



Interacting With Your Doctor

Many medical doctors, particularly general practitioners, family practitioners, or internists, see relatively few people with spinal cord injuries. They may not be aware of its complications or its impact on aging. Therefore, you, as an SCI survivor, need to learn what you can about your current condition so you can inform your doctor of your specific needs. The field of medicine is so broad that it is impossible for any physician to be an expert on everything. Moreover, information about SCI is expanding enormously. Forty years ago, there were few survivors. Now there are thousands, and we are learning something new every day.

Wanted: Team Work

You and your doctor can work as a team along with other health care providers. You can contribute to each other's understanding of SCI. Share with your doctor the following:

- Your medical history and records
- Your medications history and drug allergies
- The specifics of your injury – For instance: what are the complications relating to your vulnerable body systems such as bladder, bowel, skin, autonomic nervous system, mobility and self care?
- Your family medical history
- Your concerns about your functional level, self care, and family concerns

See if he or she would be interested in articles, brochures, videos, etc. on SCI. Sharing these specific concerns with your doctor will help him or her be aware of the potential problems related to your long-term health care.

Visiting Your Doctor

When you make an appointment with your doctor, think ahead about the information you need. Arrive with your questions already written out. Don't be embarrassed if you don't understand something. Take notes or ask your personal care attendant to take notes. Don't be afraid to acknowledge your fears.

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Questions

Ask specific questions, such as:

- What are the potential side effects of treatment, surgery, or medications that may arise as a result of SCI? If your physician is uncertain, insist that he or she find out.
- Why is he or she prescribing this treatment or medication? What will be the short and long-term effects, particularly on your vulnerable body systems? Will it affect your bowel or bladder? Will you need attendant care?
- Are there alternative treatments or medications for your condition? If so, what are the advantages or disadvantages?

Tests...

Undoubtedly, the time will come for testing and diagnostic procedures. Approach this reality with more questions such as:

- How will testing help in the diagnosis or therapy?
- Does your SCI add any new risks? Are there safer or easier ways to get this same information? What is the step-by-step explanation of the test?
- What are the costs? What will health insurance cover?
- How will your SCI affect how you prepare for the surgery? For instance, if you need a colonoscopy, will the usual enema completely empty your colon? If not, what does your doctor suggest?

Procedures....

- Will anesthesia be used and what may be the complications?
- Are there special instructions regarding preparation for the test and following the test?
- What are the possible complications resulting from the tests, particularly in view of your injury?
- How will your skin be protected? Will you need to be lifted? Will you need extra attendant care for the prep or follow up?

...and Surgeries

- If surgery is recommended, how is it expected to help? What will happen in the surgery? What are the chances it will work? What are the risks? What will be your recovery time?
- You'll also need to ask—and understand—how your SCI will affect your recovery following surgery. More important, you'll need to help your doctor understand how his or her recommendations might affect you. For example, "no lifting for six weeks" is a common post-surgical restriction. You will need to explain to the doctor what this means to you. You can't transfer, can't do shifts, can't push up hills, etc. Will your doctor authorize attendant care for six weeks while you recover, and will he or she recommend that to your insurance company?
- Should you rent a power chair or custom mattress?

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These are the concerns that you can raise which are important for office procedures, medications, testing, and outpatient or inpatient surgery.

Remember: No questions are out of bounds

Second Opinions

If you are facing major surgery, but it's not a crisis, you may wish to consult another physician. You will want to know what other treatment might be suggested. You may also be concerned about how the surgery might impact your transfers, wheeling and other activities. If your own doctor does not have answers to your concerns, consulting another is the best option.

Doctors, at times, may feel threatened by second opinions. Kievman, in her book *For Better or For Worse: A Couples Guide to Dealing with Chronic Illness*, suggests the question, "Is there someone else we should consult with?" Your best bet may be to get second opinion from a physiatrist or a physician who has had a history of treating SCI survivors and can tell you all the options with all the potential side effects.

Partners

Remember, you are in a partnership with your physician for your long-term health care. You need to tell the doctor what your body can and cannot do. Together, you and your doctor will keep you on track for a healthier and more functional life.

Resources

Building a New Dream: A Family Guide to Coping with Chronic Illness and Disability by Janet Maurer. Reading, Mass: Addison-Wesley Publishing Company, 1989.

For Better or For Worse: A Couple's Guide to dealing with Chronic Illness by Beverly Kievman with Susie Blackmun. Chicago Contemporary Books, 1989.

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