

Patient & Family Advisory Council: Working for you!

SUPPORT GROUP? YOU MUST BE KIDDING ME!

Let me just begin by yelling, “There’s absolutely NO WAY I’m going to a support group. You can pull all of my fingernails out and the answer is still NO! Do you hear me??? I’m NOT GOING—and you can just take that to the bank!!! I can do this by myself!!! I hope you’re listening!”

And then--- my friend Camille called one morning and asked if I could drive her to her meeting that night. I quickly said, “Sure”, and it dawned on me that perhaps I should have asked just what and where this meeting was going to be—Miami, Delray, Myrtle Beach—just where? I never dreamed that it was to a support group, although I had heard from a neighbor that Camille had had a lumpectomy, chemo, and radiation, but that had been months ago. And as far as I knew, she didn’t even know I had

been diagnosed with breast cancer, let alone had a mastectomy 2 months earlier.

When she got in the car and announced that we were going to her support group, I was somewhat OK with the idea because I knew I was simply her mode of transportation, and I had every intention of keeping my mouth shut and keeping my little secret, a secret. It was when the facilitator asked my name and what I’d had done that I realized where I was and why Camille had asked me to drive her, rather than Gina, who lives across the street. I admit—the thought did cross my mind to lie and simply say I was Camille’s wheels for the evening, but instead I broke out into a hot flash and tears at the same time. (let me assure you that this is definitely NOT an attractive combination). Talk about an impressive and inherently refined entrance!!!

Continued on page 2

Meet An Advisor

Elliot Natale is a spouse of a breast cancer survivor. As an advisor, Elliot strives to help others become informed consumers and their own advocates.



Advisory Council Members:

- Tom Cappadona - Chairman
- Liliana Nicholls Grant - Vice-Chair
- Natalie Sands - Co-Secretary
- Terry Zimmerman - Co-Secretary
- Jeanne Bailey
- Katharine Campbell (MCI Staff)
- Denise Del Forn (MCI Staff)
- Carol Kubetz (Radiation Director)
- Marie Lafortune
- Micrena Lafortune
- Martie Mellallis
- Elliot Natale
- Mike Sands
- Howard Zimmerman



Core Principles:

- Dignity & Respect
- Information Sharing
- Participation
- Collaboration

Inside This Edition:

- Understanding a port
- Understanding a bone marrow biopsy
- Your first chemo



Support Group (Continued...)

Right about then I decided that this was not for me, and I'd never see any of these women again, so I might as well spill the beans and give them the whole story, which I did. About 29 ladies were there that night, all in various stages of their recovery, when one piped up and stated that one of her meds was making her constipated. Another one chimed in and told her to be sure and take her pills with prune juice. Now I ask you—in all honesty, what book would you actually find that little tidbit written? Another one offered that frozen watermelon was so soothing in a mouthful of sores. (Betcha' never saw that one in print, either).

And THAT, my friends, was the reason I went back the following week, and one of the reasons I continue to go--a year later! Knowledge is POWER, ladies—whether you use it yourself or pass it on to another woman! These gals know which words to use when dealing with insurance companies so that your items are covered rather than rejected, they can steer you through the Medicare/insurance jibberish so you know just how many bras you're entitled to, and how often. They'll remind you that if you need to go to the emergency room, you make sure to tell the triage nurse if you're taking chemo, and they'll not waste time getting you seen. They know the names of the office girls who will make sure to have the doctor return your call that day—not 3 days from now. Another pearl of wisdom is to make sure you have a copy of every single doctor's report, test report and blood work report. They're yours and you NEED to keep all of these in a notebook. It's all the tips about taking charge of my care that keep me going back. And every week I learn something that I never thought I'd need to know.

When we try to explain our fears to our families, many times they're the ones who can't deal with our concerns. Men, as a rule, are programmed to find solutions to whatever comes up. They simplify things. We say we're nervous about our mammogram results or our arm that is growing puffier as we speak, and they tell us, "Oh, everything's going to be alright—you just went to the doctor yesterday—could you hand me the remote?" We, on the other hand, need to think out loud, and that just drives them crazy. It's not that we're complaining—we just think out loud. A support group allows you to do just that, and you know that no one in that room is passing judgment—because we're all in the same boat and paddling upstream. The difference is that each of us jumped in the boat at different times. If you have a question or a concern, just remember that someone in that room has already "been there and done that". There's no reason, at our ages, to reinvent the wheel—we have enough on our plates.

I was afraid that I would be stuck with a bunch of down-in-the-mouth women holding their own pity party. Quite the contrary! Luckily I felt right at home with these wonderful and caring gals. If you don't feel that way on your second visit—bag that group and hunt for another one.

I can honestly say that I've finally accepted that I'm in this stupid sorority called cancer and have paid my dues. (Hopefully I won't be asked to rejoin!) I can also honestly tell you that I wouldn't be where I am today without my wonderful support group. I wish we could call it something else, but then, I guess that's what it really is. Just remember, there are thousands and thousands of us fighting this until some good-looking researcher comes up with a cure. At that time, we'll just smother him with kisses. Until that day, we're going to need to stick together.



