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Barbara's Ovarian Cancer Story Part 2

Post Surgery - Ovarian Cancer: Process and Survival

Part II Conquering the Fear, Fighting the Cancer

by Barbara Ehlers-Mason, RN

Written in November, 2004, one year after the Surgery for Ovarian Cancer, in November, 2003

The next few weeks after my discharge from the hospital, were very busy. My sister, Nance, and my mom decorated the house and Christmas tree. My sister Lauren visited from Washington and cleaned, cooked and lent invaluable support to all of us. There were visits to the surgeon for follow-up and the oncologist for the initial visit. John and my sisters accompanied me. It was so very helpful to have someone else ask questions and write down information. It can be an overwhelming experience, especially when you're a little "spaced out" on vicodin for pain management, as I was. I signed on to be part of a clinical study using different combinations of medications for eight instead of the normal six cycles. Laurie had brought a book with her that offered a lot of information on how to deal with an ovarian cancer diagnosis and subsequent treatments. One suggestion was to research clinical studies. There is a great deal of "cutting edge" research out there but you may have to hunt for it, do your homework, and bring the information to your doctor. My oncologist's office was conducting a trial, I was accepted, and I was scheduled to begin treatment on December 21.

Even though I was dreading the whole process, I knew I had to approach it in much the same way I did the surgery, almost like an athletic event or a race. I wanted to go in as strong and as prepared as possible and with a better "attitude."

Attitude is defined as a manner of acting, feeling or thinking that shows one's disposition, opinion and mental set. We may not be able to control a situation, but we can choose our attitude about that situation- victim or fighter; passive or aggressive; depressed or striving toward joy and happiness; caught in the "why me's" or searching for the "what can I learn from this." With the help of many people and through much reading and research, my "attitude-adjustment" process unfolded.

A booklet entitled "Preparing for Chemo" suggests several things that I immediately put into action.

- 1) Get your hair cut short so that when your hair starts falling out, it's less traumatic and won't clog the shower's drain. (This worked for the drains but I was still traumatized).
- 2) If you plan to wear a wig, shop for it before starting chemo. My sisters and my dear friend and hairdresser Patty, helped with both of these steps. Watching my long hair fall to the floor was very hard



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and yet made me feel the tiniest bit more in control of what was happening to me. To my surprise, everyone loved my new hairdo. The compliments boosted my ego when I really needed it. Nance and Laurie accompanied me to the wig shop. Laughter is very good medicine-and we laughed a lot as we all played with the wigs before settling on two very nice ones. Four hundred dollars later I was armed with my hair prosthetics and a sore belly from laughing. At this writing, I'm sporting my own very short hair after nine months of wigs and hats.

3) The booklet suggests having a dental check up and cleaning before starting chemo. Also important is giving your home a thorough cleaning and perhaps scheduling someone to come in once a week thereafter- a clean house can minimize exposure to infectious agents.

4) Building up strength through exercise and a good diet can help minimize some of the side effects of chemo. This booklet and other helpful literature, is available through oncology offices and offers good practical information. I also found the library and the internet to be good resources.

Shortly after my homecoming, from the hospital, I received a telephone call from Lindy, a volunteer with the Cancer Society (set up by my husband and the cancer support staff at the hospital.) She had been diagnosed and treated for Stage IIIc ovarian cancer seven years ago. Hearing from her gave me a real boost and some good tips for dealing with the upcoming chemo. She shared her experiences with surgery, hair loss and complete recovery! She is still cancer free! In addition to advice on make-up to camouflage the fact that one has no eyebrows or eyelashes, she told me how helpful acupuncture was for her. She felt that it really minimized some of the chemo side-effects and "rebalanced" her body's energy. I had had a few sessions of acupuncture many years ago, and I immediately knew that this would be right for me. I believe in its efficacy and definitely feel the sessions have been very beneficial.

My first acupuncture session was four days after the first chemo treatment. The meds they gave me to prevent nausea worked very well. I didn't have much of an appetite and felt a little achy and tired but the only real side effect I experienced was a terrible, hand-wringing itching and tingling in my hands and feet. Amy, my acupuncturist, has worked with several people undergoing chemo, is very knowledgeable, and had a good treatment plan in place for me. I scheduled to see her 2 days before and 4 days after every chemo session. After my first visit with her, I did feel better, more energized and the itching had definitely dissipated a good deal. She gave me some suggestions on supplements and some Chinese herbs to use.

