

Dr. Jimmie Holland, Helping Spouses of Cancer Patients July 27, 2008 Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Ken Miller. I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Miller is a Medical Oncologist specializing in pain and palliative care and he also serves as Director of the Connecticut Challenge Survivorship Clinic. If you would like to join the discussion, you can contact the doctors directly at canceranswers@yale.edu or the phone number is 1-888-234-4YCC. This evening Ken Miller is joined by Matthew Loscalzo, Director of Sheri & Les Biller Family Resource Center at City of Hope in California. He is here to talk about helping spouses of cancer patient's cope with the effects of cancer.

Miller I want to start out directly by asking you about a book you just wrote. It is called, For the Women We Love. What is the book about?

Loscalzo Well what we have found is that when a woman is diagnosed with cancer, the man is rather confused about what is expected of him. In the past, men have been expected to protect women and to be supportive, but that has a whole new definition when the woman has cancer. Men are often totally confused about what is expected of them and there is no plan. Men are lost and can feel anxious and depressed. They might even isolate themselves at a time when a woman needs them most.

Miller Often men have the sense that they blew it, that they should have been able to protect their wife. Do you hear any of that at all?

Loscalzo We hear that all the time. There is a rational part of, a lot of people get cancer, why wouldn't my wife get cancer? There is a logical rational part of that, but then there is the irrational part where men feel that they should be protecting the people they love and they think, "I should have made her go to the gym more, eat better, see the doctor more." Men do not like to feel powerless, why would they?

Miller I guess you are saying that there is the combination of a little bit of guilt and then there is also a sense of not knowing what to do once you are faced by it.

Loscalzo Guilt plays out in a very different way. Women tend to feel guilt more when they get sick, because of the burden they are putting on the family and the stressors; especially on the financial and emotional side. Men tend to feel shame, and shame is different than guilt, because shame is how you feel about yourself as a person, while guilt is generally something you feel sad that you did and that you are not proud of. Men do feel shame when the women they love get sick; whether it is their daughter, aunt or grandmother. Men tend to feel shame because they are thinking irrationally. They think they should have protected someone whom they love, that is the man's job, and that is such an integrated exaggerated sense of what it means to be a man.

Miller How often are men able to put that out there? To be able to say, "I know it is irrational, but I feel ashamed." Is that more unspoken or spoken?

Loscalzo It is unspoken because men have so few opportunities to really talk about this. In the groups that we run at City of Hope, called problem solving groups not support groups, we bring women and men together in a room, these are spouses, mothers, sons, fathers and daughters, and in that context we have just two rules; be profoundly honest and deeply respectful. Within this context men are open, they are honest, and women are open and honest about what their needs are. If you think about it, men and women have so few opportunities to have grown-

up, honest and deeply respectful conversations; they have no role models for them. Miller That is true, in our parents' generation a lot of them weren't able to communicate for a whole variety of reasons. Most of our role models are on television. Loscalzo Yes, you are right. And the role models that we generally see are characters of people; they are gross exaggerations of traits that most people are not proud of. How many women or men can you watch on television that you would be proud of? There are so few role models. If you think about our parents, they grew up in a very different world. Women were not working, the men knew what was expected of them, but now all the rules are changing. People are having children later, children do not live close by, and people are getting sick when they are older. All the rules are changing for both women and men, so we are both pretty confused about what we need from each other. Miller In the groups that you run at the City of Hope there is the unique opportunity to really listen to a man in that environment where they can be honest and really listen to a woman. What do the men tell you? Loscalzo What the men tell us is that they are absolutely terrified that their wives might die. There is such a burden on men to keep things positive, to keep it upbeat, they get this message that if their wife isn't upbeat and optimistic that the cancer will come back faster. There is no data that shows that, but what we have is a situation where the man is burdened with the rational and irrational thoughts that they have about protecting someone whom they love. But men overwhelmingly are afraid of the women dying and feel that they are not allowed to talk about it openly. Miller You were telling me earlier about what happens when you ask men who their best friend is. Loscalzo Yes. Miller Could you share that story? Loscalzo There were a series of early studies that simply asked men who their best friend is, and 80% to 90% of men said their wife. When the wives were asked who their best friend is, 40% to 50% said their husbands. Men are much more socially isolated and women have much larger social support networks. Social support and physical activity and exercise are two things that consistently lead to wellness and health. Miller Essentially for men they are living with a certain amount of shame that we just talked about, they are living with the fear that their wife is going to die. This may be the closest person to them and their best friend. What are women sharing in that environment that is honest and open, what do they tell you? Loscalzo Well, that is fascinating, because what women tell us is that what they need most from men is for the men to openly acknowledge that they might die. You see where the double bind is where both women and men feel isolated. The women tell us very clearly, "If I cannot talk to my husband about the thoughts I have at 2 o'clock in the morning, or to my son, then I have no one to talk to." Women do not have the interactions with other women that they used to have, women are socially isolated as well, but compared to men, they have larger social networks. Women need for the men to at least acknowledge that they are both scared and that they are committed to each other no matter what happens. Miller I am going to ask you for real nuts-and-bolts advice here. For people that may not be used to emotional language, what words should a husband use who wants to try to open up that dialogue and be a good listener? Loscalzo First I would say that communication is the second

