

Patient & Family Advisory Council: Working for you!



MEMORIAL CANCER INSTITUTE

Patient and Family Advisory Board Newsletter

When a healthcare provider becomes a patient: What is the correct chemotherapy regimen?

It was a typical day at work when I received the fateful news in August 2006. As a clinical pharmacist providing care to cancer patients little did I know I would become my own patient.

Diagnosed with Stage 3C locally advanced breast cancer, I was to start neo-adjuvant (chemo before surgery) chemotherapy as opposed to adjuvant therapy (chemo after surgery).

Next began 3 months of “dose-dense” (high-dose) triple-drug chemotherapy, followed by an additional 3 months of weekly single-drug chemotherapy.

As a healthcare professional, I was constantly researching treatments for cancer and found there were over 20 chemo regimens for breast cancer alone.

How did the doctor determine this was the best treatment plan for me? Many factors affect treatment regimens including location of cancer, stage, age, weight, and other medical conditions.

In addition, there are several different classes of chemotherapeutic drugs which work in different ways to attack the different types of cancer. Oncologists use drugs from these classes in a variety of combinations to achieve the best outcome.

The internet “information highway” can be daunting with conflicting information on every topic under the umbrella and should be used with caution.

An informed patient is the best coordinator of care in communicating with the various healthcare providers. Knowledge is Power! See page 2 guidelines I found to be most useful as a patient.

.....Continued on page 2

Meet An Advisor

Marie Lafortune is a patient advisor, who prides



herself on being a good listener who is completing treatment.

Advisory Council Members:

- Tom Cappadona - Chairman
- Liliana Nicholls Grant-Vice
- Natalie Sands - Co-Secretary
- Jeanne Bailey
- Bettye Bradshaw (MCI Staff)
- Katharine Campbell (MCI Staff)
- Carol Kubetz (Rad. Director)
- Marie Lafortune
- Micrena Lafortune
- Martie Mehallis
- Mike Sands



Core Principles:

- Dignity & Respect
- Information Sharing
- Participation
- Collaboration

Inside This Edition:

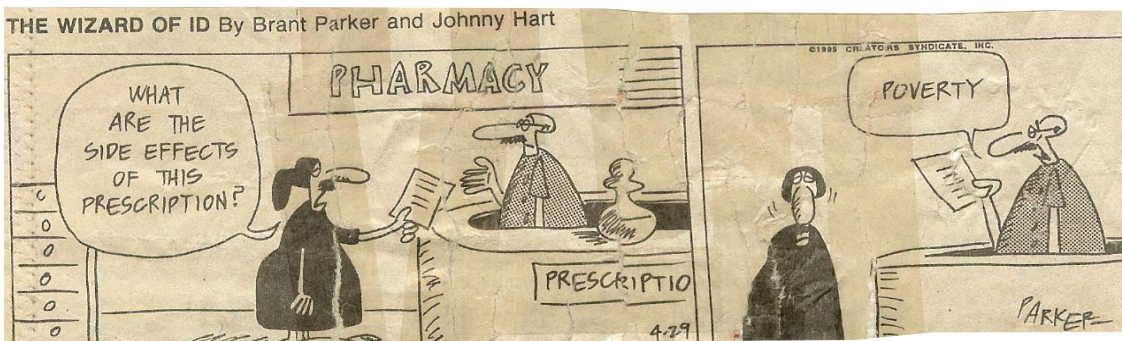
- Chemotherapy Regimen
- Financial Planning
- Radiation Experience
- Advisor Comments & Did you know...



Chemotherapy Regimen (Continued...)

