your condition

If you read an interesting article in the paper, clip it out and bring it to your next appointment. If you find something on the Internet, print out the Web pages. However, if you see a story on TV, make a note of the center or scientist in question, as well as the name of any new medication or procedure. Otherwise, if your doctor hasn't seen the same piece, he or she won't

be able to answer your questions about it. Your doctor will enjoy hearing about a media story about your condition and discussing it with you.

- Finally, ask questions at the end of your visit...

...especially if you don't understand everything the doctor said. Remember that there's no such thing as a stupid question! If you feel confused, or are concerned you'll forget everything as soon as you get home, make sure the doctor or nurse writes everything out for you.

- **Give feedback**

Ever find yourself saying "I like my doctor, but..." What do you do if you have a bad experience at your visit? What if you have a problem between visits?

If you have a bad experience, make sure to let someone know. Most often, you will need to speak to the office manager or center coordinator. Sometimes, you will need to speak to the doctor directly. Be specific; was there a problem with scheduling, phone etiquette, or billing? What do you think went wrong? What do you think should be done so this won't happen again?

Every doctor's office has a policy for dealing with complaints. Most physicians will be grateful to learn of a problem in their office. This gives them a chance to fix things before patient care is affected.

- Give the doctor feedback.

What do you do if the doctor is the problem? What if he was rude, or brusque? What if he did not listen? What if he was late or you waited longer than you should have? What if he didn't listen to you, or rushed you through your appointment?

Don't be reluctant to report a problem, even if the problem is with your doctor. If you don't feel comfortable telling the doctor directly, tell the office manager. Sometimes a doctor might just be having a bad day. Regardless of the reason, you should let the office know if you were not satisfied with the treatment you received. A good physician will be grateful for constructive criticism.

- If you have to leave the practice, let someone know why.

If you have become dissatisfied with your care, and feel the problem is irresolvable, you may want to move on. Take a moment, though, and let the office know why you are leaving; you will be helping others if your constructive criticism leads to better treatment of other patients.

Also, let the office know if you have to leave for other reasons. If your HMO won't approve your visits, your doctor may be able to negotiate a contract with them. Alternatively, you may be able to see the doctor outside of your HMO (the cost might be less than you think). If you live too far away, and it is too difficult to travel a long distance, let the office know. If your doctor hears this from enough patients in your region, he might look into starting a satellite clinic closer to you. Finally, if you move out of state, let your doctor know so he can refer you to a specialist in your new city.

- **Learn the office policies for communication between visits**

Do you ever feel frustrated because you can't get the help you need in between visits? Do you ever find yourself saying "When I need to speak to the doctor between appointments, he's never available. I can only talk to a nurse, or worse, a receptionist. Shouldn't the doctor be available to answer questions between visits?"

- Ask what the policy is for routine calls

Every doctor's office has a different procedure for handling events between visits. Some procedures are universal; if you have to reschedule an appointment, you will want to talk to the receptionist. The receptionist may also call to remind you the day before an appointment. In some offices, the receptionist will handle requests for prescription refills; in other offices a nurse or medical assistant will do this.

- Learn what to do if you have to speak to the doctor

If you have a question that requires a physician's attention, he may either call you back directly, or discuss your case with a nurse, who will then call you back. It is rare that a physician will be able to take your call right away; usually, he will be seeing patients or otherwise occupied. Because of this, let the staff know how urgent your problem is, and when you would like to be called back. Some offices have specific times scheduled to return phone calls. If you are unable to wait by the phone, leave a number where you can be reached. Take advantage of technology. Consider call waiting, so the office can reach you if you are on the phone; consider an answering machine or voice mail, so the office can leave you a message.

Also, prepare for a phone call to the doctor like you do for an appointment (see above). Keep a list of your medications by the phone, and notes about your current symptoms. Keep a pen and paper by the phone to take notes while you speak with the doctor or nurse.

Finally, some problems cannot be handled on the phone, especially complex problems such as dyskinesias and fluctuations. Often the doctor will have to take a look at you in person to really know what is going on.

- Find out how emergencies are handled

We can divide emergencies into 3 categories. These are (a) complex problems (b) urgent matters and (c) true emergencies. Fortunately, true emergencies are rare.