most important thing, not the first. Everyone says that it is the first, but in all the work that I have done, I do not think that it is. I think connection is more important than communication, because some people talk to avoid connecting. When you talk about emotional connection that is when the nuts-and-bolts come in. For women, an emotional connection comes when you do something with that person. For example, when women are at a party or at a restaurant, and one says they are going to go powder their nose, all the women get up and go with her. I do not think you have seen a situation where a man says he is going to the bathroom and five other men ask to come too. I do not think that happens very often, but that gets to the heart of it; women feel more comfortable sharing their vulnerabilities, talking about details and talking about their experiences while men feel less comfortable talking about their vulnerabilities. But once they recognize that by sharing their concerns, doubts and their fears with the woman they love, the woman feels safer and the man feels more connected to her.

Miller Let's say a woman is diagnosed with breast cancer and her husband or partner is walking around feeling afraid that she is going to die. These are things that we all think about from time to time. Again, what are the words to use to even open the discussion?

Loscalzo The most important thing to do is to ask the woman what some of her concerns are, tell her you love her and care about her no matter what happens, and that you will be there and will accompany her to her appointments. There are specific things that women have told us that they find helpful. I say to men, unless you are going to get fired from your job, be there with her. And some men will get fired so they cannot go, they have to work, or she won't have health insurance and that is a real problem in this country, however, go with her to the appointments, give her opportunities to tell you what she is feeling. One of the worst things that men can do is to minimize her feelings by saying, "Oh, you are going to be okay, do not worry about it." That makes women feel alone and isolated. Men feel that is their job but it is not what women need.

Miller When a woman is diagnosed with breast cancer, she wants to be of help to her husband or partner. What are some bits of advice for her?

Loscalzo In our groups we talk about this very openly because we are amazed at how people can be married for 20, 30, 40 years, and they say they have never had a conversation like this. We tell people that when someone gets agitated or angry or cries, that is a feeling and that means pay attention to what is going on. You want to go beyond the feelings though, because feelings can get in the way of the content. So for example, when a man makes jokes and a woman feels put down, the woman can say to him, "I know you did not mean to hurt my feelings, but what made you make that joke?" The first response the man usually gives is, "I just wanted to cut the tension," and then she could say that it creates tension and that she needs to feel connected to him. The first impulse any of us have in an emotional situation is usually the wrong one. Let the first impulse go and say, "Tell me how you were feeling when you made that joke, when you went into the other room while I was talking, or when your eyes filled up with water and you told me you did not want to talk anymore." To really nail it down and go beyond the behavior, talk about what is inside. Men tend to make jokes when they are under stress.

Miller Very common.

