

Complete Cancer Care

Part I - Getting the Best Possible Medical Care

God grant me the serenity to
accept the things I cannot change,
The courage to change the things I can,
And the wisdom to know the difference
Serenity Prayer

Friday evening. *Many of the people in the opening circle are living through the first few weeks and months of a cancer diagnosis and are looking for practical and effective advice about what they can do to maximize their chance of recovery. Drawing on his expertise as a cancer specialist, Rob outlines the approach of combining the best of western medicine with healthy lifestyle habits and wisdom-based complementary healing techniques. In the first part of this lecture, he provides advice on how to get the best care from the medical system by adopting a proactive and loving attitude towards yourself.*

The marriage of scientifically-based treatments and wisdom-based healing practices is called ‘integrative medicine’. This integrated approach, also called ‘complete cancer care’, will give you the best chance of living well after a cancer diagnosis. By empowering yourself at the level of body, mind and spirit you can make a tremendous difference in how you feel, in your general health, and even in your cancer outcome.

Getting great care from the medical system is at the foundation of ‘complete cancer care’, and is an exercise in paying close attention to what is happening, recognizing the truth for what it is, and taking the appropriate action.

Pay Attention to How You Feel

At different stages in the journey, you'll focus more on some elements of complete care than on others. For instance, gathering information and making the best possible medical decisions will dominate your thinking at the time of diagnosis and early on. Working with the emotional fallout of cancer often peaks near the end of your treatments. Nurturing your spiritual life can happen to various degrees throughout the journey.

There is no 'best way' to approach a cancer diagnosis. Everyone is different both in terms of their personality and in terms of their cancer situation. Therefore, you'll need to engage your rational mind as well as your intuition in working towards a program and strategy tailored to your needs.

Gather Information Mindfully

Carol Shields, the Pulitzer-prize winning author, wrote that being diagnosed with advanced breast cancer was like waking up on a train in the middle of a stormy night in a foreign land where everybody spoke a different language. So, the first essential step in working with the medical system is to understand this language.

What can make this complicated is that most people are highly stressed when they are diagnosed with a life threatening disease, and it's much harder to learn new information when you're stressed. As well, cancer is a complicated disease, everyone's case is unique, each person has their own way of learning optimally, and we all learn at different rates.

Being mindful in this 'foreign land' referred to by Carol Shields allows you to focus your attention on what's happening in the outer world as well as to your inner reaction. As you gather information, you can ask yourself "Do I understand what I'm being told? Is this useful?" and at the same time ask "How does this information or situation make me feel?"

Some people feel driven to get as much information as possible about their cancer, staying up late at night surfing the net for the latest breakthroughs. By way of contrast, there are some people who don't want to know anything and so don't seek out any extra information. In both of these cases, there may be underlying psychological issues. In the first example, the person may be hoping information will give them control over the situation, and in the second case, the person may be in a state

of denial. In both cases, being mindful about their feelings could be an important first step to a deeper level of healing.

If at any time you're feeling overwhelmed with the information you're reading, you can recognize those feelings and take steps to change what you're doing. For example, by being mindful, you might realize that obsessing over information is actually depleting you of life energy. You can pay attention to your inner wisdom to do what you need to do. One strategy may be to ask a loved one to gather information for you. Either way, honouring that you have psychological limits, even while being appropriately proactive, is a clear act of kindness towards yourself.

Understand Cancer and its Treatment

Try to understand the basics about cancer: its causes; how it is detected; how it can cause problems; and how it is treated. Learn about your particular case: the type of cancer; if it has spread and, if so, how far it has spread (stage); other factors determining how serious your cancer might or might not be (prognostic factors); and your treatment options. Ask about and consider the risk and benefits of each treatment option, including the option of deciding not to pursue active treatment.

By having a general understanding of cancer and the main concepts of treatment, you'll be better able to understand your cancer doctor and to collaborate in making the best medical decisions together. Don't worry if you don't understand everything at first and don't hesitate to ask for information to be repeated or for time to reflect. Acquiring information and insight is a continuous process as you become more familiar with the details of your case.

