The Club You Don't Want to Join

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J'ai donné ce discours aux " Women's Metastatic Cancer Support Group" au British Columbia Cancer Agency, ou comme le groupe l'appelle souvent: le "Club que personne ne veut joindre." Quelquefois, nous sommes en forme, quelquefois nous sommes moins bien, quelquefois nous sommes sous traitement, quelquefois, non. Mais toutes nous vivons dans un monde où le cancer est une maladie chronique, ce qui est une autre façon de dire que nous vivons à l'ombre de la mort. Alors, voici mon témoignage, je suis sûre que plusieurs patientes avec métastases vont partager quelques unes de mes pensées et expériences

I've been a member of Women's Metastatic Cancer Support Group at the British Columbia Cancer Agency, or as we like to call it, "The Club You Don't Want To Join," for almost four years along with others who have been members longer and others who were members for shorter periods of time. We are young, we are middle-aged and we are older, we are married and single, some of us have young children, teenagers, adult children or grandchildren and some no children at all.

Sometimes we are well, sometimes sick, sometimes in treatment and sometimes not. But all of us live in a world where cancer is a chronic disease, which is another way of saying we live in the shadow of dying. So, while this is my story, I'm sure that many metastatic cancer patients everywhere will share at least some of my thoughts and experiences.

My Story

I was originally diagnosed in May 1992 with breast cancer and completed a course of therapy including a lumpectomy, node dissection, chemo, radiation and five years of tamoxifen. On my five-year anniversary I was thrilled to be included in the "Survivor's Club"—it turned out to be a temporary membership. Thirteen years later, almost to the day, I was diagnosed with metastatic breast cancer to my liver and diaphragm with no option for surgical intervention.

I was totally confused—nothing hurt. I'd been "rubber-stamped"—I was a survivor, I didn't look sick, I'd been cancer free for 13 years. What the hell were they talking about? When I was re-diagnosed in 2005 my life turned upside down. AGAIN I had to tell my family … but this time I also had to tell them it was terminal … or incurable which is a softer term many prefer to use—it doesn't really matter—it means the same thing.

But I'm not here to talk about the medical challenges of living with metastatic cancer—they're well documented. What I hope to do is offer some insight as to what it's like to live with the day-to-day challenge of metastatic cancer as a chronic disease.

Living with Cancer

Living with cancer is a unique world—an ongoing dance between emotional challenges and physical limitations. Never a day goes by that I'm oblivious to the fact I have cancer—it starts first thing in the morning with my meds. And it goes way beyond tests and treatments, medications and medical appointments, support groups and statistics. It's in my head as much as in my body—perhaps even more so. It's a life occupied alternately with fear, confusion, anger, anxiety, sadness, side effects and fatigue but it's also filled with joy and laughter and fun, happiness, family and friends and love.

When I was diagnosed I insisted my oncologist give me a time frame. He told me two to five years. I've learned statistics are just that and in my opinion are of no real value. I'm doing much, much better than anybody expected and think if I'd paid too much attention to my "best before" date my quality of life would not be near what it is.

Doctors just don't know how anyone will fare with treatment and to give an "expiry date" is not in any anyone's best interest. I've met numerous people since who have outlived their statistical time frame—some by as much as ten years. More and more people will continue to live longer with all the new treatments, drugs, and trials being developed—a group of people who don't fall into the conventional categories of either active illness or survivorship.

The first year and a half I really struggled—not so much physically—getting used to meds and side effects was way easier than getting used to the fact I going to die from cancer. I put on my best game face for everyone in my world. I tried to protect them. I let them ignore the reality of my life. I didn't show my grief. I didn't worry them with details. I didn't talk to them on my bad days because we no longer spoke the same language. I felt a huge responsibility to make things easier for everyone—to lessen the grief and the heartache.

Eventually things settled down though and the fear of treatment and the prospect of death didn't seem so imminent and my life returned to "normal." But this was a new normal because now I live my life in three-month increments. Every three months I go for tests and then a week later results. This is what my mind might sound like on any given day during a three-month period:

- •OMG—tests are coming up—three weeks away—hope everything is going to be okay.
- •Whew! Made it thru another set of tests … now I can just get on with my life.
- •Why is my stomach so upset—has it moved to my abdomen?
- •Am I making too big a deal out of this?
- •My shoulder is so sore—has it gone to my bones?—should I ask for a bone-scan?
- •Are my side effects any worse?
- •Are the meds still working?
- •I hate having cancer.
- •What if the tumors have grown: what kind of treatment will I have to have?
- •Is this the start of the end?
- •Tests tomorrow—finally—I'm sure they'll be fine—they always are.
- •I hate going to the clinic—I'm too healthy—do I really want to know anyway?
- •Please let the tumors be the same as last time.
- •There can't possibly be anything wrong with me, I feel too good.

And while all this is going through my head, I'm busy doing the day-to-day things in my life—I clean, I cook, I hang out with family and friends, I go to support groups, I go for walks, I laugh, I talk about insignificant and trivial matters and watch TV.

And while all this is going on with me, people make the assumption that if I look good, I must be good and if I'm good then I must be healthy—the cancer must be under control. Controlling my cancer isn't the issue—how can I get control of my life? I live in two separate worlds—the cancer world and the non-cancer world.

