

What the Best Doctors Do with their Chronically Ill Patients

THE BEST DOCTORS...

- Remember that I am a person.** I have family and friends who love me. I have hopes and dreams and am mourning the future that I envisioned for myself. I am more than a collection of complex symptoms. Please care about me as a person. I am a person!
- Validate my symptoms and my suffering.** It means a lot to me when you acknowledge my suffering. My illness is invisible, not imaginary.
- Respond to inquiries.** Please return my call or email (or have your nurse call). I need to know that you will be there for me when my symptoms are flaring and I am at my worst.
- Are proactive.** Learn about my illness. Consult with a colleague, search the internet, or refer me to someone that you think might be able to help me.
- Get familiar with my case.** Taking a minute to refresh your memory by scanning my file can save valuable minutes during our appointment. Where have I been treated? What specialties have I encountered? What other avenues might be available to me as I search for answers?
- Take the time to answer all my questions.** Put me at the end of your day's schedule so you have a few extra minutes to help me understand my illness and medications. If that's not possible, permit me to register for a double appointment so that I can thoroughly understand my health issues.
- Aren't afraid to say "I don't know."** The best doctors can admit that they don't know everything and will brainstorm with colleagues or research an illness online and get back to me later.
- Don't blame me when the therapies don't work.** I am as frustrated as you are, but please stay with me. I know that my medical issues are complex and not easy to fix, but I am not disposable either.
- Fight with insurance companies on my behalf** to get the treatments that improve my quality of life. Sometimes insurance companies fight cost effective treatments like IV fluids or vitamin B12 shots at home that make me feel much better. Please fight for my quality of life!
- Give me credit for doing what I can to improve my quality of life.** I am likely open to unconventional treatments, when conventional ones have failed. If you know of supplements, alternative treatments, or novel therapies that might help improve my quality of life, please suggest them. Every bit of comfort or relief is valuable, even if it isn't a cure.
- Are careful with prescriptions.** Inform me of risks or side-effects of drugs or therapies, keeping in mind that I may have more hypersensitive or adverse reactions than the average population.
- Aren't afraid to talk about hopelessness and ask about suicidal thoughts.** Recognize when I need help and refer me immediately to a good counselor or support group. Understand the isolation that accompanies chronic illness and recommend treatment if I show these symptoms.