

### **Patient “Rules” When Confronted by a Serious Condition**

1. Obtain a comprehensive diagnosis through full testing, multiple imaging and several medical opinions or reviews.
2. Build your team of trusted professionals (doctors from several specialties, physician assistants, nurses, therapists and healers) and foster communication among them. Look to your team for answers, not to just one doctor.
3. Seek out “the guy” or top specialist in your area of disease. Make an appointment and get there!
4. Take a mindfulness class, go on a retreat or other activity to renew your spiritualism.
5. Identify companions to make this journey with you. Find friends you’d like to “sit next to on the flight”. Share the journey when possible to build an extended support community.
6. Involve your family in the “pace & flow” of the diagnosis, worries, options and treatment. Make them understand what it is like for you. Speak out for your needs even if you think they may not be met.
7. Maintain your own set of medical records and images so you can take them with you anywhere at anytime.
8. Devote not more than 4 hours a day on your medical issues no matter what.
9. Actively choose the treatment options that are best for you. After a modest amount of research you will know what is best for you. A gut feel will develop rather than a “finding” as a result of perfect logic.
10. Reduce your time horizon to what you are capable of handling – a moment at a time, an hour, today, this week but not more. Work with managing this level of focus and attention.
11. “Plan for the worst, live for the best.” Face the diagnosis squarely on and spend time with “the worst”. Develop a “what if scenario” to follow if the worst occurs for you and your family. Once developed, pack it away and visit it only occasionally. Then live your best.
12. Work on accepting your diagnosis and take whatever time necessary to accomplish this. Watch for any avoidance tactics that keep you from reckoning with the “new you and your new normal”.
13. Learn to accept help – help in all aspects of you life. Learn to appreciate help, not as a statement of what you can’t do but as a way of sharing your condition with others as a part of the human experience.
14. Share your new perspective of life with those around you. Everyone can benefit from the insights gained from a diagnosis of a life threatening condition. Reflect your new take on life in everything you do.
15. Recognize, feel, understand and address your sense of loss, powerlessness and aloneness. Seek the depth of these feelings and frustrations. Know these as core human emotions and as a path to oneself (with gain, power and connectedness).

## **Provider “Rules” When Assisting a Patient/Client with a Serious Condition**

1. Always see your patient/client as a human being, and then see the condition, need, disease or problem.
2. Always end the appointment with, “Do you have any other questions or concerns?”  
When hearing that these are addressed, only then are you free to go...not before.
3. Always understand you are part of a patients/client’s team and you need to work with others involved. The patient/client needs to make his/her own decisions with input from the team not simply follow your “orders” or advice.
4. Always accept the people that the patient/client may bring to the appointment. They are your communication allies and will improve your capability to provide, heal and help.
5. Always show your own humanness in the most sincere ways that you know how. Find gestures, expressions, grins, smiles and other signs that reflect the human that you are – beyond your professionalism.
6. Always know that to **heal** a person doesn’t necessarily mean to cure their disease. It means to guide a person to medical, emotional and spiritual health.
7. Always build on the patient/client’s strengths when addressing means to confront the disease. Past strengths can often be redirected to the problem at hand with remarkable success.
8. Always read your patient/client for their presence with the disease. Note how easy it is for your patient/client to feel as “the sick one”. Recognize your role to build a relationship that empowers healing. Share ownership of the condition and together discover a path toward health.
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9. Never greet a patient, or ask a co-worker to greet a patient with, “How are you going to pay for this?” or “What insurance coverage do you have for this?” without first asking the patient/client, “How are you?” (and mean it).
10. Never leave a message for a patient with incomplete information late in the day or before a weekend. Simply ask to have the patient to return the call.
11. Never provide a prognosis without having all the necessary information, or without hearing the patient ask for this type of information. When giving a prognosis, be sure the patient can hear and understand what you are saying.
12. Never indirectly deliver bad (or good) news through someone else (co-worker, nurse, sub-specialist, radiologist, pathologist or technician) rather than delivering it yourself.
13. Never deliver a diagnosis of a serious condition over the phone, when someone is alone or a celebrating a special occasion.

## **For Both Patient and Provider**

1. Seek to understand the “limbo” between wellness and severe sickness, the seemingly chronic state and the mindset that goes with it. Be true to and come to terms with approaches that address the condition that may not overcome or cure it.

These ideas were developed from my cancer journey and through my patient advocacy skills as developed in discussions with Meg Gaines. In some form, many of these ideas originated with Meg Gaines and her work with the Center for Patient Partnerships.