Marti Mehallis
Patient Advisor

Financial Assistance

How are you handling the costs of cancer care for you or a family member? Do you anticipate the need for financial assistance? There are programs available that offer direct assistance to those who are uninsured, and co-payment and/or premium assistance to those who are insured but have difficulty making those payments. The following is a list and a brief summary explaining the programs that are available to those who qualify.



(1) Patient Services Incorporated www.uneedpsi.org 1-800-366-7741

PSI is a non-profit charitable organization primarily dedicated to subsidizing the cost of health insurance premiums & pharmacy co-payments for persons with specific chronic illnesses & rare disorders. Assistance is offered based upon the severity of their medical and financial need.

(2) Partnership for Prescription Assistance www.pparx.org 1-888-477-2669

This organization offers a single point of access to more than 175 public & private patient assistance programs, including more than 150 pharmaceutical company programs.

(3) Healthwell Foundation www.healthwellfoundation.org

Provides co-payment & premium payment assistance to eligible individuals & will cover some COBRA payments under some conditions.

(4) Patient Access Network www.patientaccessnetwork.org 1-866-316-7263

This is a non-profit organization dedicated to supporting the needs of patients that cannot access the treatments they need due to out-of-pocket healthcare costs.

(5) Patient Advocate Foundation www.patientadvocate.org 1-866-512-3861

This non-profit organization is dedicated to safeguarding patients through effective mediation assuring access to care, maintenance of employment, & preservation of their financial stability. Assistance can be provided to those who qualify, based upon their illness, & have a financial & medical need.

(6) Cancer Care www.cancercare.org 1-800-813-4673

Counseling and financial assistance for non medical expenses is offered.

(7) Chronic Disease Fund www.cdfund.org 1-877-968-7233

*Elliot Natale & Katharine Campbell
Family Advisor & MCI Social Worker*

Take advantage of our free services (continued): Massage Therapist

There are three licensed massage therapists that offer free massages to patients and caregivers when they are any of MCI's three outpatient cancer centers. MCI is one of the few centers in Florida that provide this free service as part of a complimentary care program.

Antoinette Muirhead, LMT at the Breast Cancer Center, strongly emphasizes that massage therapy can provide rewarding benefits to cancer patients dealing with the side effects of chemotherapy and radiation therapy.

Antoinette, who initiated the program, has been a therapist at MCI for six years. Her specialized training in cancer massage from nationally certified instructors qualifies her to provide therapy that, when used as a compliment to conventional medical care, provides so many benefits. These include: a caring presence, relief of symptoms, pampered attention, and diversion from anxiety and stress.

Remember, although massage therapy can be an integral part of your cancer care, it is always important to communicate with your physician before receiving a massage.

*~ Elliot Natale
Family Advisor*

For More Information on the
Memorial Cancer Institute's
Patient and Family Advisory Council
contact

Katharine Campbell, LCSW

Kcampbell@mhs.net

954-430-6880 x9712

Or

Bettye Bradshaw, LCSW

BBRadshaw@mhs.net

Patient Experience: What to expect from your first chemotherapy session.

I was terrified so I highly recommend that you have someone with you. I had heard so many stories about how people would get so sick, that the thought scared the hell out of me. Once I was called to the treatment room, the nurse explained everything to me. I finally remembered to ask to see the actual foreign object I had implanted in my chest. Much to my surprise it seemed so much bigger than the size of the bump I had on my chest.

When the nurse explained to me that she would be inserting the needle in the middle of the bump to access my port, I cringed. She did offer to put a spray on me that numbs the area by making it so cold, that you won't feel the pinch. I decided I was going to be tough as nails, so I turned her down. The truth is that I really don't like the cold.

The process seemed to take forever to get started but we had to wait for the pharmacist to work up the medicinal cocktail I was going to receive. Like a good bartender, he (the pharmacist) has to make sure I was getting the exact dosage necessary for my weight. Oh yes, I forgot to tell you. You will be weighed each time you receive treatment. The dosage of your treatment is based on your weight. So now not only do I have to feel bad about getting treatment, but also having someone else know how much I weigh. There goes one of my best kept secrets.

I finally started getting my treatment as I watched a movie. I kept waiting to feel sick but nothing really happened. I was sent home and I was already prepared to feel sick. After all I had all the preparations at home, the nausea medicine, the vomiting medicine, and the diarrhea medicine.

The first day and into the evening I felt great. No effects at all. So I decided I really didn't need my medicine. I guess I am one of those people that feels why take more stuff when I don't need to. The second day went by without any event. I could not believe it. I felt great. No nausea, vomit or diarrhea. I was in heaven. Well, maybe not in heaven but you know what I mean. The third day I was great too. Until it finally hit me right after dinner. I started feeling a little nauseous so I decided maybe it was finally time to take my medicine. Well it was too late. I got so very sick that I did not know which end to keep in the toilet. Between the shivering and the sweating, the toilet and the bucket, I was a complete mess.

So the moral of the story is, even if you feel great or even fine, **take your medicine.** You may be sorry you didn't, just like I was.

*~Liliana Nicholls Grant
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. Complete the below slip below.

4. If you are interested in joining the Patient & Family Advisory Council or serving in other capacities 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: _____