STRAIGHT TALK
Don Dizon, M.D. discusses sexual health and intimacy

FROM A SON’S PERSPECTIVE
Men Against Breast Cancer founder Marc Heyison shares his advice to men supporting women they love with advanced breast cancer

TALKING: The Best Kept Secret
Three women talk about how their diagnosis affects their romantic relationships – with commentary from psychotherapist Roberta Hufnagel
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Welcome to the debut of All About Us, a digital magazine developed to address the unique needs of the advanced breast cancer community. During my years at SHARE, I have met many women bravely living with various forms of breast and ovarian cancer. I cannot express enough how much inspiration these women give me. In my experience, women living with advanced breast cancer are incredibly full of life because they know how important it is to live each and every day to the fullest. The stories you’ll find in this issue are no different.

At the same time, I have seen firsthand the issues and hardships women with advanced cancer face on a daily basis: from coping with treatment, financial concerns, and strained relationships to fear, worry, and feelings of isolation from friends and the broader breast cancer community. This is why loved ones, supporters, and caregivers are so important to the well-being of someone living with advanced breast cancer and why SHARE, other advocacy organizations, and Novartis Oncology provide needed resources, information, support, and a sense of community to those affected by advanced breast cancer.

Earlier this year, the Count Us, Know Us, Join Us program conducted a global survey of nearly 1,300 women living with advanced breast cancer. The results revealed that this community struggles to find resources that are specific to their needs, something that we in the advocacy community have heard anecdotally for years.

The global survey also uncovered that for many women, advanced breast cancer negatively impacts their personal relationships and there is a desire to talk more openly with members of the healthcare team about the impact that advanced breast cancer has on their personal relationships, including sexual health and family planning. We explored these topics in this first issue because they are often the ones that people find difficult to discuss—even with their loved ones and healthcare providers.

Speaking of loved ones, this issue also gives a voice to the men who are affected by advanced breast cancer. Breast cancer is often thought of as a woman’s disease, but there are fathers, brothers, sons, husbands, and friends who are also part of this community. Men Against Breast Cancer founder Marc Heyison gives men advice for supporting the women they love and themselves in the face of advanced breast cancer.

I’m happy to bring you honest stories from women living with advanced breast cancer. Adrienne, Amanda, and Jennie provide unique experiences on the daily struggles with maintaining a healthy, loving romantic relationship while enduring the impact of advanced breast cancer. I find their ability to speak freely about the challenges they face refreshing and hope they provide inspiration to you as you continue on your personal journey.

Regards,
Christine Benjamin
Breast Cancer Program Director
SHARE, Self-Help for Women with Breast or Ovarian Cancer
All About Us asked Don Dizon, M.D., clinician, and oncologist at the Gillette Center for Gynecologic Oncology at Massachusetts General Hospital, questions about the impact advanced breast cancer can have on a woman’s sexual health, fertility, and emotional well-being. Dr. Dizon started the Center for Sexuality, Intimacy, and Fertility for women with cancer, the only type of cancer survivorship program in Rhode Island, and helped develop the Oncology Sexual Health Clinic for Mass General Hospital Care Center.

The recent global Count Us, Know Us, Join Us survey found that some women with advanced breast cancer want more information on potential problems having children after their diagnosis. What options do women with advanced breast cancer have when it comes to starting or continuing to build their families?

Fortunately, the oncology community has been sensitized to the fertility risks associated with cancer therapy; as a result of guidance from organizations like the American Society of Clinical Oncology, most women diagnosed with cancer who have child-bearing potential should be identified prior to treatment, educated about their fertility options, and referred to a reproductive specialist. Unfortunately, while this should be happening, I remain concerned that this is not universal due to potential provider concerns (e.g., concerns that delays in treatment will adversely affect prognosis) or patient concerns (pressure to begin treatment ASAP by her support network, including significant other or parents).

For women receiving treatment, the approach requires a broader discussion of fertility and parenthood. Depending on the individual patient, the discussion may need to include a reproductive endocrinologist to maximize the chances of having a baby post-treatment or consider ways to have a baby using newer technologies (i.e., gestational surrogacy, egg donation, and IVF) or adoption.