Loscalzo

They do that with other men all the time. Miller Yes. Loscalzo But with women, it is painful and hurtful. When we teach men how hurtful it is to make jokes when women are hurting, they stop doing it, because for them they were just trying to help. Miller I am listening to all of this on multiple levels, as a doctor, a husband and as a friend. These are important bits of advice and insight. For our listeners, we would like to remind you, you can e-mail questions to Cancer Answers at the yale.edu. We are going to take a short break for medical minute and then please stay tuned to learn more about family support and want we would call gender synergies during cancer with Matt Loscalzo from the City of Hope Care Center. Miller Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller and I am here with Matt Loscalzo who is from the City of Hope Cancer Center and an expert on cancer support and gender issues. We are having a very, very interesting and illuminating conversation. Matt, let me ask you, why oncology? Why did you go into social work within oncology? Loscalzo I went into oncology in 1980, and it was a fascinating area for me because there was so little psychological and social support back then. In 1980, many people who found out that they were ill found out very late, so they died very quickly. Since the 1980s there have been such profound advances in cancer and I believe there are 10 million cancer survivors in the United States. You are the expert on that Ken, and you know about this area and have talked about it all around the world. It is a key issue now, but in 1980 it was a different picture. Before the hospice bill passed there were very few hospices. There was very little psychological or social support for cancer patients and I really felt that that was a place where I could make a contribution where other people were not. I also had a special interest in pain management and in teaching hypnosis, meditation and relaxation and physical and psychological spiritual rehabilitation to people who may have been cured from their cancer and had no one to go to. I was lucky enough to go to the team at Memorial Sloan-Kettering in 1980 and I was one of the founding members there. I found that it gave me meaning and I was able to do things for other people and that gave me meaning on a very personal level. Miller Let's get back to cancer survivorship. Thankfully, there are more and more people that are long-term cancer survivors. Years and decades after the cancer experience we hope people have a healthy life. What are your findings on how people end up in general? Are they left with a sense of a scar about how terrible the situation was, or do people end up being neutral? Do people end up growing from the experience, or all of the above? Loscalzo It is really all of those. I call cancer survivors wounded warriors because every morning when they wake up, the first thing they are going to say is, "I had cancer," even if they are cured. They have to live with that for the rest of their lives. Their family members live with that for the rest of their lives. There are patients who grow from it, who make different choices in their lives and leave jobs that they did not like. Some people leave relationships that were unfulfilling and they move on with their lives and they do better. Some people will never recover from the experience. Some of that may be physical, psychological, or spiritual. The economic impact of cancer survivorship is major and in the United States we do not have a safety net for cancer survivors. We know there is lots of data

that shows that many of these patients do go bankrupt, and going bankrupt in anyone's life is a major, major problem. It is demoralizing and humiliating, but many of these people who may have started off as middle class, have economic problems for the rest of their lives. They may not have been able to go back to the job that they once had, but ultimately, many people do say that their lives have gotten better after the cancer. They have reprioritized. Miller Let me ask you about couples from that point of view. There is tremendous stress that couples are put under when one of them has cancer. From your experience, have you seen people grow, what are the stories that they tell you? Loscalzo Well, the stories are mixed. If you are a parent of a child who has cancer, those younger relationships tend to be more at risk, so the divorce rate tends to be higher in those couples. If you look at an adult with cancer, it can definitely bring them closer because on some level when you get married, you know that this is a long-term commitment. You expect that somewhere down the road one of you is going to get ill, that is sort of built in as part of the relationship. As you get older, that happens, they are special stressors and it does stress a relationship, but when you have a relationship where you both make a commitment and a sacrifice, and you get meaning out of it, those are the relationships that you see thrive. That is not to say that it is easy, but it is those relationships that do better over time. Miller Any special characteristics of those couples that end up growing from the experience? Loscalzo Absolutely, one of the major characteristics of couples that grow through their experience are couples who solve problems together, those couples who can talk about what their concerns are and can find ways to connect with each other. A woman is going to be more on the talking side of it generally, and the man it is going to be physically doing things for her more. Our data shows, and we have published at least one large study on this, that when we look at what men contribute, men are very comfortable doing things for the women in their lives who are ill, things such as going to the pharmacy, bringing them back and forth to the physicians' office, cleaning the house and doing practical things. The emotional side is where men have a harder time. When men learn that the emotional side is their commitment and love that she needs, they will give it. Men need a plan of action; men need a mission. That is how they connect. We teach women that is how men do it, not like their girlfriends by giving details and talking about the same topic over and over again. Then men and women both grow and both reach inside of themselves. The women become more of who they are and the men become more of who they are, and they decide to be healthy, wise and courageous people. That means that what you are born with as a woman or man, is not who you are. You define who you are everyday by the way you treat people that you love, because the way you treat people that you love is the amount of respect you give to yourself. Miller Let's talk about an action plan. I want to get some details here because if a husband asks me what they can do to be of help to their wife, I want to give them some advice. Loscalzo Well Ken, I want to thank you for the indirect plug for my book. Ultimately, the book is one total action plan. We wrote this book knowing that men need a mission and a formula. Once men understand what women need in all of our groups,

