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**GUIDE TO
COMPREHENSIVE
CANCER CARE**

**PATIENT / FAMILY
RESOURCE CENTER**

SELF CARE GUIDES

TESTS & PROCEDURES

**COMPLEMENTARY /
ALTERNATIVE CARE**

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To Information, Ideas and Resources**

December 2004

from

The Duke Patient/Family Resource Center

The Duke Patient/Family Resource Center is:

- A lending library offering books, audio and video tapes, magazines and free brochures dealing with cancer and certain blood disorders and with issues of coping, survivorship, caregiving, and grieving
- Open 8:30 to 5:00 every day the Morris Clinics are open
- Located in the White Zone, first floor, of the Morris Cancer Clinic, Room 15123.
- Our phone number is 919-684-6955. Our email address is FamilyLibrary@mc.duke.edu

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Contents:

**Holiday Thoughts: The Wisdom of Cancer Patients
and Their Caregivers**



Christmas and Hanukka come but once a year and for some they bring no cheer. Those locked in a battle with cancer during this season may feel doubly miserable finding themselves fatigued or helpless, needy or impaired, right at a time when they would normally be buzzing around the house and the shopping malls, planning meals, baking goodies, preparing for trips, and being drawn into the excitement of impending family gatherings. Rather than decking the halls with bows of holly, they find themselves staring out of hospital windows or mired on the couch with the remote. If a beautiful snow falls, all the worse; a caregiver may not be able to get through and help out.



There are certain bits of advice that we who work in patient support usually offer at this point. One is to practice letting others take charge of the holiday-making and concentrate on reducing the stress on oneself. Letting go can be a learning experience for some, as it was for this cancer patient who writes:

I have always been an independent person. I was accustomed to doing for others and being the Supermom and the hardest-working employee... The struggle of allowing others to help me and simply saying "thank you" was very difficult. I remember feeling so frustrated when my husband and close friends organized a house-decorating party so Christmas would be preserved in the style to which I was accustomed. They did not do things as I would have done; however, as I watched them decorating, I realized how blessed I was to have them, and I noticed their joy at being able to do something tangible for me. I now allow people to love me by their actions. In return, I have learned to hug them and tell them how

much I appreciate them.

-Ivette Carter, *Silver Linings*, p. 193

Those tasks that cannot be allocated such as cranking out 2 dozen of your secret recipe fruit cakes or getting all the Christmas cards out will simply have to be done later, perhaps in January, when one feels more up to it; or perhaps never. People will understand. The children's grandparents or aunts and uncles might be prevailed upon to occupy them during good portions of the day. On the other hand, if there are certain holiday things one loves doing and that can be done with relative ease, by all means have at it.

For caregivers it is important to make this Christmas about love and support, rather than about the intricacies of the illness or the blameworthiness of those who haven't been helpful. Stress-causing visitors should perhaps be limited in their access. By contrast, anything that can be done to facilitate the arrival of a longed for out-of-town relative or friend should be done.



Stories, Reflections, Recipes

What I will be doing in this newsletter is passing along a collection of inspirational thoughts and stories from cancer patients and their helpers. These are not all related to the holiday season, or to religion, but most are culled from our shelves on "Coping and Inspiration" here at the Patient/Family Resource Center. Interspersed with these thoughts and stories are festive but easy recipes that might give a little zest to the holiday season.

So, to begin, you might imagine yourself seated in front of a warm fire.



Let's warm up internally with a seasonal beverage: eggnog. I've read a ton of eggnog mix recipes and none of them are easy! So here's my suggestion: get the basic eggnog mix from your friendly supermarket. There will probably be a choice of two or more types. Specialty stores - like Fowler's Gourmet or A Southern Season - may have quite fancy versions. Then follow these instructions:

Eggnog



- A quantity of eggnog mix
- One-third to one-half that much alcohol from brandy, dark rum or whisky (or a mixture of these)
- Gently and gradually stir the alcohol into the mix, then chill in the fridge for a couple of hours or more.
- To enrich the mixture just before serving, beat 2 egg whites* together with a teaspoon or two of sugar until you get stiff "peaks" on your beater. Then fold these beaten whites into the eggnog.
- Serve in glass cups if you can and sprinkle each serving with nutmeg.

* Patients with low blood counts should avoid raw eggs. Cool whip may have to be substituted for the egg-white fluff.