Q That same survey found that some women also want more information on the impact advanced breast cancer can have on their interest in sexual activity. Is this something you discuss with your patients? What advice and/or resources do you recommend?

I do discuss sexual health with patients in the context of a formal evaluation in the Oncology Sexual Health Clinic. Too often the issues related to cancer care and follow-up do not allow time to fully explore quality of life topics, such as sexual health. At our institution, we started the Sexual Health Clinic for women who are interested in using it or who bring up issues related to sexual dysfunction.

I believe sexuality must be “normalized” for women diagnosed and living with cancer. Part of the way we can do this is by bringing it up during a normal medical visit, just as we ask about other symptoms. I do not expect oncologists to become well-versed on all of the issues related to sexual health, but I do hope that they can begin the discussion and create an environment in which women can bring up these concerns more easily.

As far as educational materials, there are several books and resources available. Some of my favorites are:

• Women, Cancer, Sex by Anne Katz, RN, PH.D.
• 100 Questions and Answers About Life After Breast Cancer Sensuality, Sexuality, and Intimacy by Michael Krychman, MD; Susan Kellogg Spadt, PH.D., CRNP; Sandra Finestone, PsyD
• Guide to Understanding Intimacy and Sexuality from Living Beyond Breast Cancer

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Advanced Breast Cancer (ABC) by the Numbers

According to the global Count Us, Know Us, Join Us survey,

1 in 3
34% of women say their relationship with their spouse or partner has been negatively impacted by their ABC diagnosis.

2 in 3
The majority (68%) of women say they receive sufficient support from their spouse/partner.

1 in 3
35% of women say it is important to make information about decreased interest in sexual activity available to women with ABC.
NEWS FLASH: Romantic relationships are hard work. Throw advanced breast cancer into the mix and they can become even more difficult to navigate. Whether it’s coming to terms with diagnosis, maintaining intimacy, dealing with finances, treatment, or a shift in day-to-day roles, there isn’t one aspect of the partnership that isn’t profoundly impacted. We talked to three women living with advanced breast cancer and a psychotherapist who leads SHARE support groups to get their advice on how to keep romantic relationships strong through the roller coaster of changes and emotions the disease brings. What we found is that their recommendations all boiled down to one simple, yet often hard to achieve, tactic: just keep talking.
WHY COMMUNICATION MATTERS

Communication is especially important for couples following a diagnosis of advanced breast cancer because each part of the couple—the person living with cancer and the supporting partner—is under intense strain. There is often a natural tendency to bottle up feelings of fear, pain, and anxiety to protect your partner, or yourself, from those feelings; but, according to Roberta Hufnagel, a psychotherapist and SHARE support group leader for more than 25 years, not communicating is what drives people apart.

“If you don’t talk, you become isolated,” said Hufnagel. “You may live in the same physical space and sleep in the same bed, but you are not in a relationship other than being physically present.”

Of course, the most important issues for partners to talk about are the very topics that are often hardest to discuss: one’s worst fears. These can include fears of being ill, dying, and being unattractive, or burdensome. But both partners in a relationship must constantly fight to break through the tendency to retreat into themselves.

So, if there is a “secret sauce” to helping to navigate life with advanced breast cancer, particularly as it relates to intimate relationships, it’s talking. To get you started, here’s a look at how a few women living with advanced breast cancer say communicating has challenged them, helped them, and ultimately, brought them closer than ever to their loved ones.

INTIMACY

Each of the women interviewed for this article said that intimacy was one of the biggest changes and challenges to their relationships after diagnosis. Day-to-day life can be taken over by the fundamentals of doctor’s appointments, filling prescriptions, sticking to a medical regimen, and making sure to get enough rest.

In addition, it can be hard to get the information you need to deal with intimacy issues. Many women feel their doctors don’t bring up the topic as much as they should during appointments or even that they didn’t realize a decreased libido was likely to be a side effect of treatment.

“It is the unspoken journey,” said Jennie, who was diagnosed with advanced breast cancer in 2010 and lives with her boyfriend of two years in Los Angeles. “I feel like I am in middle school again – I’m like is this change happening to you too? What do I do?”