and I mean groups all over the world, it is amazing how women and men rise to the challenge. If you give a man a clear sense of what you want from him he will give it, and that is why it is so important for men to listen to women and for women to tell men what they really need. We help women not to say that he should do it without them telling him, because then that means he is going to fail and she is going to feel really frustrated, but have men sit down and talk directly and look at her. When men talk, generally, they do it side-to-side, and that is when we share intimate things, in a car, at a baseball game, men do it side-to-side, but when women communicate, they want the man to be doing nothing else, to be looking at her and to be giving her his undivided attention. She wants him to be able to listen to her emotional needs without trying to fix them, just listen and bond with her. We also teach men that when women tell you about their deepest concerns you should not try to talk them out of it, just try to understand it and use the feelings to connect on a much deeper level. We also tell men that it is really helpful if you ask the woman what she wants from you. One of the biggest challenges is that the ladies tell us what men do to help and most say, "Listen to me, be there physically, buy me small gifts, not big ones, spend time with me and be physically present, but it depends." This is what drives men crazy, sometimes women want you there and sometimes they find you suffocating. Men have got to listen with a deeper ear; they need to listen with their minds and hearts. Men cannot allow themselves to get upset when women get emotional. Emotions are healthy, but women should also understand that men are generally, not always, but generally, not as emotional as women are. It does not mean that men do not care, we are just different, and our differences are what have made women and men such spectacular problem solvers through the ages. Miller That is encouraging. People have their own form of intimacy and sexuality, and the way they relate to each other physically. When someone gets sick with cancer and their body is different and their energy level is different, how does that play into this entire equation? Loscalzo For the cancer survivorship population it plays a major role because when people are focused on survival, getting chemotherapy and getting themselves as healthy as they can, sexual function takes a backseat. When you have fear, it wipes out sexual drive and decreases libido that people have; that is a physiological response. However, fertility is important to all people and so the doctor should always ask if they are still planning on having children, if they have banked sperm or looked into egg preservation. Fertility is often an overlooked area so I always mention it. Sexual functioning becomes important once treatment stops, because then fatigue is less and they begin to feel healthier, they are eating differently and then retrospectively they think, what has happened to the last 6 months of my life? They want to reclaim their person, femininity and masculinity, sexual function, and for many cancer survivors, sexual function needs to be redefined, especially with men who have prostate cancer. They may not be able to have erections. They may have urinary incontinence and that makes it harder to be sexual. At the same time, when women have hormonal therapies and other kinds of treatments they do have vaginal drying and that makes sex harder and it makes it painful so they may lose their sex drive. If you

do not have the ability as a couple to talk about this in an honest way, I can refer to so many sad stories where couples who are deeply committed and loving stop touching each other because they are afraid the other person may A. Think they are ready for sex when they are not, or B. The other person will feel sexual, but the other partner will feel so guilty about having unmet sexual needs, that they just stop touching. That is a double loss and that is why you have to talk about it. Miller I think all couples in a long-term relationship have good times and bad times, but going through the cancer experience, what are the resources that people can tap into in their own communities? Loscalzo I think the person who usually knows the couple best is their doctor. I think they should always start with the doctor. I tell everyone that if they want information about their illness, start with a doctor, if you want to have information about resources related to your illness, start with the doctor. You can talk to the nurse and also with the social worker. For those people who live in rural areas where it is harder to find this, go to the largest cancer center or largest hospital in your area and call the department of social work. They often have a list of recourses that can help you. The internet can be a great resource as long as you go to a site where they are not selling you anything. Although most people are treated in small hospitals, not in the comprehensive cancer centers, the cancer centers do tend to have more resources and that would be a very good place to start. There are many superb resources out there as you know Ken, from your work as an oncologist. Miller The sense I have gotten from you is that many people really grow from the experience of cancer, and couples as well. Is that your observation? Loscalzo Well I think in most circumstances it is a choice. Life is a very hard place. No one has ever been happy that they had cancer, but many people have told you and me Ken, that it has made their lives better. Cancer is really hard, however, you have to decide as a woman and a man, when you are impacted by cancer in your family, that you are going to be a healthy and wise person and that you are going to reach within yourself and find the resiliency and the resources. Some people decide they are going to allow it to overcome their life and then they lose twice. Reach within yourself, decide that you are going to be a healthy, wise person and solve problems together with your health care team, with your doctor, your nurse, your social worker, with your spiritual advisor, and reach out to those people who have walked down this road with other patients. Miller I would like to remind our listeners that there is a wonderful book out there written by Matt Loscalzo called For the Women We Love, and it is for men whose partner or spouse has had breast cancer. It is a wonderful book and very insightful. I really enjoyed it and got a lot out of it myself. Matt, I want to thank you so much for joining us today. Loscalzo Thank you Ken. Miller Until next week, this is Dr. Ken Miller from the Yale Cancer Center wishing you a safe and healthy week.