Cancer patients need proactive game plan

Chris Carlson

For over a year now I've been managing a rare and ultimately fatal form of cancer. Though slow-moving, in cases like mine where doctors cannot identify the primary source for certain, the patient is often at the Big Roundup in the Sky within six months. Yet, I'm still very much alive and kicking, working as a consultant, and trying to keep up with my 2 1/2-year-old grandson.

There are hundreds of folks across the Inland Northwest each year confronted by cancer. It is by no means always a death sentence, and each person diagnosed with the disease has to choose how to respond. My response is but one and while it works for me it may not work for others.

"What's your secret?" many have asked.

I took the advice I've given clients for years: analyze the issue, develop a game plan, and employ it aggressively. In short, take charge and manage your care. Be proactive and positive, not reactive, passive and negative.

In the process, I've developed some fundamentally simple rules, but they work - and what's more, doctors and nurses seem to appreciate them.

"Know the enemy! Do your research. With information available on the Internet one can quickly learn almost all there is to know about their cancer, the most up-to-date treatments, the ongoing trials of new drugs and therapies. For example, I brought to my doctor's attention an experimental procedure using Yttrium-90 radioactive pellets which has shown great promise. Once we'd secured insurance approval, my doctor mastered the procedure himself, and the pellets were applied in September with so far very satisfying results.

"Work out your plan of attack! Develop with your doctor realistic steps to combat the cancer and then stick to the game plan. As with any plan, review it periodically to see if it is delivering the results you and your doctors believe are achievable.

"Stay on top of your care and know your file! Familiarize yourself with all your tests; keep track of the results by asking for copies of all the reports on everything from your blood work to the CT and MRI scans. You cannot expect anyone else to be as thoroughly familiar with your file as you should be. Doctors and nurses have dozens of patients and even in this digital age it is still difficult for them to keep track of everything. For example, there are certain "markers" by which doctors can measure progress or lack thereof. You should know those markers and ask for the measurements.

"Be patient, be polite, be prepared but be insistent! Doctors and nurses are often overworked and their time is limited. They are also human and will respond much better to patience, respect and a smile than to impatience, disrespect and whining. You can be polite and still be insistent on knowing and asking for answers. I've found it very helpful to send my doctors an e-mail or a fax just before I meet with them to let them know the issues and questions I have. Most of the time they have read these missives and are prepared. Together we save each other time which is precious to us all.

"Work with staff, especially a doctor's nurse! Too many people insist on talking only to the doctor. Just as I've found over the years when lobbying members of Congress or a governor's office, it's the support staff that usually really runs the operation. Therefore, cultivating and working with staff always pays dividends. I work hard at making sure a doctor's nurses know me, and I take the time to get to know them. Invariably they appreciate this sensitivity to their role and they turn into real allies and even advocates.

"Stay positive and stay busy! While some question the power of positive thinking, I've found there's no substitute for a positive mind-set and an active prayer life. We're all in God's hands and accepting our ultimately terminal condition (and we're all terminal — it's just a matter of when and how), but being grateful for our many blessings helps to keep perspective. One thing anyone can do is pen your life's story, which can be passed on to your children. So do it. You'll be glad you did and will find it therapeutic as well.

Following these few rules has enabled me to feel that while God has set the parameters, within that context, I am managing my care and taking responsibility. Hopefully, others too can benefit from these few rules.