Though they are hard issues to discuss, it is important to share with your partner what is happening in your body and mind and how that may affect your libido.

Adrienne has been living with advanced breast cancer since 2009 but remembers an exact moment when opening herself up to her husband, Pablo, changed their relationship for the better.

“My husband Mark joked that he could finally fulfill his Sinead O’Connor fantasies! Keeping it light and fun has helped a lot.”

“One day my husband took me to a mirror, which I had been avoiding at all cost. I fell to the ground and said, ‘I look like a monster and I don’t want anyone to see me this way,’” said Adrienne, who is celebrating her 15th wedding anniversary with her partner Pablo this year. “My husband picked me up and lay me in bed, my hair dripping wet because I had just gotten out of the shower, and he said, ‘Adrienne I don’t care what you look like, I love you.’ I knew at that moment we were in for the long haul.”

Amanda, who has been living with advanced breast cancer since 2010, says humor helps too.

“There was one point when I had gained a lot of weight, was bald, had scars on my breasts, and I wasn’t feeling attractive. My husband Mark joked that he could finally fulfill his Sinead O’Connor fantasies! Keeping it light and fun has helped a lot.” Remember that intimacy does not necessarily mean sexual intercourse. There are lots of ways to feel connected to another person.

For Jennie, real romance is just being there. She and her boyfriend, Connor, take walks when she feels up to it or sit on their deck together sipping lemonade to create the space and time for communication to happen naturally.

“This journey can leave me feeling broken,” said Jennie. “I lose my hair, breasts, fertility; it is a constant taking. Connor fills those spaces with other things to do, and his hope is inspiring and contagious.”
Many women living with advanced breast cancer experience feelings of guilt at some point. They might feel bad about asking their partner to take on new roles and responsibilities, or feel undeserving of their partner's company and support.

“I felt really guilty in the beginning when I couldn’t do anything,” said Adrienne. “There was a time when I literally couldn’t go to the bathroom by myself. I thought, how can I ask him to do any more than he is already doing?”

Some women also sense that they have imposed a lifestyle change on their partner. Jennie feels guilty because she cannot have children.

“I have not come to peace with that yet, I don’t know if I ever will,” said Jennie. “I remind myself that Connor decided to be on this journey and I can’t push him away. There is so much goodness between us that cancer cannot get no matter where it spreads. I know that is what he sees and why he stays with me.”

The best thing to do is talk about those feelings with your partner and discuss possible solutions that work for both of you. You may just find their answers reassuring.

**FINANCES**

Finances are another way in which romantic relationships are impacted by advanced breast cancer. If you are living it, you know: the bills can be overwhelming. It’s important to talk to your partner about how you will handle finances, not only in terms of future planning but also everyday spending.

“Sometimes my husband thinks I spend too much because I am in a state where I say life is short so don’t hold back,” said Amanda. “He doesn’t want to keep me from doing all that I want, but I know it does put financial stress on him. We’ve had many, many, many discussions about it!”

Partners must talk through financial decisions together, and there are other people to turn to for support as well. A trusted healthcare provider like a physician, nurse, or social worker may be able to provide advice, and most hospitals or treatment centers have financial counselors who can help with paperwork and financial aid programs.

**SEEKING SUPPORT**

It is important to know that, in addition to your significant other, there are lots of people and places you can draw on for emotional support.

“It’s okay if your romantic partner cannot provide all the emotional support you need—it doesn’t mean he doesn’t love you,” said Hufnagel. “It could actually mean that he cares so much about you that it is too hard for him to carry your fears and his.”

Adrienne and her husband seek support through their faith. They feel that God has given them this disease for a purpose and they give their time to counsel other couples living with advanced breast cancer. They also see a counselor at their church and find that speaking to someone who shares their beliefs is helpful in talking about their relationship.
Jennie's boyfriend has not wanted to talk much about her end-of-life care or admit that she could die, which sometimes leaves her feeling isolated. Instead, she has conversations about those kinds of issues with others on a message board for younger women with advanced breast cancer, her support group, and a therapist. She also finds blogging to be an emotional release that allows her to unload her feelings and leave them there.