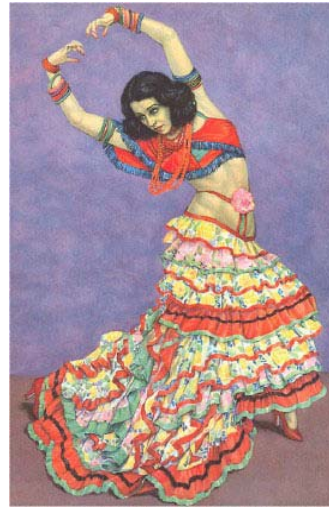
A Story: The Woman Who Danced Her White Counts Up

"I was in the hospital for experimental chemotherapy for breast cancer. A week after receiving a high dosage, my white blood cell count dropped to 100 (normal is 5,000 – 10, 000). My visitors scrubbed their hands and donned surgical masks before entering. The white count edged up slowly over the next two weeks, but my immune system remained greatly compromised.

"I had insomnia and tried to rest by listening to classical music on the radio I had brought from home. At 11 pm, the announcer said he was about the play "agitating music" and put on a 16th century tarantella. It had a solid, infectious beat played on wonderful old instruments – nasal reeds and small drums. I was seized with a compulsion to leap from the bed and dance wildly.

"Imagine what I must have looked like: a one-breasted 43-year-old

woman, completely bald, barefoot, with flowing hospital gowns both front and back. I was attached to a tube snaking from a hole in my chest to the IV pole, which had become my constant companion since coming to the hospital. I was a woman possessed by this music, in the throes of a frenzied jig.



"My exertion exhausted me, but still the music throbbed. I told myself to sit down and catch my breath, but I couldn't stop. When the music finally ended, I collapsed on the bed and listened as the announcer explained the development of the tarantella. There were a lot of spiders (including tarantulas) in Renaissance Italy and no medical antidote for their poison. The superstition held that a bite victim might survive by dancing until he dropped. Therefore, the local musicians were called upon to perform music to promote this activity. "Aha!" I said, gasping on my bed. "The chemotherapy within me must resemble spider venom."

"To amuse my morning nurse, I told her of my midnight romp. She replied, "But it's not superstition; it really works. Frenetic activity stimulates the body to release epinephrine, and this natural antihistamine counteracts the allergic reaction of the spider bite." Could the same be said about a reaction to chemotherapy? She shrugged.

Later that same day, she came in to tell me that my white counts had jumped from 700 to 3, 850! Quite suddenly, I was no longer neutropenic. Within 24 hours, with normal counts, I was sent home, holding the record for the shortest stay of any woman on that protocol.

Call it the dance remedy.

-Carolyn Keiler Paul, *Silver Linings*, pp. 148-149

Sweet Potato Frappe



OK, the main course - the turkey, the stuffing, the sweet potatoes, the green-bean casserole with onion rings on top - is about to reach the table and the patient doesn't feel quite up to it. Have chilled and on hand some of those soft cooked sweet potatoes and try the following recipe:

- 1 1/2 cup mashed cooked sweet potatoes
- 1 (12 ounce) can apricot nectar, chilled
- 1 tablespoons honey
- 1/2 teaspoon vanilla extract

Blend all ingredients until smooth and serve.

Cancer Patients Reflect on Their State of Mind - 3 Cases

From a woman facing risk of recurrence: "Surviving cancer taught me to appreciate my defenses. For perhaps the first time in my life, I realized how skillfully my mind protected me from emotional overload. My terror of dying from cancer was mysteriously self-limiting. I would be engulfed by fear, literally shaking and crying, and then I would just space out or my thoughts would turn to something pleasant. I didn't will these shifts. They just happened. I would stop crying and go on with whatever needed to be done. I simply followed along, trusting the "wisdom" within me. Such "inner wisdom" is simply another term for the defenses in action."
- Glenna Halvorson-Boyd, *Dancing in Limbo*, p. 22

From a woman living with metastatic cancer: "To live and die consciously is what I want. This means being a vessel, porous and transparent, letting the emotions rise and fall, letting heartbreak come and letting it go, feeling the emotional pain, keeping it all moving, not blocked. There may be a physical tumor in me, one location where all the cells congregate, but I am working very hard to make sure there isn't an emotional tumor in me, a mass that has the power to block the flow of feelings. I have a cancer but it is not consuming me. Rather, I am as alive as I can be; my creative juices have never been more electric; my thoughts have never been as clear. With each new status in my illness, my range of choices shrinks but I become deeper and richer, clearer and simpler to myself. "

-Barbara Rosenblum, *Cancer in Two Voices*, p. 69]

From a man struggling with recurrent lymphoma: "With the

diagnosis of cancer, I felt the door close on the first 42 years of my life. Slowly, however, a window began to open. What started with fear, panic, and denial ended up with love, forgiveness, and self-acceptance. You see, I discovered I had a choice – a choice between closing up and fearing life or opening up and living fully. I chose the latter. I chose to live in the moment, day by day – to appreciate what I had in my life instead of what I didn't have. I learned to give and accept love more freely. I put down my sword and shield, my anger and ambition. I picked up gratitude and surrender, appreciation and spontaneity."

