You and Your Doctor: Rights and Responsibilities

As part of a growing health and cost conscious public, we now take more responsibility for our health. More concerned about what we eat, drink and how we exercise, we also bring a questioning approach to health care. We are now forging new relationships with our doctors and we are less likely to sit passively and accept unquestioningly our doctor’s directions. We want second opinions, alternative treatments or medications.

As a person with SCI, you know you will spend more time with doctors and other health care professionals than most people. It is a good idea to know your rights and responsibilities as a patient as well as your doctor’s rights and responsibilities.

What are Your Rights?

As one who knows your body, your aches and pains, your specific needs related to your injury, you have the right to two-way communication with your doctor about your long-term care concerns. You have the right to whatever information you need about your injury and possible complications arising from the injury. Because you may see many different doctors and therapists after your spinal cord injury (SCI), it’s important that you feel comfortable with your healthcare team and know your rights as a patient.

You have the right to:

- See your doctor in a fully accessible environment.
- Two-way communication with your doctor about needs related to your injury as well as to other health concerns.
- Any information about your injury and possible complications.
- Refuse a medical treatment you’re not comfortable with.
- A second opinion.
- Fully understand what costs you are being charged.
Never be afraid to ask questions. There is no such thing as a dumb question as far as your health is concerned. You have a right to know and understand. You have a right to express your concerns, doubts and fears, and to be heard.

**What are YOUR Responsibilities?**

In addition to your rights, **YOU HAVE RESPONSIBILITIES TO YOUR DOCTOR.**

- You need to tell him your medical history,
- What other doctors you may be seeing,
- What medications you use or have used,
- What is your alcohol or drug history.

If you have a right to the best treatment available, then you have the responsibility to share with your doctor information that will help him or her diagnose, medicate or treat your particular problems. If you keep things from your doctor, then the treatment you receive may be ineffective or dangerous. It is also your responsibility to tell your doctor everything you know about your injury, its possible long-term effects, and complications.

In addition, you are responsible for:

- Telling your physician about your symptoms
- Understanding in detail what is wrong with you and what treatment is available and planned for you
- Following your doctor’s directions, reporting symptoms or complications or making sure your doctor knows why you cannot do so
- Keeping scheduled appointments,
- Paying bills on time

**The Power of Choice**

You have a right to considerate, respectful, and non-discriminatory care from your health care providers. While you may not have the same doctor for all of your needs, your primary doctor should have a background in SCI and related conditions. Finding someone who fits your needs can be tough, so it’s important to remember that you can change your doctor at any time. Before you decide on a doctor, make a list of what your wants and needs are. Use this list when you begin researching with your health plan provider. Once you have a few possible doctors lined up, contact their offices and ask questions to see if they meet your needs.
Working WITH Your Doctor

It’s important to feel you can trust and be comfortable with your doctor. It is unethical for doctors to pressure you into making a decision about medical treatment or place their interests over yours. Make sure your doctor helps you to understand all the risks and benefits of any treatment or procedure before making a decision. That is your right! A good doctor will take the time to answer all your questions.

Asking Questions

Doctors are required to help you understand, so never be afraid to ask questions. When it comes to your health, there are no dumb questions. It’s not uncommon for people to feel intimidated when they visit a doctor. You have a right to know and understand what is going on. To make the most of your visit, write down all your questions ahead of time. You have the right to know the risks for any procedures or treatments your doctor recommends. You should always express your concerns, doubts, and fears. Remember, your doctor is there to help, not to judge or punish you.

Taking Responsibility

It is your responsibility to share information about your medical history and medications with your doctor. It is also your job to share with your doctor everything you know about your injury and any complications. If you keep things from your doctor, then your treatment may not work or have dangerous consequences. It is also a good idea to call the facility ahead of time to make sure they have what you need. For example:

- Do they have a wheelchair accessible weight scale?
- Do they have a height adjustable exam table?
- Do they have a wheelchair accessible bathroom?
- Are there accessible parking spaces near the office?

Communication

You and your doctor are a team and no matter how troubling something might seem or how embarrassed you might feel, it’s important you communicate fully about your health concerns. Your doc will help you find answers. If there is something you do not understand, just ask for clarification. If you have a question following your visit, you can always call and ask your doctor later. If you feel uncomfortable with something your doctor or his or her staff has said or done, be honest and speak up. If you have a long-standing relationship with your doctor, working out a problem or misunderstanding may be better than looking for a new doctor.

Avoiding the doctor is NEVER a good idea! If you have more than one specialist, then it’s a good idea to make sure they talk to each other. This helps to avoid contradictions in information and treatment.
You are also responsible for any medical related expenses. If you cannot afford to take a certain medication or pay for a certain treatment plan, discuss the issue with your doctor. Doctors can work with you to find an alternative or more affordable form of treatment.

**Your Doctor has the Right...**

- To ask you questions and know about your life-style;
- To information about your health;
- To communicate with your insurance or managed care provider(s);
- To stop treating you if he/she feels that there is an ethical or personal conflict between the two of you.

**Your Doctor has the Responsibility...**

- To provide an accessible environment in which you can be examined;
- To discuss diagnoses, tests, and treatments with you in a non-technical way;
- To recommend reasonable, alternative treatments or medications;
- To notify you of non-office hour coverage;
- To keep good patient records;
- To inform you of services not covered by insurance;
- To recognize when his or her knowledge is limited and to ask for a second opinion;
- To develop a partnership with you in your quest for wellness.

The American Medical Association (AMA) encourages doctors to examine their practices to eliminate any type of medical care discrimination. The AMA also encourages consumers to understand and advocate for their rights in healthcare settings.

**Informed Consent**

Before a certain medical/surgical procedure, treatment or research study, you may be asked to give or sign your “informed consent.” You are required to know and fully understand the risks and benefits of a certain treatment or procedure. An informed consent provides you with all the important information. Be sure to read any documentation carefully and ask questions if you don’t understand. Informed consent can also involve getting a second opinion. In some cases, your insurance provider may even require a second opinion.
Confidentiality

In any healthcare provider setting, you have the right to confidentiality. This includes your name and personal information, how your medical records are handled, and how your information is shared with others. You have the right and responsibility to make informed decisions about your care. If you would like someone close to you to have access to your medical information and/or the ability to make decisions about your care, it is important to put this in writing and have your doctor include it in your file.

HIPAA – Health Insurance Portability and Accountability Act

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is another document you may be asked to sign. HIPAA is important for two reasons, first it protects health insurance coverage for workers and their families when they change or lose their jobs. Secondly, it protects the privacy of your health information by making sure that your doctors and health care facilities do not share your health information without your permission.

The Privacy Rule

The privacy rule is a federal regulation that controls policies and procedures to protect your personal and private health information. Under this regulation all healthcare providers, doctors, and insurance companies must follow strict rules when it comes to sharing your information. This can be especially important in situations where you are working with more than one doctor. You may be asked for your written permission to share information. Because your insurance provider plays a major role in paying for treatment, your doctor may share information about your condition with them as well. It’s also important to note that you are entitled to a copy of your medical record(s). You may have to pay a small fee for requesting the record.

Advance Directives

An advance directive is a legal document that lets you describe what services you want to receive if an illness or condition leaves you unable to make decisions regarding your care. This can also mean appointing someone to act on your behalf. Laws about advance directives vary from state to state. Work with a lawyer, paralegal, or advocate to write your advance directive. Once this is done, make sure all of your healthcare providers are aware and receive that information. As part of your healthcare team, it’s also important that you understand your doctor’s rights and responsibilities.