Major hospitals and most cancer centres have a librarian that can help you gather information in a way that is easiest for you to absorb and that is specific to your situation. As well, there are many books, pamphlets and hospital websites which provide reliable information. Community-based organizations like the national Cancer Societies offer free information services through their websites or toll-free numbers. They often provide trained information specialists who can also tailor the information to your needs.

Remember that information gathering can be tricky because you can quickly become overwhelmed with too much information. If trying to find good information is tiring, then give yourself a break.

If you decide not to become an expert in your own care, then ask a loved one to play that role. It's helpful to have a second set of ears hear what you are hearing and to have someone else understand what's happening. This person can help you review appointments, and also be ready to advocate for you and with you every step of the way.

Be an Active Participant in Your Own Care

Prepare for your appointments in advance by writing down any questions you have, and bringing copies of test results with you. If possible, bring someone with you to every appointment. Beforehand, decide who will record or remember the information. At the visit be open and honest and, if need be, ask for clarification from your cancer doctor when you're unsure or feel you are receiving conflicting advice.

Another way to empower yourself is to have a copy of your own medical file. Because the medical system is a human institution, and sometimes reports go missing, most physicians appreciate it when you come up with a photocopy of a missing lab test or have summarized the results in a nice graph—this saves everyone valuable time.

I recently had a discussion with one of my breast cancer patients about starting a new hormone pill. I warned her about the possible side effects, including thinning of the bones. I wanted to order a bone density test before I started her on the medication. She reached into her bag and pulled out a binder with her complete medical history. She flipped to the 'bone' section and showed me a normal bone density report from three years before. A quick photocopy, a prescription for her new medication, and we both went away satisfied.

She had obtained a copy of her test results by going to the medical records department of her hospitals and her other physician's office, quoting her legal right for a copy of everything written about her. She updates her file by requesting a copy of every new report.

Remember You are the Most Important Person

Try not to be intimidated by your cancer doctors. Remember the reason for your appointment is to make sure that you're receiving the best possible care. Make sure the session works for you. For example, if your doctor is talking too fast or using overly complex language, speak up. A simple

line like, “I’m sorry, I’m feeling a bit overwhelmed. Can you repeat that a bit more slowly?” or “I don’t know that word you just used...can you explain it to me?” can put you back in the driver’s seat.

It is empowering to understand the facts of the situation. The medical system is meant to deliver the best possible physical care for you. You have a right to understand what’s happening in your body and to review the pros and cons of the treatment options with your doctor. You are the most important person in the clinic or hospital room—not your doctor.

You can use the same attitude of pro-activity and self-love in reviewing the appointment afterwards. Do you feel you had all your questions answered? Are you getting conflicting information? Are there any other professionals or services which could help you with the problems you are facing? Do you have a clear understanding of what the care plan is during treatment and in long term follow-up? What are your responsibilities? What can you do to improve your health and chance of recovery?

If you feel your medical team can help you more, then say so, and ask for what you need. If it’s answers to questions that you need, call for clarification or ask for an appointment. The cancer centre nurse may be able to address many of these questions and concerns. And, as one of the weekend attendees recommended, ‘Squeak gently but persistently.’ Ultimately the squeaky wheel gets the grease.

When you advocate for yourself, you send a powerful message to your body and psyche about healing and wholeness. By being proactive and by being fully collaborative with the people on your care team, you can feed the flame of inner confidence, heighten your inherent strength, and invite in the universal capacity to heal.

Become More Comfortable with the Unknown

As you learn about cancer and its treatment, you’ll quickly discover that medical science does not have the answers to all the questions about cancer. For instance, why any one person develops cancer while someone else does not is not fully known. Scientists know that certain habits, like smoking, predispose people to cancer, but multiple other factors may also contribute such as genetics, the aging process, other environmental contaminants, an impaired immune system or just plain bad luck. The point is you may never know what caused you to develop cancer.

When you can accept that there are many unknowns in the causes, treatments, and the possible outcomes of cancer, then you can begin to let go of trying to know, for certain, what the future will bring. You can then focus your energy on the things you can control in the present.

For example, you *can* get the best care offered by the medical system and you *can* empower yourself. With a foundation of knowledge and a plan to be a partner in your own care, you can begin to relax and tap into the incredible healing potential of connecting with others, expressing both your fears and your love, and finding meaning and purpose in your journey.