All nurses have extensive medical and pharmacological training, and can communicate your problem you are having efficiently and reliably to the doctor. In particular, neuroscience centers employ specially trained nurses who are experts in neurological medications. If you have a matter that you feel is very complex, however, and you feel it would be best to speak directly to the doctor, let the nurse know.

Urgent matters require a rapid response. Sometimes you will not be able to wait for a return call. You might have run out of medication or you might have had an alarming reaction from a new medication. Let the staff know the nature of your problem and that you need to speak to the doctor or nurse right away.

Finally, though rare, emergencies do happen. A true emergency might be a serious reaction to a medication, or a new symptom that makes you suspect a stroke or other unrelated problem. Again, explain the emergency to the staff, and ask to speak to the doctor immediately. If for any reason you cannot get through, or if the doctor is not available, you should call your primary physician immediately, or dial 911. It is better to get to an emergency room and receive immediate medical attention than to wait until you might have a chance to discuss the symptoms with your neurologist.

- Find out how what your doctor's office does when the office is closed

Most doctors' offices use an answering service or a voice mail system to receive messages after hours. Either way, you will always be able to reach your doctor, or an associate who has agreed to handle emergencies for him.

If you need to cancel an appointment or request a prescription refill, leave a message as instructed. Don't forget to leave your phone number, including area code, and whether or not you need to be called back.

If it is an emergency, and you have to page the doctor, make sure you will be available when he calls back. If you don't receive a call back within a reasonable time, the doctor might have a problem with his pager, or otherwise may not be able to return your call immediately. If this happens, don't panic, but call your primary MD or 911. You will always be able to get prompt medical attention for your problem.

- **Hold your doctor responsible**

We do not mean to make it seem like all communication problems are the patient's fault. Doctors have to accept much of the responsibility for communicating effectively with their patients.

There are many areas where physicians can improve their communication skills, and that's a topic we could write volumes about. Briefly, some of the areas physicians need to work on are:

- ...listening carefully to the patient's problem.
- ...writing down instructions in clear language.
- ...explaining how medications work.
- ...allowing time for questions.
- ...answering phone calls promptly.
- ...communicating with a patient's primary physician.
- **Study medical terminology**

You probably sometimes wonder why doctors talk in medical jargon. It may seem like they are being paid by the syllable. Medical jargon can be intimidating, and most doctors will try to avoid using it when speaking with a patient. Sometimes, however, it is necessary to use technical language.

For example, some of the medications used to treat a condition known as trigeminal neuralgia (TGN) are also used to treat epilepsy. We call these medications "anti-convulsants." Similarly, the term "trigeminal neuralgia," although a mouthful, has a very specific meaning. "Tri-" mean three, "geminal" means arising from, "neur" means nerve and "algia" means pain. Even if a medical professional has never heard of TGN, he or she can infer a lot about the condition simply from its name: a painful condition affecting a nerve that has three roots. Using the proper medical terms helps doctors, patients and healthcare professionals know exactly what they are talking about, and can also help us all to better understand how treatments work.

Here is a wild idea: learn a little Latin or Greek! It is difficult to understand neurological disorders without knowing something about these languages, and if you speak the same language as your doctor, you will be able to communicate more clearly.

You can also find out a lot by looking in glossaries and medical dictionaries. Although a glossary of medical terms is beyond the scope of this talk, glossaries are available. Or, you can make your own, by asking questions and taking notes. Finally, consider buying a concise medical dictionary. Stedman's is a good choice.

One final helpful hint: the language of medicine isn't as mysterious as it seems. A lot of words are built up from prefixes, roots, and suffixes that appear again and again. For example:

dys-	abnormal or disturbed
hyper-	excessive
hypo-	insufficient or underneath
derm-	skin
a-	absent
neur-	nerve
gangli-	a clump of nerve cells
-algia	pain
-otomy	cut
-ectomy	removed
hyster-	uterus

So, "neuralgia" means nerve pain, a "neurectomy" is a procedure where a nerve is removed, a "gangliotomy" is a procedure where a cluster of nerve cells is cut, and a "hysterectomy" is a procedure where the uterus is removed, a "hypodermic" needle is one that goes under the skin. Cool, eh? Or should we say "hypothermic?"