

You and Your Doctor:

2008

A Short Guide To Your Rights And Responsibilities



*Promoting Health and
Preventing Complications
Through Exercise*

Rehabilitation Research and Training Center on Spinal Cord Injury



What Are Your Rights?

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:

- **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.**
- **See your doctor in a fully accessible environment.**
- **Fully understand what costs you are being charged**

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 is 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.

For more details on choosing a doctor check out the Craig Hospital's guide to changing or choosing a doctor at:

<http://www.craighospital.com/SCI/METS/choosingYourDoctor.asp>



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 (AMA, 2001). 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.



Take 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 (AMA, 2001). It is also your duty to make sure the facilities you visit are **accessible**. This means calling ahead of time to make sure they have what you need. For example:

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

For tips on accessible healthcare facilities visit the Center for Disability Issues and the Health Professions website:

<http://www.cdihp.org/briefs/brief3-facilities-access.html>

Communicate

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 Responsibilities:

- **Selecting a doctor and/or healthcare facility that is accessible;**
- **To share your symptoms and concerns with your doctor;**
- **Understanding in detail what your condition is and what treatment options are available to you;**
- **Following your doctor's directions, taking medication and following any treatment plans appropriately;**
- **Show up to scheduled appointments on-time;**
- **Encourage your doctors to communicate if you have more than one specialist or physician.**



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.

For more info on being an active healthcare consumer read the resource guide Making Preventative Healthcare Work for You at:

<http://www.nrhrehab.org/documents/research/preventive.pdf>



The Health Insurance Portability and Accountability Act (HIPAA)

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.

**To Find Out More About HIPAA
visit the U.S. Dept. of Health &
Human Services website:**

<http://www.hhs.gov/ocr/hipaa/>

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.

Your Doc 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 Doc Has The Responsibility...

- 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 provide an accessible environment in which you can be examined;
- 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. You can find a detailed list of physician medical ethics principles on the AMA website:

<http://www.ama-assn.org/ama/pub/category/2512.html>.

You can also find out more about patient advocacy and many other healthcare related issues at the AMA website.

Take Home Tips

Remember That:

- You and your doctor(s) are a healthcare TEAM
- Don't hesitate to discuss sensitive subjects with your doctor, chances are good he/she has seen it before
- If you feel the doctor doesn't take your concerns seriously, address it quickly to see if you can resolve the issue, otherwise it might be time to think about changing doctors
- The HIPAA Privacy Rule protects the way your personal health information is shared in a healthcare setting
- You have a right to accessible, non-discriminatory and considerate healthcare
- You have the right to seek a second opinion in matters of treatment or surgery

Resources:

- American Medical Association (AMA), 2001. The Patient-Physician Relationship," adopted June 2001. [Accessed July 16, 2007]. http://www.ama-assn.org/apps/pf_new/pf_online?f_n=browse&doc=policyfiles/HnE/E-10.015.HTM&&s_t=&st_p=&nth=1&prev_pol=policyfiles/HnE/E-9.132.HTM&nxt_pol=policyfiles/HnE/E-10.01.HTM&
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- Kievman, Beverly with Blackmun, Beverly. *For Better or For Worse: A Couples Guide to Dealing with Chronic Illness* . Chicago: Contemporary Books, 1989.
- Kailes, June Isaacson. Making Preventive Health Care Work for You – A Resource Guide for People with Physical Disabilities, 2006. The Center for Disability Issues and the Health Professions, Western University of Health Sciences. [Accessed Aug. 17, 2007].
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For more information or alternative formats, please visit our web site at: <http://www.sci-health.org> or call 1-866-380-4344.

Disclaimer

This fact sheet only provides general information. It is only for informational and educational purposes and should not be used to diagnose or treat a medical condition. It is not a substitute for professional medical advice relative to your specific medical conditions. Always seek the advice of your doctor or other qualified health provider before starting any new treatment or with any questions you may have about your medical condition.

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