-Eric Trules, *Silver Linings*, p. 195]

Dessert: Bread Pudding!



Not that hard to make and very, very palatable. Give it a try.

- 3 1/2 cups milk
- 1/4 cup butter
- 2-3 cups dry bread pieces. Crusty French is best, slightly stale is OK
- 1/2 cup sugar
- 2 eggs, slightly beaten
- 1/2 cup sherry (or madiera)
- 1 teaspoon cinnamon
- 1 teaspoon mace
- 1 teaspoon nutmeg
- 1 cup seedless raisins

Preheat oven to 375. Scald milk, add butter and let it melt, then pour the hot liquid over the bread pieces. Soak about 5 minutes, then add the sugar, eggs, sherry and spices. Add raisins and mix. Pour mixture into buttered baking dish. Set dish in a pan of hot water. Bake until a knife inserted in the center comes out clear, about one hour.

Finding Who's Out There for Us: 2 Stories

Rachel Naomi Remen, counselor to many patients facing life-threatening illness, recounts the story of Mary, starting at the

point where she learned her young son's diagnosis with an untreatable cancer:

"When she heard the diagnosis, Mary had left the doctor's office and gone home. Her son was now back at school. She had walked up her front steps, flung open the door of her house, and howled at the top of her voice. Still screaming her outrage, she had gone from room to room, flinging open windows, shaking her fists in the air, and shouting. Mary's home was in a conventional neighborhood where many of the families were Irish Catholic. Her husband, concerned as always about what the neighbors would think, followed after her, closing windows as she opened them and trying to calm her to no avail. She continued to howl, and he, overwhelmed and frightened, had called the family therapist they had been seeing as a couple. The therapist had called back almost immediately, and her husband had rushed with the phone to the bedroom where Mary stood shouting before the open window. "Mary, Mary," he had said, "the therapist is on the phone." With this she had rounded on him and screamed, "The therapist? The therapist? *YOU* talk to the therapist, Harry. I'll talk to God!"

-Rachel Naomi Remen, *My Grandfather's Blessings*, p.346

Victor Frankl, who would become a world renowned psychoanalyst, narrated this story from his experience, as a prisoner, counseling patients in the Nazi death camps. The book from which it is taken, *Man's Search for Meaning*, seems quaint when read today - everything is "man" this and "man" that. His discourse seems to contain no "woman." But the most touching story in the book concerned a young woman. I recalled it this week from reading it in college 42 years ago, and found it again yesterday.

"This young woman knew that she would die in the next few days. Yet she was cheerful in spite of this knowledge. Pointing through the window, she said, "This tree here is the only friend I have in my loneliness." Through that window she could see just one branch of a chestnut tree, and on the branch were two blossoms. "I often talk to this tree," she said to me. I was startled and didn't quite know how to take her words. Was she delirious? Did she have occasional hallucinations? Anxiously I asked her if the tree replied. "Yes." What did it say to her? She answered, "It said to me, 'I am here - I am here - I am life, eternal life.'"

- Victor Frankl, *Man's Search for Meaning*, pp. 68-69



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Glenda Halvorson-Boyd & Lisa K. Hunter, *Dancing in Limbo*

Rachel Naomi Remen, *My Grandfather's Blessings*

Victor Frankl, *Man's Search for Meaning*

Holly Clegg & Gerald Miletello, *Eating Well Through Cancer*

The New York Times Cookbook

Other Books in Our Collection

Norman Cousins, *The Healing Heart*

Max Lucado, *Grace for the Moment*

David Spiegel, *Living Beyond Limits*

Bernie Siegel, *Love, Medicine & Miracles* and *How To Live Between Office Visits*

John Robert McFarland, *Now That I Have Cancer, I Am Whole*

Rachel Naomi Remen, *Kitchen Table Wisdom*

Terry Tempest Williams, *Refuge*

Harold Kushner, *When Bad Things Happen to Good People*, and *When All You Ever Wanted Isn't Enough*

Edward M. Hallowell, *Dare to Forgive*

Bob Stone & Jenny Stone Humphries, *Where the Buffaloes Roam*

Herbert Fensterheim & Jean Baer, *Don't Say Yes When You Want to Say No*

Irene Pollin & Susan K. Golant, *Taking Charge*

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