The following guidelines I found to be most useful as a patient:

- ❖ Obtain 2 opinions from medical oncologists with similar treatment plans (a third opinion may be necessary as a “tie-breaker”).
- ❖ Know your diagnosis, stage, and treatment plan including names of medications, dose, frequency, and expected side effects.
- ❖ Discuss treatment plan with oncology physician, nurse or pharmacist and keep a written copy.
- ❖ Keep copies of test results, lab results, and physician phone/fax numbers; take to all appointments.
- ❖ Report side effects to physician or nurse. Some side effects are treated with other medications or may affect the treatment regimen.
- ❖ Ask healthcare provider of any dietary precautions or interactions with medications including over-the-counter medications, vitamins, and herbal remedies (many herbal remedies have not been clinically proven or FDA-approved for use with other medications).
- ❖ Keep written, ongoing log of all medications you are taking including date started, name, dose, and time of administration. A pill box divided by times of day (example: morning, afternoon, evening, bedtime) may be useful to keep track of when to take medication.
- ❖ Useful websites:
 - www.cancer.gov (National Cancer Institute)
 - www.asco.org (American Society of Clinical Oncologists)
 - www.nccn.org (National Comprehensive Cancer Network)



Jeanne Bailey
Patient Advisor

Advisor Comments: *"I am very happy about the improvement in Memorial Cancer Institute. Everybody really really cares about the patients. If you are waiting for a long time, you can see one of the staff walking up to you and asking you how they can help you. A BIG FIVE for them . That's team work. I, as a patient, like the advisory council , it expands my mind and makes me feel safe. What's the advisory council? Basically it's a meeting once a month where we meet together and try to analyze the issues that surround our patients in the oncology environment. It's true that we only meet once a month but the results are grand. And that's why you (the other patients out there) should join the program and bring with you new ideas, new issues regarding you, your family and someone close to you. And besides, that's what we are, a big family. We are out there to support each other and getting involved is one step towards a better future."*

Advisor Marie

Now is the time to begin planning!

A diagnosis of cancer for you or a family member is a life changing event that you may never have predicted. Although financial planning should be a normal priority for predictable events in your life, you are now faced with what may be a serious change in your current and future financial outlook. The details of any financial goals you had in mind may change and you will have to prepare for implementing possible adjustments in your plans. Here are some tips that may be helpful:

- 1) Don't panic.
- 2) Review all your combined assets and accounts(including IRA's, investment, broker age, retirement plans, money market accounts) with your family members.
- 3) Review your life insurance coverage.
- 4) Review your health insurance coverage. What are your co-pays, deductibles, and maximum out-of-pocket expenses?
- 5) Do you have disability insurance?
- 6) If possible, increase emergency savings.
- 7) If possible, set aside money in tax advantaged accounts such as a health savings account, cafeteria plans or education savings accounts.
- 8) LIMIT/AVOID credit card debt.
- 9) If applicable, are your accounts joint accounts?
- 10) If necessary, establish new payment plans for paying off current and anticipated debt.
- 11) Identify and share with family members your current and new financial goals and how you can work together to achieve them.
- 12) It may be helpful to set up auto pay for your bills.
- 13) Apply for Social Security Disability Income if applicable.
- 14) Seek financial assistance.
- 15) Prepare or update wills and other advance directives.
- 16) Access your Social Worker for assistance.

Don't panic, you can develop an ongoing strategy for handling this crisis. You can arrange to talk to an experienced social worker assigned to each center. You may call 954-276-5750 to talk to any member of Memorial Healthcare System Eligibility Team who can work with you or a family member to help apply for financial assistance.

*Elliot Natale
Family Advisor*

Upcoming Events

February 7, 2008 @ 5:30 p.m.

March 6, 2008 @ 5:30 p.m.

April 3, 2008 @ 5:30 p.m.

Patient and Family Advisory
Committee meeting

To RSVP: Katharine Campbell
954-430-6880 x 9712

February 27, 2008 @ 12:00 p.m.

I Can Cope Lecture Series:
Finances and treatment issues
Free community lecture
To RSVP: Bettye Bradshaw



Knowledge Is Power!



Did you know... that wigs (also called cranial prostheses) and mastectomy are often covered by your insurance company? Most insurance companies will pay for 2 , or sometimes more, wigs and mastectomy bras. Be sure to get a written receipt with the company name and , if possible their business license number. Medicare Advantage Plan patients, who were originally on Medicare, and have medical bills that their new plan refuses to pay, may ask to be reenrolled in the original regular Medicare retroactively so that Medicare can pay your bills at its usual rate. Call the Medicare hotline (1-800-633-4227) and talk to a knowledgeable caseworker. Also, don't forget that MCI offers a Look Good...Feel Better group where you can receive a free make-up kit and great tips and tricks.