The side effect of itching, burning and tingling is called neuropathy and is fairly common with the types of chemo protocol I was on. After my second and third sessions, the symptoms worsened! I turned to the internet to learn more about neuropathy and what, if anything, I could do about it. I found an article by Cindy H. Makencon, website: www.ovarian-news.org, entitled "coping-Tips for dealing with neuropathy." She offered a great deal of helpful information including reports of studies on the benefits of taking fairly large doses of L-Glutamine Sulfate and Chondroitin. I forwarded this information onto



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Carolyn, the research nurse in charge of my clinical study, and she shared the information with the oncologist. I had already started taking L-Glutamine when I met with him. He had further researched and developed a new treatment plan for me which included large doses of L-Glutamine, a change in one of the chemo meds, and the addition of a medication called neurontin. The combination of all these things worked! The neuropathy gradually subsided and I've had no further problems.

I believe a few other factors contributed to my being able to handle the chemo pretty well. I continued to increase my exercise regimen, progressing to walking everyday and then back to the gym for step-classes, albeit modified, and lifting light weights. Exercise builds muscle strength, increases oxygen and blood flow and for me, was and is a real physical and mental energy boost.

I came across a book entitled: "Herbal Therapy & Supplements- a Scientific and Traditional Approach" written by Merrily A. Kuhn, RN, Ph.D. and David Winston, a herbalist and ethnobiologist. The book was part of an at-home study course that I needed to complete for my RN Continuing Education Credits. The book offers a comprehensive guide to many common and some less common herbs and supplements, their uses, adverse effects, contraindications, and drug-herb interactions. After careful research, I started using several herbs and supplements designed to minimize chemo side effects and boost my immune system. I was careful to use things that do not stimulate estrogen in the body as my cancer was estrogen-receptor positive. I started taking these supplements one or two things at a time in smaller doses in order to monitor any unfavorable reactions, before adding more. Most importantly, I notified my doctor that I was taking supplements and having acupuncture.

At the end of this article, I will offer a complete list of the supplements and herbs that I have been using and some information regarding the rationale for each of these additions.

For several months, our kitchen counter resembled a drug and supplement store. I had to write up a daily schedule of what to take when. It was worth it! Once the neuropathy was under control, I tolerated the remainder of the chemo treatments pretty well. I was able to work full time and exercise, and my appetite and energy levels were good. Physically, acupuncture, exercise, diet, and supplements were, and still are, valuable tools which helped me deal with the chemo and recover from its serious effects.

On another level, the emotional and spiritual aids were an even more powerful part of the healing process. Previously, I mentioned my visualizations regarding pre and post operative healing and seeing myself healthy and cancer free. Now, it was time to take it a step further and include it as a powerful adjunct to the chemo medications. Rather than seeing the meds as a poison, I started to visualize it as "nectar from the gods," washing through me and being taken up by my immune cells as a potion to destroy cancer cells. A few weeks before my first treatment, I read an article about a young local girl who had battled cancer at age 16. She wrote a book about her experience and included her thoughts on seeing her chemo as "nectar from the gods." I admired her outlook and incorporated it into my work.



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My husband, John, created a special tape for me to listen to while receiving the infusion of chemo. This guided exercise included relaxation, healing messages, and suggestions for picturing my immune cells taking care of things and using the chemo effectively. Before each chemo session, even before they started the IV, he would do a relaxation exercise with me. This ritual became a very important part of the process. By working on my "attitude" towards the chemo and by connecting with these parts of myself that can be powerful self-healers, I felt I was taking back control of what was happening. Feeling that you are part of the healing process instead of a passive receiver of medications etc., is very empowering.

Rituals and routines are very comforting, especially when you're experiencing stressful times. My "chemo ritual" evolved from the very first session. The night before, I meditated and did my healing visualizations at bedtime. John drove me to the oncology center. I selected my chair and we settled in with his relaxation exercise. My sister, Nance, arrived bearing muffins and silly magazines. After visiting and chatting, John left for work and Nance and I munched muffins and laughed at the National Enquirer stories. About an hour before the infusion was completed, my brother, Tom, would arrive for a visit and to take me home. Somewhere in the session, my sister, Laurie, would call from Washington to check in and often John would "pop in" in his travels. I always had company and felt lovingly supported. Sabrina included me in her meditation every morning and my mom would stop by the day after the session for tea and a chat. Every three weeks from December 21 through May 27, we followed this routine. The nurses and my family got to know one another and we became a real team!

Returning to work seven weeks after surgery was another normalizing routine that made me feel like I was taking back my life. Except for the day of chemo and the following day, I've worked full time, feeling productive, healthy and normal. My co-workers have been very supportive and caring. They even threw me a graduation party to celebrate the completion of chemo.

Even before my last chemo, I was researching what to do to prevent a recurrence of the disease. I found information on a clinical study for Ovarex, a vaccine designed to prevent a recurrence of ovarian cancer. After many phone calls, letters and haggling with my insurance company, I was accepted into a study being conducted at Stanford's Cancer Center in Palo Alto. It involved monthly infusions for the first three months and then every twelve weeks for the rest of the year, with routine labs and CT scans. I've experienced only mild side effects and feel fortunate to have access to one more tool.