The first thing every person should do, according to Hufnagel, is assess who you are and what helps you cope. If you are religious, avail yourself of that. If you are research oriented, read books or surf the Web for information. Then, whatever coping mechanism you choose, try to share it with your partner and encourage him or her to try it with you at least once.

“As long as there is talk about it, whatever you are doing, it’s good,” said Hufnagel.

GOOD COMMUNICATORS

The good news is that having advanced breast cancer can often improve the way couples communicate. Living through the diagnosis and treatment reinforces that couples can count on one another, that they can work together to overcome obstacles and that their love is strong.

“It might be hard in the beginning to talk about something, but I know it’s easier if we do,” said Jennie. “To psych myself up to talk about the tough topics, I remind myself that in the history of our relationship, it’s better once we have talked about things.”

That’s not to say that communication is always easy. Adrienne’s advice is to keep trying. If communication lines drop, seek out a neutral counsel who can assist in getting you talking again. And if you are open, your partner is likely to follow.

“Nothing says I love you more than hugging your partner and speaking your heart’s truth.”

“How Communication Can Help Partners

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<th>Receive and offer emotional support</th>
<th>Get help making decisions</th>
<th>Share advice and encouragement</th>
<th>Clarify misunderstandings</th>
<th>Learn new coping strategies</th>
<th>Plan for the future</th>
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Source: Livestrong.org
What was your inspiration for CancerMatch?
I started CancerMatch (www.cancermatch.com) in 2005 because people with cancer want to be part of a community instead of feeling isolated. After attending a LIVESTRONG event with 2,000 cancer advocates from various cities, I couldn’t help noticing while looking around and meeting people that many were single. Starting CancerMatch was a logical decision; those people living with cancer understand things about each other that others do not.

When you’re diagnosed with cancer, you have to make adjustments. To have a platform where you don’t have to be burdened by your cancer or challenged to explain it is helpful—you don’t have to explain that you may be in the hospital for a couple of months, or your relationship may only last a short while, or that you can’t make a date because you don’t feel like it—the other person will understand rather than take it personally.

What are some of the difficulties CancerMatch members face when dating?
People often find it difficult to understand that you may not have a lifetime with the person you’re dating, but that it doesn’t mean that you can’t have a wonderful, beautiful relationship. A person with cancer knows that two years are just as valuable as 20 years. Living with cancer allows for this realization more than for people who have not experienced cancer. For those on CancerMatch, it’s about understanding a change in life that you both share that you don’t have to explain. CancerMatch has grown quickly (the website currently has 41,000-42,000 people active and grows entirely by word-of-mouth) because all members don’t procrastinate like many do when illness isn’t a factor. CancerMatch provides an entirely different way of looking at romance.

Can you briefly describe how the website works? Who can join CancerMatch?
CancerMatch is a free service that is quick and simple to join. You are not required to be specific about your diagnosis and health status to join, but over time, members often become more open about their health. People with all stages of cancer are active on the website, including many with advanced disease. CancerMatch has a chat option and a virtual support group. I regularly see female members use the site to talk about both cancer-related topics as well as relationships. Members are mostly from the United States, but it’s actually an international forum, including members from Canada, France, the UK, and Belgium.

CancerMatch also has an LGBT version called Out With Cancer (www.outwithcancer.com). We are working on the next generation of the website, which will merge both versions. We also hope to allow video and instant messaging. This update should be completed by the end of 2013.

The Count Us, Know Us, Join Us global survey uncovered that despite receiving adequate support from significant others, marriage and romantic relationships are likely to suffer after a diagnosis of advanced breast cancer. How can resources like CancerMatch help?
When you have the fear of death put into a relationship, it will obviously have an impact. Cancer’s impact is also physical. When faced with a cancer diagnosis, I think it’s important to remember to ask: does this alter the expectation of my relationship? CancerMatch allows people to put their diagnosis aside and focus on their relationship instead. We’ve had a number of weddings over the years, which is so gratifying.
from a son’s perspective
Are you listening or are you solving?