Family Advisor: Elliot Natale

Refried Beans... The Radiation Experience

After completing 6 months of chemotherapy and beginning to recover after surgery with my bare scalp starting to show signs of hair growth, I completed the final step in my cancer treatment...radiation. I thought this would be a piece of cake after all that I had been through, and as a healthcare professional, I had some background as to what to expect. I had already lost all my hair so what could be worse? Would radiation cause me to lose my hair again? What exactly is radiation? After consulting with the radiation healthcare team, I learned that I would receive external beam, light-ionizing 3D-CRT (conformal radiation therapy) daily (Monday – Friday) of 180 units (measured in megavolts) for 28 doses to the breast and neck area followed by 5 boost treatments pinpointed to the tumor site, for a total of 33 treatments. I started my research again as a dutiful patient to make sure I was knowledgeable of the radiation process. I found myself more confused than ever with all the different types of radiation and found it difficult to understand how radiation could basically burn me from the inside out without me seeing or feeling it. At least with chemo I could see it and feel the needle prick.

After the initial consult, I went back in a couple of days for a “set-up” where CT scans of the treatment area were taken and I was given small tattooed dots as markers. The CT scans were compared with a previous PET scan to “map” the organs and treatment area so that a plan could be developed. I then went back for another visit just prior to starting the radiation for the “simulation” where I was put under the machine for what I call the “dry run” and the skin was marked with washable markers and tags to make sure everything lined up. Once all these steps were completed, I began radiation.

The actual radiation only takes a few minutes. I would have to lie still during this time while the machine delivered the doses and the staff ran out of the room closing a 6” thick door behind them. The machine would move around me making strange sounds. I was overcome with anxiety at each radiation visit. After the first week my skin in the treated area began to get red like a sunburn and the radiation oncologist prescribed various creams to apply after treatment. Occasionally my skin would need a break and the doctor would hold treatment for a couple of days. Each week my skin was evaluated by the physician and periodically blood labs were monitored. CT scans were repeated frequently to ensure the targeted area was being radiated. In addition, the machine is monitored to ensure the correct dose is delivered. By the time radiation treatment concluded I had finally learned all of the staffs’ names.

What I learned from radiation:

- ❖ Review treatment plan with radiation oncologist and radiation therapist. Don't be afraid to ask questions or for an explanation of anything that is not understood.
- ❖ Consultation should include introductions to staff and a tour of facility.
- ❖ Ask healthcare provider of any dietary precautions or interactions with radiation, over-the-counter medications, vitamins and/or herbal remedies.
- ❖ Report expected and unusual side effects to physician or nurse; sometimes radiation doses are held due to adverse reactions.
- ❖ Do NOT shave or apply any products to treatment area unless otherwise approved by radiation oncologist.
- ❖ Keep detailed records of lab results, appointments, radiation days with notation of days if radiation is held.
- ❖ Compare records with the healthcare providers at periodic evaluations.

Jeanne Bailey, Patient Advisor

Can't Get Enough...Want More Information?

The Patient & Family Advisory Council wants to open the lines of communication.

There are several ways this can be done:

1. Add your name to our email list to receive quarterly newsletters. Just send an email to

MCI-PFAC@mhs.net

Note “Add to the PFAC newsletter list” in subject line of your email.

2. Call and leave any suggestions or comments for improvement at 954-430-6880 x9700

Make sure to leave your name and phone number if you want a return call.

3. If you are interested in joining the Patient & Family Advisory Council, serving in another capacity, or receiving the newsletter just call 954-430-6880 x 9700. Leave your name, number & that you are interested in serving. Or, complete the slip below and send it to:

Memorial Cancer Institute
801 N. Flamingo Rd. Suite 11
Pembroke Pines< FL 33028
Attn: PFCC/Katharine Campbell

To obtain past issues of the PFAC Newsletter please call or email Katharine Campbell.

I am interested in hearing more regarding the Memorial Cancer Institute Patient and Family Advisory Council
(Please check all that apply):

I am interested in serving as an advisor or in some other capacity of the PFAC

Please send me the quarterly newsletter Please send to:

Name: _____

Address: _____