This past year has been one of lessons for me. I would have preferred the "universe" had given me a gentle tap on the shoulder instead of this Giant Thump on the head to let me know I had things to learn about myself and how "I am" in the world. Here are some of the things I have learned from this experience:



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1. Pay attention - perhaps if I had agitated more forcefully with my doctor that something was NOT right, she would have responded with more attention. LISTEN to your body and trust your intuition.
2. Don't take anything for granted - people, job, health, hair. When you face the loss of these things, you realize how special people are, how the day-to-day routine of a job is a gift, how precious good health is and even how much better a "bad hair" day is than NO HAIR!
3. There are a great many sources of invaluable information out there through people, libraries and the internet. Taking advantage of these resources allowed me to create a comprehensive plan to restore my health and fight the disease using a combination of Western and alternative therapies.
4. We do have choices in how we deal with a crisis - probably the best choice for me was to reach out and ask for help. The more people I told about my health issues, the more positive energy came my way. I felt empowered rather than vulnerable and armed with my helmet (a wig, which, by the way, I got complements on) and my armor (acupuncture, supplements, chemo, prayers and visualization) I was ready to do battle. I was "Warrior Princess" instead of cancer patient.
5. Laughter is GOOD MEDICINE!

At this writing, my labs and CT scans are completely normal. I'm back to my normal routines of work and exercise. I'm sporting a "Jamie Lee Curtis" hairdo. I am excited about decorating and shopping for Thanksgiving and when we all come together, we'll have a lot to be thankful for! Before we dig into our feast, I'll be asking each person to write on a piece of paper, one thing that they are grateful for. Each of us will then withdraw one of these papers from the basket and try to guess who wrote the message. It will be easy to guess mine. I'm grateful for all the love and support from my family and friends (with a special thanks to my son, Matt, and my husband for shaving their heads to support me and to my son, Mike, and his band for dedicating songs to me at concerts and their fund raising for the Cancer Society.) I'm grateful for the prayers and best wishes that came my way from people I don't even know. I thank you!!! Well, of course, that's more than one thing on my piece of paper but so what! It's time to celebrate!

Happy Thanksgiving 2004 and celebrate every day of your life.

Barbara's Complete Ovarian Cancer Fighting Supplement List:

Three Imperial Mushroom Capsules - available through acupuncture office

A) Reishi- Immuno stimulant: enhances immune system; use is sanctioned by the Japanese Health Ministry as an adjunct treatment for cancer; Increases activity of chemotherapeutic agents and reduces



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adverse effects such as nausea, decreased white blood cell counts; helps protect the liver against damage caused by viral, drug and environmental toxins.

B) Shitaki- strengthens immune system response; improves survival times of cancer patients when used concurrently with chemo.

C) Maitake- best known for cancer fighting properties; many doctors in Japan use it to lower blood pressure and blood lipids; effective as an anti-tumor agent and immune system modulator.

Echinacia- used in Germany along with chemo in the treatment of cancer. May enhance white blood cell counts in persons undergoing chemo.

Cat's Claw- reduces side effects of chemo; used in clinical practice in Europe for cancer & HIV; has important immune enhancing properties; helps increase the number of T-cells, the true soldiers of the immune system. In Austria, it is used together with conventional treatment (chemo, radiation &/or surgery) to treat hundreds of cancer patients per year.

Graviola- scientists have been studying this herb since the 1940's - four studies were published in 1998 re: significant anti-tumor properties and selective toxicity against various types of cancer cells (without harming healthy cells; Purdue University has conducted a great deal of research on the Annonaceous acetogenins family to which graviola belongs) much of which has been funded by the National Cancer Institute or the National Institute of Health.

Acidophyllis- rebalances intestinal flora (especially important when you're taking a lot of medications.)

Multivitamins with Vitamin E

Calcium Supplement

IP-6 with Inositol- has been studied extensively for over 20 years; has powerful effects on the immune system.

Wheat Grass Juice- increases hemoglobin; rebuilds the blood; improves body's ability to heal wounds; washes drug deposits from the body; neutralizes toxins and carcinogens in the body.

Green and White Tea- Chinese believe green tea is a cure for cancer and a longevity tonic; boosts immune system function; research being done all over the world and in the US by the National Cancer Institute re: anti-tumor activity. Both green and white tea are excellent antioxidants.

Website for researching herbs- Plant Database Raintree Nutrition



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I used the guided relaxations/visualizations CD's from the Stress Education Center-Dstress.com

1. #209 Stress Management for Pre and Post-op Survival
2. #208 Stress Management for Healing

Reference:

Health Update from SELF Magazine by Jennifer Nelson November, 2004

Ovarian cancer: a not-so-silent killer

"Early diagnosis is crucial. When disease is caught before it spreads, 80 percent of women will survive."