

Some Tips For Consumer Self-Advocacy with Health Care Professionals

1. Be organized and prepared:

- ◆ Write your questions out ahead of time in checklist form (check each one off during your appointment)
- ◆ Bring an updated list of medications and doses with you – it saves time during the exam and is much easier on the memory. With the potent medications we are taking, it is important that the doctor has a complete picture of all of your medications.
- ◆ Bring a patient advocate or a witness if you feel you need one. They can help you assert your rights or simply your thoughts, or they can help you remember later what the doctor said. You may want to have your advocate take notes ahead of time, to ensure that the doctor doesn't overlook any of your concerns. Have them take notes during the exam as well.
- ◆ Don't take "no" for an answer. Some clinics and/or some procedures have policies against permitting anyone into the room other than the patient. If you have trouble getting permission, assert that you have a cognitive deficit/disability and request the presence of the advocate as your personal attendant. Because of the nature of the meds most of us use, a cognitive deficit is not an unreasonable assertion to make.
- ◆ Arrive a few minutes early to organize your thoughts and papers. You will feel much more confident going into the exam if you're not rushed.
- ◆ In emergency or hospital situations, be prepared with a written list of medications and doctors' contact information. Have these lists prepared ahead of time, and carry them with you whenever you travel or when you know you are going to the hospital.
- ◆ Register with MedicAlert. As an alternative to carrying lists around with you, register with MedicAlert. For \$35 the first year (and \$20 each additional year) you will receive an emblem (necklace or bracelet) from them, and all of your medical information will be available to hospital or emergency personnel by phone. Memory keys with your health information are also available from them. Information can be easily updated on the Internet or by phone. The web site is a www.medicalert.org, or you can call at 1-800-432-5378 to register.

2. During the Exam:

- ◆ Be assertive – find your place of power. Assert your needs in a firm but pleasant way. Hostility is generally not necessary, and is usually very non-productive and alienating. All that's really called for is to act and assert your needs on a level playing field with your doctor.
- ◆ Don't let the doctor intimidate you. They may know medicine, but you know you.
- ◆ Demand dignity and respect. Don't settle for less. You can always fire the doctor and hire a different one. You are the consumer. You are in charge. Don't give your power away.
- ◆ If you think the doctor is missing something, repeat it firmly. For example, if you are concerned that certain medications might interact badly, and you're not sure that the doctor has considered this about these two medications, don't be shy about raising your concerns until you are satisfied. Your very health and well being are at stake. And doctors are human – they can and do forget details or overlook the trees for the forest.
- ◆ When it is important to you, be uncompromising about what you need in order to feel safe. For example, if it is important that your primary physician be consulted before surgery, withhold your consent until your terms are met. This places pressure on the health care provider to comply with your needs, where they might not otherwise place much weight on your request. Remember – you are in charge. On the other hand, don't hold out so far that it puts your health at serious, unnecessary risk, unless you do so knowingly, and have decided that the risk is worth it to you. Always require the doctor to disclose risk factors to you when contemplating this course of action.
- ◆ Focus on issues pertaining to the doctor's specialty. Make sure she or he understands the bigger picture, but don't stray too far out on a tangent.
- ◆ Be aware and respectful of the doctor's time and commitments to other patients. You may and should request exceptions to their rules under special circumstances, but don't try to over use this – it is likely to backfire.
- ◆ Don't expect doctors to advocate for you. Only you (or your appointed advocate) is likely to consistently do this. If you hand your power over to the doctor, you are not likely to get the return you are hoping for. Hold on firmly to your self-determination. Only you can make fully informed decisions.
- ◆ Don't expect the doctor to have much information or expertise about how to get on with your life if you're living with chronic pain. Therapists (PT, OT, mental health, etc.) may be more useful. The most helpful experts though, tend to be others who live with the same limitations.

3. Potential Pitfalls:

- ◆ Where rigid policies exist, demand exceptions when special circumstances warrant. Be aware, though, that sometimes the clinic is not capable of offering the services you are requesting. Also, be aware that if you cry wolf too many times, you will cease to be taken seriously. Worse yet, you may become blackballed altogether, so err on the side of caution when exercising this request.
- ◆ If you feel that you are not receiving the services or respect to which you are entitled, exercise your recourse options. In any size practice, you may switch doctors, or make a complaint to the AMA (or CMA in California). You may also request the assistance of a patient advocate, case manager, or liaison who represents your private insurance company, or you may consult with an attorney about potential litigation. Alternative dispute resolution, like mediation or arbitration may also be available to you. In larger clinics associated with hospitals, you may also have access to intervention by the Risk Management Office. This office, part of the hospital, is authorized to resolve disputes before they escalate into litigation. Additionally, any state run facility is required under law to have an ADA Compliance Officer, who can help if the issue at hand involves lack of physical accessibility or reasonable accommodations.*
- ◆ Stereotypes, Disrespect and Judgmentalism. All of these are serious and frequent problems, especially (anecdotally) for those with chronic conditions, conditions that cannot be quantified, women (especially heavy women), people with disabilities, and others. If you pick up on this kind of behavior, call the doctor on it, either in the office, or with a follow-up letter, copied to the supervisor (if there is one). Do not let this behavior go unchecked, or it is likely to result in poorer quality of health care for you, as well as a waste of your time and money. Again, all of the options listed above may be available to you, as well, to help you resolve this serious matter.

Finally, respect the doctor, and expect respect in return.

** This is a partial but incomplete list of ways in which to redress your complaints about a doctor or clinic. For a complete list of options and requirements for filing a complaint, consult an attorney. Some time limits and/or statutes of limitations may apply to any or all of the options listed.*