Nothing is more natural than being there for someone you love. For this reason, breast cancer has and always will be, a family issue that men and women must face together. I know this all too well—my mom was diagnosed with breast cancer 21 years ago. Like all men in this situation, I can’t think of a time when I felt more fearful, helpless, or hopeless. It was my mom and I couldn’t fix “it.”

Are you listening or are you solving? What is expected of men has changed a lot over the years; while the typical male role used to be defined as strong, independent, and reliable, men these days are also asked to be emotionally available—a true sign of strength. This is especially true of men who are called upon to support a loved one with cancer. Men, in some cases, are not comfortable talking about situations that make them feel powerless or admit that they can’t solve a loved one’s problems. That’s okay because we can have a profound impact on the life of someone diagnosed by being there for them, which I learned in the halls of my mother’s hospital and is why I started Men Against Breast Cancer (MABC).

Stress creates a unique opportunity to redefine how you communicate. First, you must realize that you can’t “fix” what has happened. I often recommend men who attend our Partner in Survival™ workshops to ask the woman they love during conversations, “Am I listening or am I solving?” Many times, the person with cancer just wants to be heard. With the right tools, knowledge, and attitude, every man is capable of making a real difference in the life of someone with breast cancer.

Communicating and coping with breast cancer. There are many interpretations of the word “caregiver,” but what it boils down to is being there for the person you love, helping them back to health, and continuing to support them after treatment has ended. Especially for women with advanced breast cancer; their breast cancer may never go away, and neither should your support.

You can’t overestimate how important it is to talk to the woman you love—about breast cancer, your feelings, her feelings, and your relationship. When you have these conversations, be honest, courageous, delicate, supportive, and nonjudgmental. Reinforce how much you love her and that you are there for her. Most importantly, learn how to not say anything at all. Often times, she’ll just want to be heard and held.

Men need care, too. Many men overlook one aspect of supporting someone with breast cancer: being mindful of your own health. Over the years, I’ve seen men ignore their own physical and psychological needs. My suggestion to men is: Don’t just grin and bear it; communicate your concerns as well. Rather than giving up activities that make you happy, simply cut back on them to make time for your new role, as it is appropriate in your own situation. If you need to reach out for emotional assistance, it is normal and will provide you with insights to help navigate the crisis of breast cancer. Also, identify ways to help you cope with your loved one’s diagnosis as well.

Finally, seek social support for yourself. This can take the form of another family member, a friend, colleague, or an advocacy organization, like MABC. Once you have this in place, you’re on your way to being there for the person you love with breast cancer.

By: Marc Heyison, founder of Men Against Breast Cancer, the first national nonprofit organization designed to educate and empower men to be effective caregivers when breast cancer strikes a female loved one, and author of “It’s Not Rocket Science: A Guy’s Blueprint to Caregiving.”
For more than two years now, I’ve been a very good little Stage 4 advanced breast cancer patient both physically and mentally. My oncologist doesn’t use words like cure or remission and neither do I. We say manage and chronic disease. The best words we can say are: “no evidence of active disease.” I’ve been lucky enough to hear those words once after a routine PET scan.

But just this week I allowed myself a radical thought. What if I kick cancer? What if it just goes away as mysteriously as it appeared?

This is very dangerous thinking, but it sure does feel good. Why can’t I say “I’m kicking it as I log a personal best time in the 2013 NYC Half Marathon?” Why can’t I say “I’m kicking it as I celebrate this accomplishment at a brunch thrown by my joyful husband?” Why can’t I say “I’m kicking it as I become a hot-line peer counselor for other women with the disease?”

Or how about this: In a recent segment on Eyewitness News about women and running, I didn’t mention the “C” word once. I was just a runner, not a runner with cancer. I’m kicking it.

I had a PET scan this week and the person performing the study told me I was doing very well as I lay in the tube emitting my positrons. So I’m kicking it. The doctor hasn’t called me yet; I think the results must be good. I’m kicking it. I’ve started training for the New York City Marathon in November and I want a personal record. That’s called kicking it.

I’m getting a kick out of this.

-Noirin, New York