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After awhile people began to forget that I have cancer and so they're inclined to see me as I always was because it's been almost 4 years. I can assure you that I'm not the same - I live with it every day. But because I've been dealing with this for a long time some people tend to act like it's over—but it's not and when it is that means I will have died. Right now I might be fairly healthy but who knows when things will change—in 3 months maybe??

Pet Peeves

As a group we regularly spend time discussing our pet peeves and frustration about people—including those in the medical field - who just don't get it. For instance:

- •*But you look so good!* The common perception is that people who have cancer look like they have cancer. Please be aware that looking good has nothing to do with—it doesn't mean crap. You should see me on a bad day.
- •*"How are you doing?" We call it the look.* The frown in the middle of the forehead, the squinty eyes and the head tilted just ever so slighty—something like this ______. Rarely have I found someone who *really* wants to know. Most people don't want to talk about IT—about cancer and death and dying—but it's part of every metastatic patient's world so be *very, very* careful if you're going to ask with that kind of look on your face. And by the way, sometimes we're just fine.
- •*Well, we could all get hit by a bus tomorrow.* Please don't patronize me. I've already been hit by my bus. I hope you won't ever get hit by this one. Don't minimize my situation.
- •*Oh come on, you can do it!* If I felt that I could, I would.

Sometimes the emotional toll of cancer incapacitates me as well as the physical. Please understand it has nothing to do with you

- *Oh, don't talk like that. You'll be fine.* There's every likelihood that I won't be fine. I'm a realist. If I want or need to talk about what life will be like when my cancer progresses or after I die, *do not,* under any circumstances, give me that fake, terrified, cheerful smile.
- *When you ask me how I'm doing* include my whole world. Please remember that I am much more than my disease. Remember that we really did have things we used to talk about BEFORE cancer. Those things are still important to me.
- *Please don't edit me.* Yes, I have a lot on my plate. But it's not your job to withhold bad news from me. I'm an adult. I don't want to be left out of the loop. Don't avoid subjects that you think might be too sensitive for me. Let me make that decision. I need to know what's going on—good, bad or indifferent—my mind remains intact. I don't need to be protected from life.

There are more but I think you get the idea!

Our Losses

Having cancer diminishes us in ways that others can't comprehend. Certainly some of our losses are visible—our hair, our breasts, our beautiful skin, our basic body functions or our energy. But our losses go much deeper than that:

- We lose confidence in our bodies.
- We lose our independence.
- We lose our jobs.
- We often lose our individual identities—from motherhood to business executive.
- We lose feelings of sexuality and femininity.
- Young women lose their fertility.
- We lose our self-esteem.
- We often lose our financial independence or security.
- For some it is a loss of faith or a questioning of religious values.
- We lose relationships or the hope of having one again or the energy to pursue one.
- We can temporarily or permanently lose our memory.
- We lose parts of our bodies that can't be seen.

We wonder who the woman in the mirror is. We know who we used to be but now we have to re-invent ourselves to live a life we never expected. We lose the ability to live life without fear. We know we can't move past cancer so we have to work out how to live with it and that can change on a daily basis or at a ten-minute doctor's appointment.

The Group

We are a resilient group of women, a diverse group who love to laugh, shop, eat, drink wine, travel, play with our children, walk our dogs, write poetry, go to the theatre. A sisterhood of individuals whose paths, under ordinary circumstances, would likely never have crossed.

But together we are a force to be reckoned with! We share a wealth of information in the art of living with cancer as an extreme sport. We share our frustrations and our anger. We compare notes on medications, doctors, managing side effects, upcoming trials and how best to manage our way through an often de-sensitized medical system. We encourage each other when we're feeling anxious or dismissed, sad or confused, sick or just when we're down in the dumps. We speak the same language.

Our group is not just about cancer—it's about our lives. We're not a therapy group—we're a support group. We talk about the possible and the unthinkable. We come together to talk about our worlds without having to censor our thoughts or our tears, without having to sugar coat what we are thinking or feeling and we know that in our space we are understood and safe.

Our hearts break every day—for ourselves, our families, our friends, and for each other. We listen to each other's fears, hopes, and dreams, and sometimes we have to grieve the loss of our friends—and we do this together as well.

The women in my support group have become my very dear friends. I never leave a meeting feeling anything other than grateful for the time and the space. Some days I just need the comfort of being with them, other times I hope that something I've said might help or inspire someone else. Some days I want to talk, other days I don't. There's no pressure to be anything other than what you are.

I really want to pay tribute to everyone one that has ever been part of our group—for all your thoughts, your courage, your generosity, and wisdom—without you I'd have much less insight. And, of course, let's not forget the laughs, the treats and shoes. You keep me sane!

I feel privileged to be part of such an extraordinary group of women. While I never ever wanted to join this club, I am so very grateful it exists and don't know how I would have coped without it these last few years.

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Originally diagnosed at 40 with breast cancer, then at 53 with metastatic breast cancer and now 58, Marlene Mills considers herself in pretty good shape. She is retired and single, loves where she lives, cherishes her family, her friends, going on retreats, reading, writing and being the best she can be. She speak on the subject of living with cancer and has a personal blog: <http://changingtimes-marmills.blogspot.com>.